

BIRTH & BETRAYAL

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1. When births go terribly wrong, Florida protects doctors and forces parents to pay the price | April 8, 2021
<https://www.miamiherald.com/news/state/florida/article247417990.html>
2. Distraught over dead son, mom can't sue doctor. Doctor can threaten to sue her, though | April 8, 2021
<https://www.miamiherald.com/news/state/florida/article247418465.html>
3. Mom was consumed with caring for brain-damaged son. Florida could have paid her. It didn't | April 8, 2021
<https://www.miamiherald.com/article248152975.html>
4. Florida protected OB-GYNS from paying for their mistakes. They handed taxpayers the tab | June 1, 2021
<https://www.miamiherald.com/article251785778.html>
5. Mom devoted her life to her disabled son. A hospital said she was using him to make money | April 26, 2021
<https://www.miamiherald.com/news/politics-government/state-politics/article247418705.html>
6. Accused of refusing aid to disabled kids, a Florida agency responded — by hiring a PR guru | Dec. 29, 2021
<https://www.miamiherald.com/news/politics-government/state-politics/article256800317.html>
7. DeSantis signs into law bill overhauling safety net for families with brain-damaged babies | June 22, 2021
<https://www.miamiherald.com/news/state/florida/article252283013.html>

8. Facing fierce criticism, head of Florida's troubled program to aid brain-damaged kids quits | Sept. 15, 2021
<https://www.miamiherald.com/news/health-care/article254270808.html>
9. 'These findings boggle my mind': Audit savages Florida program to aid brain-damaged kids | Oct. 22, 2021
<https://www.miamiherald.com/news/politics-government/state-politics/article255197882.html>
10. After 33 years, parents of brain-damaged kids get to express disgust with Florida program | Sept. 16, 2021
<https://www.miamiherald.com/article254302113.html>

Miami Herald

April 8, 2021



As Jamie Acebo recovered from a difficult delivery, this was the photo she was shown of her newborn daughter. Emily Michot, Miami Herald

When births go terribly wrong, Florida protects doctors and forces parents to pay the price

By Carol Marbin Miller and Daniel Chang

A birth gone horribly wrong left Jasmine Acebo with profound brain damage and a bleak future, one defined by wheelchairs, mechanical airways, feeding tubes, frequent hospitalizations, in-home nursing and constant pain.

Unable to work, her overwhelmed mother became dependent on food stamps and sometimes cash assistance. She watched helplessly when her newborn convulsed with seizures. She saw her daughter turn blue and nearly suffocate during a feeding.

A Florida program promised help: medical care, money for expenses — a lifeline of support.

But that help, said Yamile “Jamie” Acebo, was often delayed, denied or deficient. And it included what she viewed as a shameful suggestion from a program administrator making a home visit: Would Acebo wish to place her daughter in an institution? The thought of Jasmine, surrounded by strangers and not the mother who loved her, was horrifying.

“I will care for her until the day the good Lord takes her home,” said Acebo, a single mother living with her parents when Jasmine, her first child, was born.

In every other state but one, Jamie Acebo and hundreds of other parents like her could have pursued multimillion-dollar lawsuits to recoup the costs of raising a catastrophically disabled child. But a Florida law enacted in 1988 — to reverse what advocates and lawmakers called an exodus of obstetricians fleeing high malpractice insurance premiums — stripped them of that right.

Florida’s Birth-Related Neurological Injury Compensation Association, also called NICA, aims to lower obstetricians’ malpractice costs while providing families of those who suffer the most severe birth injuries with monetary compensation and “medically necessary” health care. It prevents parents from suing, even if the doctor or hospital may have made an egregious mistake.

The law was also supposed to provide a dignified existence and financial cushion for families crushed by the delivery of an infant with devastating brain damage. But some parents say NICA is indifferent to their fears, anxieties and depression, and hostile to their needs.

Jasmine’s special bed collapsed? Can’t it be welded? NICA asked.

Jasmine’s energy-hungry medical devices inflating the monthly power bill to \$500? NICA offered \$25.

Jasmine’s outgrown her wheelchair? Stretch it out, said NICA.

“They were supposed to take care of her for the rest of her life,” Acebo said. “They were nickel-and-diming me for 27 years.”

A bill in 2013 could have made NICA more responsive to the Acebos and other families. NICA’s executive director, Kenney Shipley, argued for its defeat. “Most of this is pretty silly since we are not here or funded to ‘promote the best interest’ of the children,” she wrote in an email, and later predicted lawsuits against NICA if an “ambiguous standard” were adopted.

NICA pays parents of children with neurological injuries \$100,000 upfront and promises a lifetime of health care, much of which actually comes from Medicaid, a different state program

KENNEY SHIPLEY, EXECUTIVE DIRECTOR, SENDS A MEMO TO LOBBYISTS FOR NICA

From: Kenney Shipley [REDACTED]
Sent: Monday, September 30, 2013 4:40 PM
To: [REDACTED]
Subject: FW: Proposed Topics for NICA Legislation (2014 Session)

FYI. I'll be working on talking points. I hope we can get the group together that supported us before. Most of this is pretty silly since we are not here or funded to "promote the best interest" of the children. We have the Benefit Handbook on the website which has everything listed below including instructions and address to file a petition if they choose. I will try to set up a time to discuss and let you know.

Kenney Shipley
Executive Director
NICA

that insures impoverished and disabled Floridians. When a child dies, as Jasmine did in 2017, NICA pays families an additional \$10,000 for funeral costs.

Appeals and internal records show that Jasmine's mother was one of many parents who spent years locked in frustrating fights with NICA after learning that \$100,000 is woefully insufficient to care for a child with severe brain damage. They say NICA doesn't inform them about benefits to which they are entitled, while rejecting or slow-walking coverage for therapy, equipment, medical treatments, medication, in-home nursing care — even wheelchairs.

To assess NICA's performance, reporters from the Miami Herald, in partnership with the nonprofit investigative news organization ProPublica, examined court records, board minutes, actuarial reports, state insurance records, emails, legislative records, medical studies, archival records and case management logs for deceased children, as well as Health Department and financial services reports. Two families provided reporters their full internal files. Reporters observed board meetings and interviewed parents, doctors, lawmakers, lawyers, ethicists and health care administrators.

The Herald filed a lawsuit seeking additional records, including unredacted case management logs for deceased children that would show how NICA handled claims. NICA administrators fought to keep the records secret, and a judge ruled in NICA's favor, saying families had a right to privacy.

Reporters examined all 1,238 NICA claims filed at the Division of Administrative Hearings, or DOAH, from passage until today.

The investigation revealed:

- NICA administrators narrowly define what medical care is necessary in a way that is far stricter than private insurance — or even the federal Medicare program. The program's definition of



Kenney Shipley has headed Florida's Birth-Related Neurological Injury Compensation Association since 2002. Courtesy: NICA

medical necessity ensures NICA spends less on care for children, causing friction and frustration.

The Herald found instances of NICA questioning the medical necessity of wheelchairs, medication, physical therapy — and extra feeding bags for a child with a gastrostomy tube.

“At some point, nickel-and-diming people has a diminishing return, if any return at all,” Jim DeBeaugrine, a former head of the Florida Agency for Persons with Disabilities, said of NICA.

- If families push back, the program sometimes spends more money fighting them than it would have cost to provide help. NICA paid lawyers nearly \$3 million to wage an 11-year fight against parents who sought compensation for giving up jobs and careers to care for their disabled children — a suit NICA ultimately settled, giving parents essentially what they wanted.

NICA paid \$138,000 in legal fees and costs fighting a mother's request for \$11,058 in reimbursement for a treatment that could help her daughter swallow. NICA turned down a mother's request for a wheelchair, modified van and an occupational therapy program for her child, then, when she appealed, twice hired a private investigator to tail the mother and son. Even with the \$100,000 one-time payment, NICA families often end up in financial hardship, generating requests that go beyond the scope of traditional insurance.

“A lawsuit against the physicians would have covered all of these expenses, but that right was taken from us,” wrote one parent, David Morgan, who sought help buying a TV and other equipment for his bedbound, pain-wracked young daughter. The request was denied.

- While many NICA families live in constant financial jeopardy, NICA has an ever-growing stockpile of money: nearly \$1.5 billion. The program doles out about \$3.5million annually to investment managers. NICA's lobbyists are paid nearly \$100,000 yearly — a total of \$888,000 since 2011 — to, among other things, fend off efforts at legislative reform.

After the Herald and ProPublica began investigating NICA, administrators hired a public relations firm for close to \$100,000 annually to generate favorable press — and proposed an increase in money for NICA families, noting that it would be a public relations boon whether it passed or not.

“It’s a scam,” Alex Sink, Florida’s chief financial officer from 2006 through 2010, said of NICA. “The pot is getting bigger, and people are feeding off the investments. They have no incentive to reduce the money in the fund in order to help parents. The priorities have gotten totally misplaced.”

▪The program has long resisted efforts to include the voices of parents on its board. NICA’s board has never included a parent or an advocate for disabled or medically fragile children. In 2013, when a lawyer for NICA parents suggested adding a mom or dad, administrators refused to consider it. The program said adding a family member “could lead to the perception of favoritism by other parents” receiving benefits.

“We know that there is a lot of depression among the parents of medically complex kids and a high divorce rate,” said Gwen Wurm, an assistant professor of clinical pediatrics at the University of Miami Miller School of Medicine. “We know that the siblings of medically complex kids are affected. Anything we can do to help maintain these families has benefits beyond the children themselves.”

In the weeks ahead, the Herald and ProPublica will explain how NICA has saved the state’s medical malpractice insurers hundreds of millions of dollars in payouts to families by shifting those costs onto Medicaid, which is funded by Florida and U.S. taxpayers. The news organizations will show how doctors and hospitals attempted to strip parents of their rights to make decisions for their children after those parents rejected NICA benefits in hopes of retaining the right to sue for malpractice.

Citing “the complex nature of [the] subject matter,” Shipley, the executive director, and other administrators declined to speak directly with reporters, but they answered more than 100 questions by email.

The program said lawmakers “created NICA to solve a specific challenge and it has done so very well.”

“We are proud to manage one of the state’s most fiscally sound programs, maximizing the impact of every dollar,” NICA said.

INVESTMENT PROFITS

NICA said the program’s \$1.5 billion in assets does not present the whole picture. Administrators calculate at least \$1.05 billion in liabilities for future expenses to care for those in the program.

“It is not ‘extra’ money to be spent freely,” administrators said, “but instead must be carefully managed by NICA to ensure that it is available to provide quality care for children in need.”

Administrators quoted a 22-year-old report from the Archives of Pediatric and Adolescent Medicine, now JAMA Pediatrics, which said NICA recipients were more pleased with the care they got than parents of other disabled children who filed lawsuits.

Not everyone is upset with the help NICA provides. In the early years after entering the program, Rock and Shawna Pollock fought with NICA constantly: over reimbursement for a blender, feeding bags, mileage to and from the hospital, home renovations and a device used to attach an iPad to their disabled son's wheelchair, records show. "They're trying to nickel-and-dime us," Rock Pollock said in a 2011 deposition in his son's case, echoing Acebo's complaint almost to the letter. "Right now we're living in hardship."

But in a December interview, Pollock said his relationship with NICA has improved, and he now owes much to the program, which has helped the couple provide for Rock Jr. "The only people that's there for my family is NICA," the elder Rock Pollock said. "They take care of him."

Susan Camacho's grandson, Jesus Camacho, whom she is raising, also is a current NICA claimant. "NICA has never disappointed us," she said.

Modeled after a similar program in Virginia — the only other one in the nation — NICA emerged in an era when insurers blamed jury verdicts for escalating premiums on medical malpractice coverage for doctors, particularly obstetricians, whose errors could cause ruinous disabilities requiring a lifetime of care.

At the time, the Legislature also passed several laws to clamp down on verdicts — which were reported to be as high as \$6.2 million in 1991, and as much as \$33million in 2017 (in an instance where the doctor was not a NICA participant), for cases of catastrophic birth-related brain damage. In addition to creating NICA, the Legislature passed laws in 1988 requiring voluntary arbitration, and pre-suit investigations to establish negligence prior to filing a lawsuit. Lawmakers informally called the NICA legislation "the bad baby bill." Newspapers adopted the moniker.

PROTECTING DOCTORS

Since NICA's inception, 1,238 families have petitioned for coverage, an average of three claims per month. A little more than a third — 440 petitions — have been accepted for compensation. Of those approved, 143 children were deceased when their parents applied. Another 50 children died after their claim was approved.

But if NICA was a trade-off, many parents say it was one-sided. While the program provided discount-rate protections to doctors, hospitals and insurers, parents like Jamie Acebo believe it passed the pain onto them alone.

West Palm pair challenges 'bad baby' law

By MICHAEL LASALANDRA
Palm Beach Post Staff Writer

WEST PALM BEACH — A West Palm Beach couple has filed the first challenge to the state's "bad baby" law, suing their obstetrician and St. Mary's Hospital over the birth of their brain-damaged son.

Darrell and Stacey Bass, who filed the lawsuit Wednesday in Palm Beach Circuit Court, contend that the Florida Birth-Related Neurological Injury Compensation Plan, which gives doctors and hospitals immunity from malpractice lawsuits in cases of brain-damaged babies, is unconstitutional.

The law, passed in 1988 to ease the insurance crisis obstetricians faced, provides compensation that might be far less than the millions of dollars juries sometimes award in malpractice cases.

The Basses' lawsuit names as defendants St. Mary's, Dr. David Feld and the West Palm Beach obstetrical group of Gerson, Casale, Silverman.

"This child is very severely brain damaged with significant motor impairment," said the couple's attorney, Phillip Taylor.

The child, Kyle, was born in March 1989 at full term and weighed 9 pounds, 5 ounces.

Stacey Bass, a nurse, said a brain scan showed damage throughout the baby's brain from lack of oxygen at birth.

"Physically he is very delayed," she said. "He's probably at the 4-month level, even though he's 16 months. He tries very hard, but he just can't reach for things. He can't hold onto anything. He can't even open or close his hands around an object. We have to put braces on him and splints to keep his hands open. And he has seizures. He went on steroids to relieve the seizures, but that gave him a problem with his immune system."

The lawsuit says that tests performed soon after Mrs. Bass' admission to the hospital showed the fetus was in no distress at the beginning of her labor. However, it says that St. Mary's staff and Feld failed to review fetal heart monitors and did not recognize when the baby went into fetal distress.

The suit also says Feld should have performed a Caesarean section.

Mrs. Bass said she has struggled to deal with Kyle's condition.

"I went through a lot of denial and a lot of anger," she said. "There was also a lot of shock and fear. I was afraid he was going to die. It was devastating. It still is. I do OK some days, and

some days it just hits me. I can't even express it. Nobody can understand. He's our first child. We have to take every day as it comes. We pray a lot. We depend on the Lord. That's all we can do. It's all in his hands. I have to depend on his strength. I sure don't have any left."

Under the no-fault program, the parents of a baby born with brain damage may not sue for malpractice unless they can prove their child is the victim of a physician's "willful and wanton disregard of human rights."

Instead, they are compensated with money from a Florida Birth-Related Neurological Injury Compensation Association fund, which pays the child's medical expenses for life, plus \$100,000.

"Physicians and hospitals need to be held accountable," Taylor said. "Parents of brain-damaged babies don't have the same rights as any other citizens."

Don Chester, spokesman for St. Mary's, declined to discuss the case. "It is in the legal system now and a matter for the courts to decide," he said. "It's a new law and the court has to decide the validity of it."

Feld did not return phone calls made to his office.

The 'bad baby' law: A headline from 1990.

Not only are NICA parents excluded from the program's governance, but every member of the program's board of directors, all men, has a stake in blocking reform.

In addition to the chief operating officer of Florida's largest malpractice insurer, The Doctors Company, NICA's unpaid board includes two physicians, a hospital administrator and the board chairman, who is designated as the representative of Florida citizens. His day job is running an insurance agency.

There are two physicians on the board, both of whom are obstetricians who participate in the program. They were each involved in a delivery that led to a NICA-compensated claim. Board members did not respond to emails from journalists.

NICA, Acebo said, "wasn't created for me. It wasn't created for my kid." She added, "They had all the power."

NICA covers a specific type of injury to the brain or spinal cord of a newborn caused by oxygen deprivation during labor, delivery or immediately after birth. For NICA to compensate families in such cases, the newborn must weigh at least 2,500 grams (5.51 pounds) and the injury has to occur in a hospital. A child must be substantially impaired both physically and cognitively to qualify.

If the doctor has paid a \$5,000 annual premium and the hospital has paid a \$50-per-birth fee, families are prevented from suing. Some parents fight to avoid the program by arguing that their child's injuries don't fit the criteria. That can lead to expensive court battles with dueling doctors and anguished parents.

In the budget year ending on June 30, 2020, NICA earned six times as much in investment income, \$124.6 million, as it spent on families of brain-damaged children: \$19.8 million. The program called its fees to investment managers "reasonable for the level of assets under management."

Flush with cash, the program paid its lawyers \$16.9 million between 1989 and 2020— more than NICA spent, combined, on therapy and doctor and hospital visits for children during the same period, which was about \$10 million. And unlike the standard settlement awarded to families, the money paid to NICA's attorneys has increased over the years — from \$75 an hour to as much as \$400, depending on the assignment.

The \$100,000 lump sum paid to families dealing with hardship remains set at the same level as 1988, although it has half as much buying power. The \$5,000 annual assessment for obstetricians is also the same as in 1988, even as the cost of every other type of insurance, including standard malpractice coverage, has gone up.

Also unchanged is the program's reliance on Medicaid. NICA has saved the state's medical malpractice insurers hundreds of millions of dollars in payouts to families by shifting some of those costs onto Florida and U.S. taxpayers through Medicaid —though that policy is currently the subject of a pending whistle-blower lawsuit in federal court.

'BAD BABY'

Jasmine Acebo was born on July 26, 1989, at 6:06 p.m. Her time in NICA dates back nearly to the program's inception, making her mom — as much as anyone in Florida— an authority on the program, and her records, 4,639 pages of which were obtained by the Herald, an archive of its practices.

Her mother recalls the birth vividly.

Then barely 20, Acebo lay in her bed at Hollywood Memorial Hospital, groggy and exhausted. She had given birth for the first time two hours earlier, and she still hadn't seen her baby. Her cousin, who was working a shift that night as a neonatal intensive care nurse, walked in. She wasn't smiling.

Even through the fog, Acebo could tell that a somber Madeline Otero wasn't there to offer congratulations. "She had her nurse's hat on," Acebo said, "not her cousin's hat."

She handed Acebo a Polaroid: A tiny newborn, lost in a tangle of tubes. A ventilator in her mouth. A drain from her stomach. An IV in her scalp, the only place nurses could find a vein. A heart monitor. Wires and cables.

As the gravity of what she saw gripped her, Acebo silently prayed: *Oh my God. Lord, save her. Heal her. Make her better so I can take her home. Heal my baby, please.*

In an April 1993 deposition that was part of the NICA screening process, NICA's paid medical expert said that during Jasmine's delivery the doctor trying to break Acebo's water pierced the placenta that carried blood and oxygen to her brain. As her lifeblood drained away, so too did any chance for Jasmine having a normal life. What she would have in abundance — besides unrelenting pain — was her mother's devotion.

Jamie Acebo faced a future she could not comprehend. A friend, a paralegal who had just delivered a stillborn baby, made an appointment for Acebo to see a lawyer and accompanied her to the consultation. When Acebo described the case to the lawyer, he told her about NICA. In his sworn testimony, the NICA expert described how, most likely, Jasmine's placenta was inadvertently punctured during an attempt to hasten labor. Her heartrate plummeted from the normal 140 beats per minute to 65.

"That's bad, isn't it?" the expert witness was asked under oath.

"It sure is," he replied. "It's as if they shut off the blood supply of this kid."

"They got what we would consider to be a less-than-optimal infant," the expert said.

In more stark language, he called Jasmine a "bad baby," apparently referencing the law's nickname.

Frank Rainer, general counsel for Memorial Healthcare System, which owns the hospital where Jasmine was born, said in a prepared statement that "even with the best intent, the best medicine and the most skilled experts, there is still a possibility of a negative outcome anywhere in medicine."

He added: "High-risk obstetrics has become a challenging service to provide in our community because of the small pool of highly specialized physicians available and the risk of costly litigation in this field."

Reporters were unable to reach the obstetrician who delivered Jasmine in 1989.



Jamie Acebo holds a friend's daughter in one arm and holds her baby daughter, Jasmine, steady on the table during a birthday celebration for Jasmine.

Most children accepted into NICA are diagnosed with an injury called hypoxic-ischemic encephalopathy — one of Jasmine's conditions — in which oxygen deprivation and limited blood flow cause damage to a baby's brain during childbirth. The condition can result when the umbilical cord is wrapped around a baby's neck or when a mother's uterus ruptures. Delays in performing Cesarean sections can contribute to brain damage.

When NICA was signed into law, Florida OB-GYN insurance premiums were among the highest in the country, especially in South Florida. NICA claims the program has reduced medical malpractice premiums for obstetricians from what they would otherwise be by between \$62,000 and \$88,000 a year — and \$1,200 to \$1,800 annually for all other doctors. An actuarial study of NICA reported by an organization of Florida OB-GYNs in 2015 arrived at a similar conclusion, finding that the program saved obstetricians on average \$57,535 a year in the cost of their malpractice insurance.

That said, obstetricians in Miami-Dade and Broward counties still pay among the highest malpractice insurance rates in the nation — higher than doctors in states without a NICA program.

NICA said Florida continues to experience a medical liability crisis because of excessive lawsuits, but that "the situation is unquestionably better than it would have been if not for NICA."

‘HAVING YOUR STOMACH RIPPED OUT’

R. Fred Lewis both defended and sued insurance companies before then-Gov. Lawton Chiles appointed him in 1998 to the Florida Supreme Court. He and his wife, Judy, also raised a severely disabled child, although one not covered by NICA.

He likened learning of his daughter’s disabilities “to having your stomach ripped out.” “That pain of not knowing what will happen when you are not around — that is a devastating burden to carry,” Lewis said of his now-deceased daughter, Lindsay Marie.

Lewis, now a law professor at Florida Southern College, called the claim that doctors were fleeing the state — the justification for NICA and other lawsuit restrictions —an “absolute lie.” “But if you tell a lie long enough and hard enough, people will believe it,” he said.

Far from a loss of obstetrician-gynecologists, the number of Florida OB-GYNs actually grew from 546 in 1975 to 911 in 1983 to 1,047 in 1987, the year before NICA was adopted. That’s a 92% increase during a time when Florida’s population grew 70%. As of last June, the most recent tally, the number of Florida OB-GYNs hovered around 2,000. NICA administrators, however, say there was “an actual exodus of obstetricians from the state’s hospital delivery rooms” before NICA’s passage as some chose to limit their practice to gynecological care.

Lewis said NICA was in fact part of a broad-based state and national movement aimed at expelling jurors from the civil negligence system — an effort that sought to minimize compensation for plaintiffs by leaving justice in the hands of administrative judges, who are appointed by the governor and Cabinet and don’t answer to voters.

“They are trying to do away with jury trials in the state, and I find it very troubling,” he said.

JUST SAY NO

NICA says it is set up to pay families for the treatments and services they need. But an examination of thousands of pages of court records and internal documents found that the answer to many requests is no.

A mother wanted a nurse to care for her child on the school bus. “NICA does not pay for nursing services at the school,” the program responded.

A father requested a blender to puree fresh fruits, vegetables and meat for his 5-year-old son’s feeding tube. “We need a medical reason why [the child] needs blenderized food rather than baby food which is already pureed and available,” an administrator said.

A parent asked for a higher electric bill subsidy during Florida's sweltering summer. "AC is wonderful and we all want it, but it is not medically necessary," the director, Shipley, wrote.

And NICA sometimes rejects a specific request from one family only to approve it for another family later. A case manager told Acebo that NICA could not pay Jasmine's longtime personal nurse while Jasmine was hospitalized with gallstones in May 2016. This past year, the program offered to do exactly that for two other families whose children were hospitalized with COVID-19, calling the pandemic "extraordinary and unprecedented."

In its dispensing of care, NICA typifies much of the state's effort on behalf of Floridians with special or critical health needs: Florida ranks near the bottom for virtually every measure of the state's spending on services for people with disabilities.

"NICA is set up like most insurance companies," said Sean Shaw, who served as the state chief financial officer's consumer advocate from 2008 through 2010. "It's set up to not pay claims."

When deciding which requests to grant as "medically necessary," NICA staff, including those with training in health care fields, often defer to Shipley. The executive director, paid \$176,900 a year, is a former insurance claims adjuster and is not a doctor.

Hired in 2002 at \$118,000 a year, Shipley, who supervises a staff of 16, currently makes \$30,000 more than the director of the state Agency for Persons with Disabilities, who heads a department with 2,700 employees.

Though NICA may function like an insurance carrier, some of its practices exist practically nowhere else in the insurance world.

Nearly every time they submit a bill, parents are required to sign "perjury statements" attesting at the risk of criminal prosecution that they are not committing fraud. That includes minor invoices for blood work, medications and travel to doctor appointments.

A mother complained to NICA about the suspicion she endured when trying to get reimbursed for her child's medications: "She spoke for about six minutes straight as to how humiliating it is for her to deal with NICA" and "having to deal with employees who laugh at her and her troubles," a case management log said.

NICA said the perjury statements are a safeguard "to prevent health care fraud" after "unfortunate instances of some claimants falsifying documents and misrepresenting payments when seeking reimbursement." The Herald asked the agency for examples of such fraud. NICA said it would not provide specifics.

TRAPPED IN HER ROOM



By the time she was 11, Jasmine had a pump for her feeding tube, a pulse oximeter, a tank of concentrated oxygen, a humidifier for her artificial airway, a nebulizer and other equipment paid for mostly by Medicaid. Family Photo

By the time she was 2, Jasmine had a permanent feeding tube and a tracheotomy to help her breathe. She constantly cried, and rarely slept, meaning Acebo rarely slept, “awakened by Jasmine’s gasping and choking,” the family’s lawyer wrote at the time. Jasmine required round-the-clock care.

The entire family sacrificed for Jasmine’s needs. Jamie’s younger daughter and son missed family Thanksgiving dinners and her church’s Easter egg hunts. The younger daughter could never play on the school soccer team or be a cheerleader. Her son never got to join the football or basketball teams.

From the day of Jasmine’s acceptance into NICA in June 1993, Acebo said administrators did virtually nothing on her behalf until either she or her daughter’s nurse begged them.

By age 11, Jasmine had a pump for her feeding tube, a pulse oximeter, a tank of concentrated oxygen, a humidifier for her artificial airway, a nebulizer and other equipment paid for mostly by Medicaid. The family got a wheelchair-accessible van from NICA to transport Jasmine.

When Jasmine was 13, she, Acebo and her 70-year-old grandmother were living in Acebo’s 993-square-foot childhood home in Hollywood. The hallways and bathroom were too tight for Jasmine’s wheelchair, requiring two people to lift her 73-pound frame. She was sponge-bathed in bed, and her hair was washed in the kitchen sink, Acebo wrote in a two-page letter to NICA, pleading for help in August 2002.

“I love my daughter dearly and I am only requesting on her behalf a reasonable solution so that we can improve her quality of life and make her as comfortable as we can possibly make it for her.”

Records show NICA paid for a home modification a year later.

Over time, as Jasmine needed more medical equipment, Acebo's electric bill spiked from about \$100 per month to \$500, she said. In 2007, the electric company threatened to shut off the power when her unpaid tab rose to \$2,099, records show.

NICA paid what was in arrears, then made Acebo pay the program back in twice-monthly \$50 installments, records show. In an email to reporters, NICA called the "no-interest loan" a "goodwill gesture beyond the regular support provided to the family."

At the same time, NICA caseworkers offered Acebo an electricity offset of \$25 per month for future power bills.

It was then that NICA mentioned it could pay Acebo to care for her daughter at home. That was news to Acebo. For the first nine years of Jasmine's life, Acebo said, Medicaid was paying for four hours of in-home nursing care daily, meaning that Acebo became her daughter's de facto nurse the rest of the time, suctioning her artificial airway, filling her gastrostomy tube and managing other medical equipment.

Now she learned that NICA could pay her a minimum-wage salary to stay at home and do those things. It had been that way for years.

Acebo asked about back pay. NICA said no.

Because her daughter needed constant supervision — and Jamie Acebo needed to sleep — Acebo retained in-home nursing. But the nurses she could hire at Medicaid's low reimbursement rates often were unreliable, a common refrain among NICA parents hamstrung by the low payment schedules. In one 2006 instance, NICA's case management log shows she called to report that "the night nurse was sound asleep, the humidifier was empty of water, the machine was very hot and Jasmine was having trouble breathing."

Some of Acebo's greatest frustrations involved getting Jasmine from place to place: Acebo said, and NICA's records largely confirm, that she struggled for years with wheelchairs that were too small for Jasmine's expanding frame, with a stuck wheelchair lift on her van and with the van itself, which constantly broke down.

NICA told reporters it bought Acebo a wheelchair in 1999 and adjusted it in 2001. Jasmine's log noted four years later: "Old chair cannot be made any bigger."

"They kept modifying the same wheelchair," Acebo said. "I'm telling them the wheelchair isn't fitting her properly and they're just sending out mobility companies, and the guy is coming out and saying, 'Look, we can't stretch it out anymore.' "

NICA bought Jasmine a new wheelchair in February 2006, at a cost of \$7,751, the log said.



Jamie Acebo holds a favorite photograph of Jasmine, her first-born child. Emily Michot, Miami Herald

In the ensuing 11 years, Jasmine’s muscles and joints stiffened, a common condition among people with cerebral palsy. Her legs gradually drew up, splaying her knees outward — and drawing her feet inward — as if in some cruel, lotus-like pose. It eventually became impossible for Jasmine to fit in the chair, Acebo said. There is no record of Jasmine getting another wheelchair. NICA administrators said they never turned down a request for a new wheelchair, but Acebo said NICA already knew Jasmine’s had reached its limit and could no longer be expanded.

Jasmine, who had been taken for long wheelchair strolls around the neighborhood, even trick-or-treating in her previous one, became a captive, Acebo said. “She doesn’t go outside anymore. I don’t have a way to get her outside,” Acebo said she told NICA.

Jasmine’s van was a similar story, Acebo said. In July 2002, NICA provided Acebo the modified van. By May 2005, the van’s wheelchair lift was broken, and it took nine months for the repairs — authorized and paid for by NICA — to be made, records show. After that, Acebo said the van was frequently inoperable, and it sat in her driveway corroding with rust.

ACEBO TIRES OF HER DAUGHTER BEING EXAMINED IN THE LOBBY

Subject: Re: 777639507634

Yes i'm not taking her to [REDACTED] I'm going to take her to [REDACTED] he has been the one for the last couple of months admitting her in the hospital and I told him I wanted him to take over her case permanently and he said he be happy to. [REDACTED] office can not accommodate her they always see her downstairs in the lobby or in a empty room full of medical equipment. So [REDACTED] is where we will be going.

Sent from my iPhone

On Nov 7, 2016, at 10:25 AM, [REDACTED] wrote:

Do you have a plan for transport and everything???? Will the office accommodate Jasmine's needs?

Thanks,

[REDACTED]

In April 2011, NICA signed over the van's title to Acebo. "NICA will no longer pay repairs or insurance," the log said. Henceforth, the notation added, the program would "pay for ambulance transportation for Jasmine when she needs to go to the doctor's office."

NICA told the Herald that the van "went unused for long periods of time" and that Acebo "did not submit a request for another van." Acebo said the van went unused because it was always broken. She said NICA knew Jasmine was entitled to a new van — or should have known. The handbook says vans will be replaced at "approximately 7 years or 150,000 miles." Acebo's was older than that.

In response to questions from the Herald and ProPublica, NICA said that using ambulance rides instead of replacing the van was "a better fit for meeting the needs of the family, and that the family was pleased with this result." Acebo said she was anything but pleased.

Jasmine's many doctor appointments were now especially challenging, Acebo said. She would call an ambulance or transport service to take Jasmine from her home to her North Miami Beach pediatrician. But the stretcher was too big to fit in the office elevator, and the doctor would descend to the lobby and examine Jasmine there —in front of strangers — or, alternatively, in a storage room.

When Acebo complained to NICA about her daughter being on display, caseworkers suggested she find a doctor who would make house calls, she said. Acebo found a doctor whose office had wider elevators.

NICA EMAIL TO ACEBO OFFERS TUTORIAL ON HOW TO GET HELP

Suppliers should note that neither physicians' orders, nor supplier-prepared statements, nor physician attestations by themselves provide sufficient documentation of medical necessity, even though they may be signed by the treating physician or supplier. There must be information in the patient's medical record that supports the medical necessity for the item and substantiates the answers on the CMN (if applicable) or DIF (if applicable) or information on a supplier prepared statement or physician attestation (if applicable). (See Medicare's Program Integrity Manual (PIM), Chapter 3 (<http://www.cms.gov/Regulations-andGuidance/Guidance/Manuals/downloads/pim83c03.pdf>

* The patient's medical record is not limited to the physician's office records. It may include hospital, nursing home, or home health agency (HHA) records and records from other health care professionals.

, Section 3.4.1.1,

for additional instructions, regarding review of documentation during pre- and post-payment),

One saving grace was that the ambulance rides were Jasmine's sole contact with the outside world: sunlight streaking through the windows, a breezy gust before entering the building, people to watch in their go-to-work clothes. "Then she would come back home and go into that room," Acebo said.

In the fall of 2016, Jasmine developed her first pressure sores during hospitalizations for gallstones. Her doctor prescribed a specialized \$900 air mattress to prevent the bedsores from worsening, but Medicaid refused to pay. "I'm not going to have my kid suffer," Acebo wrote to her caseworker, "while Medicaid jerks me around with all this red tape."

Acebo faxed over prescriptions and emailed color photos of her daughter's wounds. Her caseworker replied in a Nov. 17, 2016, email: "Neither physicians' orders, nor supplier-prepared statements, nor physician attestations by themselves provide sufficient documentation of medical necessity."

NICA agreed to pay the next week.

FIGHTING PARENTS

By strictly defining what medical care is necessary, NICA administrators were able to hold down costs. Asked by a NICA attorney what constitutes medical necessity, one of NICA's pediatric neurology consultants offered this explanation in a 2005 sworn statement: "If it were not administered, there would be a worsening of a patient's medical situation." Parents, trying to give their children the comforts and care that other families take for granted, bristled.

David and Esther Morgan encountered NICA's interpretation of medical necessity in 1997. NICA refused to pay for a TV and VCR so 3-year-old Melinda Morgan, at the time enduring the misery of kidney stones and compression fractures on top of her profound birth injuries, could watch educational videos in her bed and, in the words of her behavioral therapist, "escape the pain and frustration of her physical condition."

Her father appealed and was grilled in a deposition by a lawyer from NICA, who asked him to swear that no one else in the family was watching the TV.

Even with Morgan's assurances, NICA rejected reimbursing the \$500 cost of the TV and VCR. The family's conflict with NICA would expand into a yearlong legal fight over an ever-increasing list of issues, ranging from in-home nursing care to high electric bills to accessibility modifications for the Morgans' home. NICA didn't like the judge's ruling, appealed, then settled in an agreement that remains secret except for the cost of the lawyers: \$172,000.

Despite the long slog through the courts, David Morgan still relies on NICA to help with his fragile, now 27-year-old daughter, and he has made his peace with the program.

"NICA has turned out to be a lifesaver. I would be in total bankruptcy if it weren't for NICA."

'THE ILLS OF PANDORA'S BOX'

NICA's legal clash with Flor Carreras over a new therapy that could free her daughter from a lifetime attached to a feeding tube also included administrative hearings, entreaties to an appellate court — and a \$2,009 trip to Costa Rica by NICA's then-administrator and a consultant.

Starved of oxygen in the womb, Maria Theodora Carreras was born in February 1989 with severe brain damage — years later, a neurologist wrote, she was still functioning at the "newborn" level — and dysphagia, a disorder that makes it difficult to swallow and causes chronic lung infections and recurring fevers.

Carreras, who could not be reached by the Herald, found hope for Maria Theodora in a Hungary-based doctor who used electrical stimulation of the palate and throat muscles to help children overcome the disorder. Maria Theodora's pediatrician and therapist recommended the therapy. She asked NICA to pay for it.

NICA said no, warning in a legal pleading that approval would "literally unleash the ills of Pandora's Box against the [program's] funds." Carreras took Maria Theodora to Budapest anyway and she then asked an administrative judge to make NICA reimburse her for the treatment and travel expenses.

The judge wrote that Maria Theodora was later able to swallow water from a bottle, as well as bits of banana, mango and peaches. She also had fewer fevers, a stronger cough reflex, and less drooling and wheezing — evidence of decreased aspiration.

Carreras' determination to give her daughter the pleasure of eating would prompt a three-year legal battle — and a trip by NICA's then-administrator, Lynn Larson, and a consultant to the former Miami family's new home in Costa Rica to judge for themselves whether the girl had benefited. In December 1995, a Miami appeals court sided with Carreras, ordering NICA to pay for the treatment — and the litigation.

Larson declined to discuss NICA, citing a nondisclosure agreement she signed when she left the program in 2002.

At a Miami hearing that year, Maria Theodora's pediatrician, Dr. Alberto Saenz Pacheco, accused NICA's attorney of trying to force Carreras to abandon hope that her daughter might someday eat on her own. "You're just condemning her to the tube feeding the rest of her life," he said.

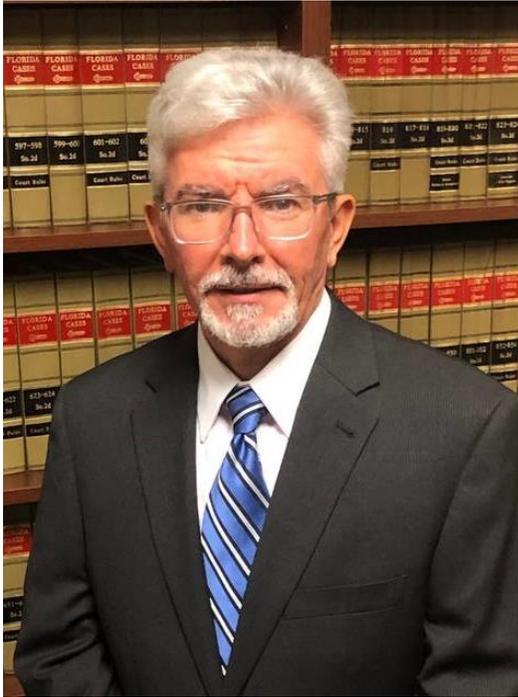
The total bill for Maria Theodora's treatment was \$11,058. The fight over it: \$80,000 in fees and costs for the family's lawyers, whom NICA ultimately was ordered to pay, and about \$44,000 for NICA's own lawyers.

Celia and Curt Lampert's now-23-year battle with NICA has so far included three appeals to the Division of Administrative Hearings, a class-action lawsuit and two trips to the First District Court of Appeal in Tallahassee. The family's relationship with their son Tyler's health care provider became so antagonistic that NICA twice hired a private investigator to tail them. The Lamperts declined to discuss Tyler or NICA, but documents detailing the agency's history with the family show NICA administrators were suspicious that the parents were exaggerating Tyler's needs.

In December 2003, Curt Lampert called NICA's claims manager. "He is upset because he feels that we are playing God with his son's health," said the log entry. "He went on to state that he didn't think Kenney [Shipley] or I cared."

After the Lamperts appealed NICA's denials, the program hired a Pompano Beach private investigator to shadow the family, which, by then, was in the process of moving to a suburb of Atlanta. The investigator billed for nine days of surveillance during two weeks in August 2005, including airfare, a hotel, rental car, meals and video, for a total of \$10,387.

The investigator reported the quotidian details of Celia Lampert's life: Lampert takes her son to an appointment at Sunshine Therapy. Lampert takes Tyler to Wendy's. Lampert walks her "two small dogs on leashes." Lampert buys dinner at a Burger King drive-thru. Tyler and his mom visit Blockbuster Video. Tyler swims inside his hotel swimming pool and dries himself with a blue towel. Mother and son shop at Target and later eat at Chuck E. Cheese.



Attorney David Caldevilla has represented families involved in disputes with NICA involving disputes over their disabled children.

Without addressing the Lamperts directly, NICA told the Herald it hired the investigator — the only time it did so — because the program “perceived inconsistencies between a child’s medical condition and [the] family’s requests related to the child’s condition.”

The Lamperts’ battles with NICA included requests for a wheelchair, as well as a therapy designed to improve the muscle tone in Tyler’s arm — which NICA rejected. In an August 2005 order, an administrative judge said that, in denying the wheelchair, NICA “failed to objectively consider Tyler’s limitations, and overlooked the testimony” of its own expert — who had said a wheelchair was “appropriate for[Tyler’s] use.”

A fight over compensation for the Lamperts’ caregiving hours prompted more litigation, beginning with a 2006 class-action lawsuit filed on behalf of NICA families by Tampa lawyer David Caldevilla. The suit sought to enforce the law requiring NICA to pay parents for the time they spent as unpaid nurses — even as some of them had been forced to quit their jobs to perform that role.

Fifteen months after the lawsuit’s settlement in November 2012, Shipley told the Lamperts they were eligible for up to 12 hours per day of paid caregiving. But the administrator rescinded the offer amid a disagreement over how much care Tyler required and whether the couple was owed back pay.

In 2015, Judge Barbara Staros ordered NICA to restore the original offer of 12 hours of paid daily caregiving.

In a footnote, Staros weighed in on one of NICA’s accusations against Celia Lampert, whose zealous advocacy for her son had so bedeviled NICA.

She wrote: “NICA’s characterization of Mrs. Lampert’s role in Tyler’s [care] as ‘over-active involvement and manipulation’ is rejected.”

Over 11 years, the class-action battle cost NICA \$2.8 million, spread among 10 law firms. NICA was also forced to pay Caldevilla \$96,610 in legal fees for representing the Lamperts. NICA has spent \$412,986 in legal fees battling with Tyler’s family, some of which is included in the

\$2.8 million. That means, in total, NICA has spent just shy of a half-million dollars in litigation wars with the Lamperts.

‘WITHOUT CARE OR KINDNESS’

NICA administrators and their allies long have maintained that families were satisfied with the program and grateful they were spared the uncertainty and heartache of a protracted malpractice litigation.

“Recipients are seen to be receiving excellent care, and participating families are overwhelmingly satisfied with the level of service, and they support the system,” the Florida Obstetric and Gynecologic Society, wrote in a February 2007 report.

NICA’s own records over the past two decades raise doubts. Around 2001, seven NICA families complained to the state’s insurance commissioner.

They said Larson, executive director at the time, never disclosed the benefits they were entitled to receive, failed to meet some “covered needs” and showed favoritism in dispensing needed care, minutes of a NICA board meeting say.

A survey by the Florida Insurance Commission at the time found that more than two-thirds of NICA families polled reported they “were treated without care or kindness.”

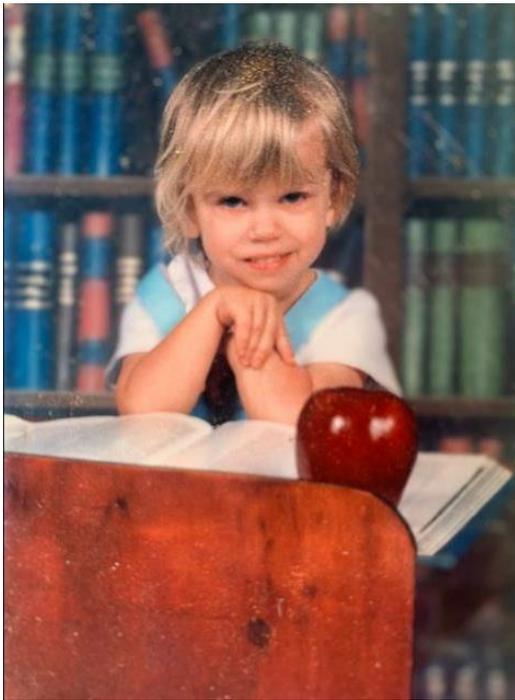
Shiple was hired the next year, the program said, and made several changes, including developing NICA’s website, producing the program’s first benefits handbook and ensuring parents knew about some benefits, such as reimbursement for gas and mileage.

Another round of complaints — this time to lawmakers — prompted a second survey. But this one, completed in 2012, reached a far different conclusion: that most NICA families were happy. The survey noted that many parents wanted NICA to switch to direct deposit for reimbursement and caregiving checks, and that many families found the program’s benefits handbook “confusing.”

It took seven years after that for NICA to make electronic banking available to families. The agency said the process was time-consuming and required multiple security measures to protect sensitive information.

The two surveys had key differences: About 85% of NICA parents responded to the first survey. Half of the families ignored the second one. And while the first survey was administered by the state insurance commissioner, the second was done by one of NICA’s lobbyists, whose firm has been paid more than \$440,000 since 2011 to represent the program.

In 2017, the parents of Delaina Parrish — a NICA child who astonished and delighted doctors by graduating from college last year and launching a career despite her physical disabilities —



Delaina Parrish was born without the ability to walk or speak words. She was accepted into NICA. Source: Family photo.

attended a board meeting to urge administrators and board members to “help families.” Patricia and Jesse Parrish said NICA staff was “denial-driven,” not motivated by compassion, wouldn’t publish meeting dates and set arbitrary limits on what they’ll pay for.

The Herald asked the Parrishes late last year if the program has improved since then. Patricia Parrish said she is disappointed NICA still has not added a parent to the board, doesn’t inform parents of new benefits and won’t encourage other parents to attend meetings and offer input.

She said: “Why do they get to play God?”

Though unable to communicate verbally, Delaina Parrish uses a computer that tracks the movement of her eyes and generates words and sentences on a monitor or through an automated voice. The technology was provided by the manufacturer, not NICA.

Now 23, the University of Florida grad has a consulting business and a platform from which to advocate for others with disabilities. She was accepted into NICA when doctors believed it was likely that the 11 minutes she was deprived of oxygen at birth, requiring resuscitation, would impair her mind, as well as her body. But Parrish’s intellect is as vibrant as any.

In a recent interview, Parrish said the program looks only at “what is required at the minimum” when deciding whether to help those in its care.

“If we don’t have their financial support,” she added, “we can’t live our best lives.” NICA disputes that administrators don’t make families aware of their benefits and options. The program “regularly informs families in advance about care and services that might improve their situation,” administrators said.

As an example, the program noted it offered last year to buy \$29,000 robotic “exoskeleton” suits to help some children strengthen the muscles in their legs. “NICA staff contacted all families with a child who could benefit from” the technology, NICA said, “and then assisted them with the process to get this new equipment capable of improving their daily lives.” Five clients have gotten them so far, NICA said.

The publicist NICA hired to burnish its image urged news organizations to publish stories about the device. Shipley, the executive director, said in an email to the technology's developer that NICA was "looking to do a positive news story" about the equipment.

In the months after NICA hired its media consultant, the program did something it had resisted for most of its 33 years: It considered legislative change.

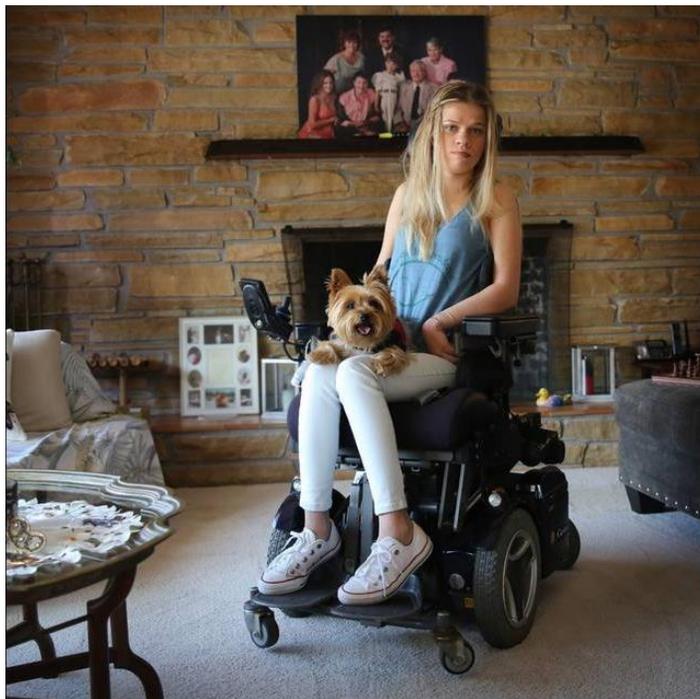
Once before, lawmakers introduced a bill that would have required NICA to operate with greater transparency and "in a manner that promotes and protects the health and best interests of children" in its care.

That bill, in 2013, required NICA to inform families in writing each year of the "types and full amounts of benefits available from the plan for the injured child's "projected needs. And it proposed adding a NICA parent or guardian, as well as a Florida lawyer, to the board of directors.

That's the legislation that Shipley dismissed as "pretty silly" in a 2013 email to NICA's lobbyists. One board member warned that while the proposals "sound innocuous, "they could result in "all sorts of bad law" being forced upon the program. Another board member wrote: "If it's not broken, don't fix it."

The bill died in committee.

Now, with the public relations firm brought into the fold after the Herald submitted a series of public records requests and questions to NICA, the agency is proposing legislation. It would increase the one-time parental award from \$100,000 to \$250,000. The bill was amended to raise the death benefit from \$10,000 to \$50,000.



Delaina Parrish is today able to communicate because of a machine that translates her eye movements into words. The machine came from the manufacturer, not from NICA. She recently graduated from the University of Florida.

Even if it isn't approved, the proposal could serve a second purpose, one of NICA's publicists noted in a February 2020 internal email: "Making a public announcement about [it] would help greatly to insulate NICA against media criticism."

A RENTED CASKET

Every year, Jamie Acebo wondered if it would be her daughter's last. Her last birthday. Her final Christmas. The last time hearing her siblings tease each other around the dinner table.

In the spring of 2016, Jasmine was hospitalized with gallstones. Jamie Acebo had other children at home, so she arranged for Jasmine's nurse to work her shift at the hospital, ensuring Jasmine was repositioned and bathed, her airway suctioned, her feeding pump refilled properly.

Acebo and Jasmine's nurses recognized the subtle, nonverbal signs others missed: Jasmine would grind her teeth and bite her lips when she needed medicine for the pain. That was the only way they knew, and could ask for pain medication.

When NICA administrators found out about the NICA-paid nurse deployed to the hospital, they moved to claw back \$2,240 from Acebo — money she didn't have.

"We are not required to pay a private professional caregiver during a hospital stay," Shipley wrote.

After an attorney pleaded Acebo's case, Shipley offered to let Acebo repay the money in \$25 weekly installments.

In the winter of 2017, Jasmine was hospitalized again with gallstones, and her prognosis wasn't good. Because of Jasmine's fragile state — and her profound disabilities — none of Jasmine's doctors was willing to perform necessary surgery. "Right now it's in the hands of God," Acebo wrote in a Feb. 27, 2017, email to her caseworker.

Acebo said she was repeatedly encouraged to sign a "do not resuscitate" order.

Jasmine's mom said, and wrote in emails at the time, that one of the doctors reminded her that Jasmine was "not a productive member of society" and had, in any event, exceeded all expectations by living more than a quarter-century.

"You know, she's had a lot of miracles, and I think hers are just about up," she said she was told by one of Jasmine's doctors.

Acebo's answer: "If God wants her, he's going to have to come and get her, because I'm not signing a DNR."

NEUROLOGICAL INJURY COMPENSATION PLAN

Itemized Charges:

14	Nursing Care by Parents 3/13/2017-3/19/2017	504-S	\$1,050.00	14	Miscellaneous 3/20/2017- 3/20/2017 fed ex	504-T	-\$33.34
14	Miscellaneous 12/30/2017- 3/6/2017 fed ex	504-T	-\$299.58				

152945

Fed ex 3/20/2017

Memo: ACEBO: NURSING CARE BY PARENTS, MISCELLANEOUS

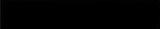
03/20/2017

152945



\$717.08

PEMBROKE PINES, FL 33020



Items:

Description	Amount	GL Code
Nursing Care by Parents 3/13/2017-3/19/2017	\$1,050.00	504-S
Miscellaneous 12/30/2017-3/6/2017 fed ex	-\$299.58	504-T
Miscellaneous 3/20/2017-3/20/2017 fed ex	-\$33.34	504-T
Total:	\$717.08	

But as Jasmine’s condition worsened, doctors warned Acebo that the stress of reviving her would result in cracked ribs, one more excruciating indignity for a daughter who had endured them all her life.

On March 19, 2017, Acebo signed the DNR. She held Jasmine’s hands, stroked her face and whispered, “Mommy loves you.”

“You don’t have to fight for me no more,” Acebo said. “You can go home.”

“And, once I said that, the monitors just started to go down.”

The last entry in Jasmine’s NICA case management log is a payment to a funeral home.

Even in Jasmine’s death, Acebo felt betrayed by the program. Acebo was left with a choice: She could afford a funeral, or a burial, but not both.

The \$10,000 NICA pays as a death benefit was adopted in 2003, nearly two decades ago. Costs have gone up.

Though Acebo's Baptist faith eschews cremation, it was the only choice she could make — a casket burial was beyond her means, she said. For \$3,500, she rented a casket, which was returned after the service. Jasmine was then cremated.

Jasmine's ashes rest in an urn atop the dresser in Acebo's bedroom in her Pembroke Pines home.

NICA administrators told the grieving mom to forget about the remainder of the \$25-a-month repayments.

On the day after Jasmine died, Jamie Acebo received an email from NICA. Administrators were mailing Acebo her final paycheck for her time taking care of Jasmine. Total earned: \$1,050.00.

But NICA was not yet paying by direct deposit, despite parents clamoring for that in the survey five years earlier. Acebo received her checks by FedEx, and the delivery service costs had piled up. NICA insisted on being reimbursed.

NICA deducted \$332.92 for three months of FedEx charges, whittling her final paycheck down to \$717.08.

Miami Herald

April 8, 2021



Ruth and Jean Jacques filed a complaint with the Florida Department of Health. They said they received a form letter back. Courtesy of the family.

Distraught over dead son, mom can't sue doctor. Doctor can threaten to sue her, though

By Carol Marbin Miller and Daniel Chang

ORLANDO- On the day Reggie Jacques was born, doctors at Winnie Palmer Hospital in Orlando told his parents that there was no hope, that his brain had gone too long without oxygen during his difficult birth. But Reggie refused to die.

On his sixth day, said parents Jean and Ruth Jacques, doctors urged them to remove Reggie from his ventilator. They said he would surely stop breathing. The couple agreed a month later. But Reggie wouldn't die.

Around Day 60, doctors asked the couple to sign a “do not resuscitate” order. They declined. And Reggie still refused to die.

For 95 days, Reginald Jacques refused to die.

But on the 96th day, Sept. 19, 2016, something felt wrong. Ruth Jacques surrendered to an irresistible impulse to hold her son after a day’s work for an Orange County social services agency. “I was driving the car like a madwoman,” Jacques said of her early-evening trip to the hospital.

Jacques flew through red lights. Uncharacteristically, she left her car in a parking space for disabled drivers. She ran up three flights of stairs to the Neonatal Intensive Care Unit, where, she said, Reggie’s monitor was beeping, and he appeared to be in distress.

She picked up her infant son from his bassinet — all tubes and bandages and chirping monitors — and placed him gently on her chest. “With the little strength he had left, he lifted up his head and looked back at me,” she said.

“One minute later, his heart stopped. It was more like our heart stopped.”

Four years later, Ruth Jacques’ heart beats for two as she wages a campaign to demand answers from the doctor who delivered her son. She believes Florida’s state-sponsored Birth-Related Neurological Injury Compensation Association, or NICA, robbed her of the right to seek justice through the courts for the harm he suffered at birth and three months of agony as he fought for life.

Florida lawmakers created NICA in 1988, responding to obstetricians’ complaints that their malpractice insurance premiums were too high. The law bars parents like Jean and Ruth Jacques from pursuing lawsuits against doctors and hospitals when a baby is born with catastrophic, even fatal, brain damage from oxygen deprivation or asphyxia during childbirth.

If the birth injury meets NICA criteria, even in cases where the doctor or hospital may have made a glaring error, parents typically have little choice but to forgo a lawsuit and accept the program’s compensation, which consists of a \$100,000 settlement upfront, and “medically necessary” and “reasonable” health care for the duration of the child’s life.

If the child dies, there is an added \$10,000 funeral benefit.

The Jacqueses hoped to sue their obstetrician and hospital for negligence, only to learn from their attorney of the law that created NICA. Stripped of that right, they settled for filing a malpractice complaint with the Health Department. They received a form letter saying their complaint had been dismissed because the doctor’s actions did not violate the profession’s “standard of care.” There was no further explanation. Ruth Jacques said neither she nor her husband was interviewed by investigators.

The Jacqueses cannot appeal the investigation’s outcome, or even read about it, beyond the form letter. In Florida, those records are sealed and available only to the doctor.

That wasn’t the state’s only betrayal, Ruth Jacques said.



Jean Jacques snuggles next to the son he would never bring home from the hospital. Family Photo.

The day after Reggie’s death, overcome by anger and despair, she did the only thing she could think of: She printed leaflets warning prospective patients to stay away from Dr. Ricardo Lopez, the obstetrician who delivered Reggie. She said she handed them out in front of his Orlando medical office — and distributed a few to patients in his waiting room.

“I felt like the world was shutting me up,” she said. “I wanted to be heard.”

Ruth Jacques said she was silenced again. She learned that Lopez was free to do what she could not: file a lawsuit. Her attorney told her that if she persisted in protesting, she might end up a defendant.

A lawyer for Orlando Health, which owns Winnie Palmer and employs Lopez, wrote to the Jacqueses’ lawyer in January 2017: “I respectfully demand that Ms. [Jacques] cease and desist from further attacks on Dr. Lopez and [the hospital] regarding this matter.” Then the couple’s lawyer wrote to Ruth Jacques.

“I understand your anger,” the lawyer explained in an email. But, she added, “Any kind of verbal attack or public complaint about Dr. Lopez or Orlando Health could lead them to sue you and your

husband personally.”

Alayna Curry, an Orlando Health spokeswoman, said the hospital would not discuss Reggie’s calamitous birth, even though his mother has.

“Our medical team respects the wishes of our patients when it comes to their delivery experience,” she said in a prepared statement. “When a medical emergency arises during a delivery, time is of the essence and our physicians will speak with the patient about the recommended course of action.”

‘YOU BETTER PUSH’

There is sharp disagreement over precisely what was said and when inside the delivery room. Ruth Jacques provided the Herald a copy of her medical records, which contain a notation from Lopez that, based on “severe” fetal heart recordings, “a C-section was offered.”

“The patient refused,” Lopez wrote.

A nurse also reported “Pt refused C-section” in a notation dated two days after Reggie was delivered. Jacques said she did no such thing, and the records do not contain a signed form from the mother refusing a C-section. The form is considered an industry “best practice,” but not a requirement.

HER LAWYER TELLS RUTH JACQUES SHE NEEDS TO STOP CRITICIZING REGGIE'S OBSTETRICIAN

I also want to confirm our discussion on the phone today about the leaflets and online posts you have been making about Dr. Lopez and Orlando Health, and what happened to Reginald. I understand your anger, and why you wanted to do that. But as I have told you in the past, those are a very bad idea. Any kind of verbal attack or public complaint about Dr. Lopez or Orlando Health could lead them to sue you and your husband personally. This is true no matter what negative thing you say about them, but it's especially true when you use terms like "_____" that imply that they caused Reginald's death on purpose. Writing that kind of untrue thing is a legal tort known defamation, or libel, and the only way to defend yourself if they sue you for it would be to prove it was true that they intentionally murdered your baby. We both know that's not true, and you would lose the case. I also am not qualified to represent you in such a case if they did come after you, so you would need to hire a different attorney. Furthermore, if I am successful in getting you into NICA, you will get paid at least \$\$\$\$ which is enough money that Dr. Lopez or the hospital may feel it's worthwhile to have their lawyers come after you, and take that money. With all this being said, my advice to you is to do your best to take down whatever comment you made on Facebook that got posted to Winnie Palmer's Facebook page, and not to write or say any other bad stuff about Dr. Lopez or the hospital in public or online. Hopefully, if you do that, they will let the matter drop.

In a 2017 letter to the state Health Department, Ruth Jacques insisted that Lopez never told her that Reggie's life was in danger, she said.

"You better push, or you're going to have a C-section," she said she was told by the doctor. "In my understanding, he is threatening me [with] a C-section if I don't push, not that the situation ... was an emergency."

Ruth Jacques did continue pushing, according to her medical records. Lopez attempted to deliver Reggie using a vacuum device, which popped off the infant's head three times before the fourth pull succeeded.

Dr. Nicole Smith, medical director of maternal fetal medicine practice at Brigham and Women's Hospital, Harvard Medical School's teaching hospital in Boston, said in general the responsibility lies with doctors to explain their rationale and the benefits and risks of continuing in labor or moving to a surgical delivery.

"Mothers maintain the right to decline a C-section," Smith said in an email, "but it is the provider's responsibility to ensure that they understand the risks and benefits to the extent possible in what is typically a highly stressful situation."

Smith did not review Ruth Jacques' case or comment on the delivery.

Ethical guidelines of the American College of Obstetricians and Gynecologists also place the onus on the obstetrician to provide the patient with "adequate, accurate and understandable information."

The group advises, however, that even a signed form does not guarantee that the ethical obligations of informed consent have been met.

Reggie's parents believe their son would have lived had Lopez initiated a timely C- section, potentially preventing Reggie's brain from being starved of oxygen. But they will never really know.

Like many NICA families, the Jacqueses said they had no idea that they had lost their right to file suit.

Ruth Jacques said she signed forms acknowledging that her doctor and the hospital had informed her of NICA before Reggie's birth. But she didn't read them. She said her OB-GYN had her sign them on her first appointment. At the hospital, the forms were tucked inside a stack of documents handed to her when she showed up in labor, distracted by impending motherhood, too late to change her mind and seek out another hospital.

After they lost Reggie, and learned that a lawsuit was foreclosed, the couple said their sorrow would turn to outrage when they discovered that Lopez had a history with NICA.

Aside from Reggie's case, the doctor has been named in four NICA claims, including two petitions filed prior to Reggie's death. Not every NICA claim is accepted for compensation. But one of the first two lodged against Lopez was.

Two other claims were submitted after Reggie died. Those two were rejected because the newborns weighed less than 5.5 pounds — the legal threshold to qualify for NICA, a requirement intended to eliminate very premature babies from eligibility. In the case of a rejected claim, the family can sue. But none of the rejected claims has been followed by a lawsuit.

Being named in a petition does not mean a doctor committed malpractice — even if the claim is compensated. It only means that the case meets the narrow criteria of the program.

BONDED BY SORROW

If NICA families are members of an unenviable fraternity, families whose child died are its saddest chapter.

A total of 1,238 NICA claims have been made from the inception of the program through the beginning of April. NICA said at least 440 of those were accepted for coverage, which includes at least 143 from parents whose child had died by the time the claim was accepted.

Another 50 children whose claims were accepted for compensation died after they entered the program, NICA said in an email. Among those 50, the average life span after acceptance was 8.2 years. The oldest lived 29 more years. The youngest survived one day after the claim was accepted.

For some parents, NICA, a no-fault program, cannot provide what they want most: accountability.

But there are practical considerations, said David Studdert, a Stanford University professor and expert in health law who co-authored a study of NICA in 2000.

Some of those families who were accepted into NICA likely would have gotten nothing had they been allowed to pursue a lawsuit.

But there is catharsis in discovering what went wrong, who is responsible — even in just being heard — said Kenneth Feinberg, a lawyer who has designed and administered compensation funds in the wake of some of America's worst tragedies: the Virginia Tech massacre, the Sandy Hook Elementary shooting, the rampage at Pulse nightclub, Sept. 11.

The fund established after the Sept. 11 attacks was entirely voluntary, and 97% of eligible claimants opted to take the money, Feinberg said, forfeiting the right to sue. The program had an unusual feature: Claimants could appear before Feinberg or a staff member behind closed doors to express their grief; 1,500 did.

“All kinds of people came to vent, angry, not at the federal government. Angry at God,” Feinberg said.

Feinberg said many described the program as an exercise in justice, but he saw it differently. “I don’t think those words have much meaning when you’ve lost a loved one,” he said. “The best word I use is mercy.”

REGGIE NEVER CRIED

Jean Jacques’ father died in March 2015, on the same day the couple returned from their Caribbean honeymoon cruise, leaving them despondent and Jean Jacques as the lone male heir. They decided they wanted to become parents right away. They were hoping for a boy, someone to carry forward Jean Jacques’ father’s last name and legacy.

They found a house suitable for raising kids. Ruth Jacques’ family threw a baby shower. They painted the walls of Reggie’s nursery teal and gray, bought a brown crib and attached stickers of giraffes, lions and zebras to the walls.

On the morning of June 14, 2016, Ruth Jacques went to see her obstetrician for a regularly scheduled appointment. She said there was no indication that Reggie was ready for delivery, so she went to work at the social services agency where she was a neighborhood coordinator.

But the next morning, she woke up with a fever and tremors, so she went to Orlando Health Winnie Palmer Hospital for Women & Babies. There, her water broke, and she went into labor. Lopez had not been her obstetrician previously but was there for childbirth.

To Ruth Jacques’ ears, Lopez was accusing her of failing to adequately push what she later learned was a 10-pound baby.

When Reggie finally was born, he was essentially lifeless. His first two Apgar scores — measures of his vitality, on a scale of 1 to 10 — were zero and zero. He required four doses of epinephrine to start his heart.

“Normal babies, when they are born, they cry, they open their eyes,” said Jean Jacques, an Orange County Schools paraprofessional and full-time student at the University of Central Florida. Reggie did not cry.

He was placed on a ventilator — which doctors would recommend unplugging six days later, Ruth Jacques said. Bereft of answers, Ruth and Jean Jacques asked for a meeting.



Every year on the anniversary of her son's death, Ruth Jacques files a new complaint with the Florida Department of Health, she said. It is a symbolic gesture. The department has already said Reggie Jacques' treatment did not violate the 'standard of care.' Family photo.

It took place a week after Reggie's birth, in a conference room near the intensive care unit, with a U-shaped wooden table. Ruth Jacques' father, sisters, aunt and the family's pastor joined the couple. She recalls a hospital lawyer standing against a wall opposite her and Lopez sitting at the head of the table, his arms folded across his chest. He didn't look at her, she said. The doctor barely spoke.

What happened? she asked. Why was her baby on a ventilator with little to no hope of survival? "He looked at me in the eye, and he said: 'You did not want to have a C-section,'" Ruth Jacques said.

"And I said to him: 'So, are you implying that I killed my baby?'"

Ruth Jacques said the doctor unfolded his arms and wrapped one under his cheek.

When the meeting adjourned, Ruth said, she met separately with a Winnie Palmer neurologist. "I was informed that my child would 'never walk, talk or ever be able to do anything for himself. He would live in a vegetative state.'"

At first, the couple resisted removing life support. "We were praying that God would help," she said. But the strain became unbearable, the couple said. They said one doctor told them: "If you really believe in God, why would you do that to your child?" The family relented.

"That was the hardest decision for us to make," Jean Jacques said.

Ruth and Jean Jacques and extended family members gathered round the newborn as a musician played soft and somber notes on a guitar. Someone recorded Reggie's heartbeat on a disc and handed it to his

father. A doctor shut off the ventilator, then pulled the breathing tube from Reggie's mouth and throat, the parents said.

Reggie gulped for air. His mother covered her ears to muffle the sound of his gasping. Jean Jacques paced the floor. The couple fixated on Reggie's heart monitor and the clock just above it. It seemed like hours, they said. And then, unexpectedly, Reggie began to breathe on his own.

HIS FINEST OUTFIT



Ruth and Jean Jacques with their son Raphael, who will never know his older brother Reggie. Emily Michot, Miami Herald

Reggie lived another two months. He never left the hospital.

He wore his finest dress-up clothes only once — the day his parents buried him. He was laid to rest inside an impossibly small white coffin, dressed in a short-sleeved, buttoned-down shirt and a tie that was too big for his slender body. The tie and shirt were both white, the color of purity.

The couple buried Reggie far from their home, at Greenwood Cemetery. They didn't want Ruth Jacques visiting her son daily. She needed time to heal.

But a year after her son's death, Ruth Jacques took a job as a grants coordinator with Orange County's government downtown, which is near Greenwood, a historic cemetery. Her son's graveyard is visible from her office. The boy who lived 96 days was laid to rest near Orlandoans whose full lives gave them prominence, including a U.S. Senator and two mayors.

Jean and Ruth Jacques preserved Reggie's short life in pictures: His arms and legs stretched out like a wooden puppet from the contractures — a shortening and hardening of muscles and tendons — that brain damage wrought. An oxygen tube extended from his nostrils. In one photo, he appears to be looking directly at the camera, though the doctors had said he was incapable of such purpose.

Ruth Jacques found direction in her son's death, vowing not to let the same thing happen to other parents.

She took to her keyboard, writing to state lawmakers. And to the Florida Justice Association, a group of lawyers who represent litigants like her. Her email to the trial lawyers recounted Reggie's birth and death in detail. It covered seven pages and said Reggie "will always be a memory of a scar that will never truly heal." There was no response, she said.

She wants Lopez to remember, as well. And so, she said, every year on Reggie's birthday — and on the anniversary of his death — she files a new complaint with the Department of Health. It's a symbolic act, but she wants to remind the doctor that Reggie lived, and that he died.

“He is going on with his life, while we the families are stuck on yesterday.”

Jean and Ruth Jacques, now 35 and 32, live in a modest home in Orlando. They’re raising the little brother Reggie never got to know, 3-year-old Raphael. Another child, Reynaud, was born on Jan. 15. The money she received from NICA will never replace the loss, Ruth Jacques said.

“That’s blood money,” she said. “It’s not going to bring him back.”

Miami Herald

April 8, 2021



Justin Nguyen, 24, is supported by his sisters, Jennifer and Jessica Pham, and his mother, Julie Nguyen, as they use a Hoyer lift to help transfer him from his bed to a chair in his bedroom in their Jacksonville home. Justin suffered severe brain damage at birth. Emily Michot, Miami Herald

Mom was consumed with caring for brain-damaged son. Florida could have paid her. It didn't

By Daniel Chang and Carol Marbin Miller

Over two decades, Choi “Julie” Nguyen bounced from one low-paying job to the next: dishwasher, custodian, manicurist. As a single mom raising two daughters and a profoundly disabled son, Nguyen could never hold a job for long.

Inevitably, the nurses Nguyen relied on to care for her son, Justin, would arrive late or not at all. Who would suction his mechanical airway, fill his feeding tube or turn him in bed to prevent pressure sores? Who was going to sleep on the couch at the hospital when Justin had surgery or fought life-threatening infections?

Ultimately, Nguyen faced the impossible choice of holding down a job and paying the bills — or looking after Justin and being constantly, hopelessly broke.

Florida's Birth-Related Neurological Injury Compensation Association had agreed to help Nguyen shoulder the crushing financial weight of raising a child whose oxygen deprivation at birth left him catastrophically brain-damaged.

Under NICA's own rules, she should not have had to choose between parenting and a paycheck.

State lawmakers created NICA in 1988 to stem what the law's advocates called an exodus of obstetricians fleeing Florida and its high malpractice insurance premiums. The law holds down insurance costs by shielding doctors from potentially ruinous malpractice awards for birth injuries like Justin's, which require a lifetime of medical care. It also forecloses lawsuits from parents like Julie Nguyen.

In exchange, NICA agreed to compensate her claim in 1998 with \$100,000 upfront and a pledge that future expenses for her son's "medically necessary and reasonable" care would be paid.

In October 2020, Nguyen and her daughters, Jessica and Jennifer Pham, 32 and 31, respectively, learned — from Miami Herald reporters — that NICA offers many more benefits than they ever knew were available.

Though Jessica and Jennifer Pham long had told Justin's NICA caseworkers about the family's struggles, they said NICA never offered, nor even mentioned, the one thing that would have made the greatest difference in their brother's life: a steady paycheck for Julie Nguyen for caring for her child. It is a NICA benefit lawmakers authorized in 2002, when Justin was 6.

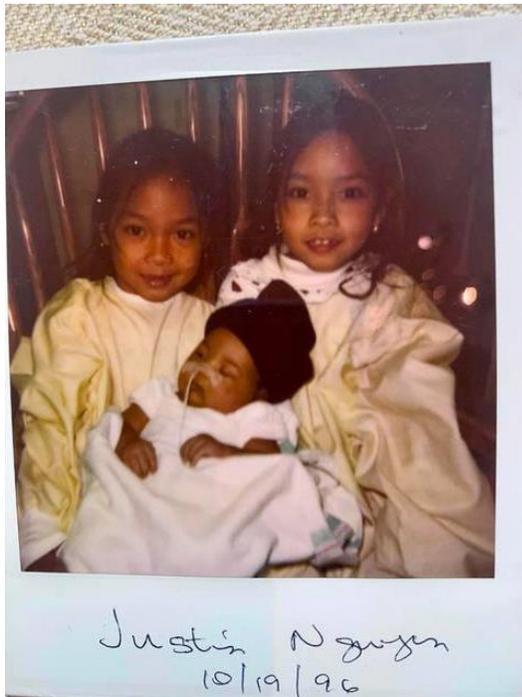
Now 24, Justin has lived far longer than doctors predicted. It has not been an easy journey, Jennifer Pham said.

"It always felt like we were alone in this," she said. "Had we known about all these benefits, things would have been easier."

NICA administrators would not agree to an interview but answered questions about Justin's family by email after Jennifer Pham formally waived privacy protections.

SYMPATHY, NOT HELP

Administrators said they weren't aware Nguyen, 60, was having problems with in-home nursing because it was being paid for by Medicaid, a separate state insurer for low-income and disabled Floridians. "NICA also would not have been independently aware if Ms. Nguyen was having difficulty maintaining employment," the program added.



Jennifer, left, and Jessica Pham visit their brother, Justin Nguyen, at the hospital after his birth and emergency surgery. The nurses would take Justin from his incubator and place him in his sisters' arms. They could hold him only for a short time because of his delicate condition. Family photo.

In 2004, NICA said, the program mailed a benefits handbook to all families — marking the first time in the program's history that benefits were spelled out in writing for them. Nguyen, a Vietnamese immigrant with a limited command of English, could not read it.

Although approximately 20% of Floridians were born in another country, according to the Census Bureau, the NICA handbook is printed only in English.

Jennifer Pham said NICA absolutely knew the family was struggling with nurses, the insurers that administer Medicaid's benefits and Justin's constant hospitalizations — as reflected in more than 8,000 pages, obtained by the Herald and ProPublica, documenting NICA's interactions with the family.

In October 2020, one day before she spoke with the Herald for the first time, Jennifer Pham wrote to NICA pleading for help with nursing as the coronavirus pandemic made caregiving a challenge. The younger of the sisters had made similar complaints to his caseworkers in the past, including in August 2017 when she had the staffing agency send NICA a list of dates that nurses had missed their shifts, emails show.

"We don't have any shift nurses and it's been a struggle working full-time from home and caring for Justin," Jennifer Pham wrote in the Oct. 21, 2020, email to Justin's caseworker. "Finding quality nurses in adult care is difficult," she added two days later.

NICA's caseworker had only sympathy to offer — not help. "I am so sorry there is such difficulty with finding nurses right now," she replied on Oct. 26, 2020. "I hope the situation improves soon."

Program administrators have had the chance to do more than hope that things improve. But when state legislators proposed reforms to strengthen the program for families, NICA worked to put an end to the proposal.

A 2013 bill would have required NICA to provide families with an annual update on available benefits for their child, and it would have given parents something they have lacked from the program's start: a seat on NICA's board of directors, which is made up exclusively of health care industry and insurance interests.

Internal emails obtained by the Herald show that NICA's executive director, Kenney Shipley, considered the effort "silly." In one email to a past president of the Florida Obstetric and Gynecologic Society and a lobbyist, Shipley wrote "we are not here or funded to 'promote the best interest' of the children." The bill died before reaching the Senate floor.

Justin's family was oblivious to all that. They were busy raising Justin.

Emails and other correspondence in Justin's case files illustrate the family's frustrations, although usually the problems were resolved, according to records. Taken alone, each episode might be little more than an annoyance, said the sisters, Jessica and Jennifer Pham. But in the aggregate, the questioning, delays and denials wore them down. A sampling from the files:

Dec. 28, 2015: For the past six months, NICA has not paid a promised \$25-a-month subsidy to offset the high energy costs of Justin's medical equipment. "I apologize," Justin's case manager writes in an email when Jennifer Pham points it out. The caseworker suggests that, in the future, one of the nurses or family members could remind the caseworker about the subsidy "on her perjury statement," the sworn pledge parents sign with every expense report attesting to their veracity. The payments resumed.

March 14, 2016: Jennifer Pham tells a caseworker that Justin's medical supply company has been unresponsive to the family's needs. Medicaid, which provides much of Justin's care, has made it difficult to switch companies. In an email to her supervisor, a caseworker minimizes Jennifer Pham's concerns over Justin's broken hospital bed, which was eventually fixed. "It was in a stuck position," the caseworker writes, "but not life threatening."

Nov. 1, 2016: The specialized chair that supports Justin in the shower is seven years old, and the netting has ripped. NICA will pay only as a last resort, meaning after the Nguyens document that Medicaid and other agencies had refused. The family says it asked Florida's state disability agency, the Agency for Persons with Disabilities, to underwrite the cost of a new chair, \$1,003. That was two years earlier, and the family is still waiting for an answer. "It is just taking way too long," Jennifer Pham writes. A caseworker declines to help, saying "other avenues have to give denials before NICA can step in." Medicaid eventually pays for the shower chair.

March 20, 2017: Justin needs new wipes. They're ordered from a medical supply company, and NICA was supposed to pay directly for these. But when Jennifer Pham placed a new order, the company wouldn't deliver "because Justin has an overdue balance of \$1,700." Jennifer Pham writes: "Will you please help me sort this out?" NICA asks the vendor to send future invoices directly to the program instead of to the family.

Nov. 15, 2017: Justin's NICA-owned van breaks down, and the family leaves it at a repair shop. The shop owner has been waiting two days for NICA to authorize repairs so he can order parts. "I am frustrated at the authorization process," Jennifer Pham writes. "Justin had to undergo emergency back surgery two weeks ago, and we had to cancel his doctor's appointments for this week because of this issue." NICA calls the repair shop later that day to authorize repairs.

Nov. 18, 2017: The van has been repaired, but the shop won't release it until NICA pays the \$2,385 bill. The family is waiting at the shop on a Saturday morning. "Justin has two follow-up surgery appointments on Monday," Jennifer Pham writes. "This is such a stressful situation." The shop releases the van later that day, and NICA sends payment two days later.

April 9, 2018: Justin has been hospitalized again for back surgery, and his wound will not heal. His sister asks NICA to pay for a wound-care supplement. A caseworker asks Shipley for permission. Shipley approves the claim, but only after complaining in writing about Justin's Medicaid HMO, which actually

WHAT PARENTS MUST SIGN AND SUBMIT WITH ANY REQUEST FOR REIMBURSEMENT FROM NICA

Dear Parent(s):

The following is a statement which must be signed, dated and returned to our office each time you send in a request for reimbursement. Each time you receive a check from our office, another statement will be enclosed for the next requested reimbursement.

Please remember to sign and date this form and attach it with your request for reimbursement.

I affirm, under penalty of perjury, that the attached item(s) do not contain any false, incomplete or misleading information, that I have not omitted or concealed any material information, and that I have not already received reimbursement from a third party for the attached item(s). This item(s) is being submitted for payment by NICA under Statute 766.31, F.S., and I understand that NICA is materially and substantially relying upon this affirmation in processing the attached item(s) for payment.

Parent's Signature

Date

delivers Medicaid benefits: "This is a good example of why HMOs shouldn't manage care for these types of individuals for Medicaid."

June 25, 2018: Jennifer Pham emails a caseworker that Justin's Medicaid plan stopped paying for bags for Justin's feeding tube, and the family's medical supply company won't release additional supplies without a NICA authorization, which hasn't arrived. "We are out of feeding bags now," she writes. NICA agrees to pay for feeding bags while the supplier resolves the Medicaid denial.

Oct. 16, 2018: An adult, Justin weighs 100 pounds, and NICA won't pay for a protein supplement until a medical supply company provides a doctor's prescription and proof that Medicaid won't pay for it either. The supplement retails for about \$15 per container. Justin's Medicaid insurer now pays for the protein supplement.

Oct. 2, 2019: Justin has just been released from the hospital for urinary tract infections leading to septic shock. A caseworker says NICA won't reimburse for Vibramycin, a name-brand antibiotic that costs \$78 for a three-day supply, until the family supplies his hospital records. "I will need to know more information before I can reimburse this." She adds that a letter of medical necessity from Justin's doctor, addressing the need for the brand-name drug, "would be very helpful to us." Jennifer Pham asks Justin's doctor to prescribe an antibiotic that Medicaid will pay for.

Oct. 3, 2019: A caseworker questions why NICA should pay for Benadryl — an over-the-counter drug retailing at less than \$7 per bottle — that doctors prescribed to control Justin's seizures while he was in the hospital. The caseworker thought it was to be used for itching. "I will ... need a letter of medical necessity from the doctor since the cause could be related to his neurological birth injury or it might not be." NICA pays the claim after Jennifer provided caseworkers with a Medicaid denial letter and hospital records proving doctors prescribed Benadryl for seizures related to Justin's birth injury.

April 24, 2020, 4:52 a.m.: For at least five years, NICA has been paying only \$25 monthly to offset the family’s power bills — sometimes late but eventually after the family complained. “Electricity and water are constantly running at our home whether it’s through [Justin’s] humidifier, nebulizer, suction machine, [ceiling] lift, feeding pump, refrigerator and microwave for feedings and medications, baths” and laundry for soiled linen, Jennifer Pham writes. She requests a higher subsidy.

April 24, 2020, 8:57 a.m.: A prompt response provides good news. “She makes a good case for an increase,” Shipley tells a caseworker. “Let’s increase to \$100/month,” she adds without explanation. “I will consider other families as well if the nurses can get us enough information to evaluate.”

BUILDING TRUST



A polaroid of Justin Nguyen in the intensive care unit at University Medical Center in Jacksonville. Family photo.

Program administrators knew Justin’s injuries were profound soon after he was born at University Medical Center in Jacksonville, now UF Health Jacksonville, on Sept. 17, 1996.

Labor lasted 16 hours, the delivery complicated by the umbilical cord being wrapped around his neck, according to medical records. Doctors predicted that he might live a little more than a decade.

According to a note in Justin’s medical records, NICA’s pediatric neurology consultant reported in June 1998 that “as Justin’s brain damage is quite severe, he will likely be bedfast” — unable to leave his bed.

“Child is at near-vegetative state — physically and mentally,” the notes say. “Fetal distress was present early in labor but continued in labor,” the notes say, underscoring the word “continued.”

The notes add: “Post natal course was a disaster.”

Justin’s diagnoses included cerebral palsy, spastic quadriplegia, epilepsy and neuromuscular scoliosis. Because NICA is a no-fault compensation fund, Nguyen need not have determined who was responsible for his injuries to qualify.

Jennifer and Jessica Pham, 6 and 7 when Justin was born, had to grow up fast to help meet the needs of their brother. He would spend the vast majority of his time flat on his back, and he had to be properly hydrated and turned regularly to prevent pressure sores. He became the focus of the family’s life.

As caregivers, Justin’s mother and sisters had more grit and devotion than training and resources. Because of their mother’s limited English, the sisters had to deal with NICA. Jennifer Pham said it was she who called NICA in tears in 2002, pleading for help after it became increasingly difficult to take her



Jennifer and Jessica Pham play a game of chess while watching over their brother, Justin Nguyen. The sisters, 6 and 7 when Justin was born, are now in their early 30s and remain devoted to his care. Family photo.

brother to doctor appointments strapped in only by a shoulder harness. Although NICA would provide the van, it took almost half a year from when it was requested in writing, the family said.

The sisters learned to crush, mix and monitor Justin’s medications, feed him with a syringe, bathe and dress him. And they learned to relate to Justin through touch and sound and by reading the subtle cues — his eye movements, his breathing patterns, his faint facial expressions.

“You’re guessing whether he’s in pain, if he’s thirsty, if he’s too hot, if something is pinching his side,” Jennifer Pham said.

The family’s primary interaction with NICA was submitting receipts for out-of-pocket expenses, Jennifer Pham said. Sometimes it took months for NICA to reimburse them for items the program could have paid for directly, the sisters said.

In addition to the van, NICA paid a nurse five hours each week to help coordinate Justin’s care from 2012 to 2017. In early 2020, NICA also agreed to pay for Justin’s twice-weekly physical therapy.



From left to right are mom Julie Nguyen, daughter Jennifer Pham, son Justin Nguyen and daughter Jessica Pham, celebrating Justin's 12th birthday. Family photo.

Jennifer Pham emphasized that the family is thankful for that and the other help NICA has provided, including the \$100,000 payment that all NICA families receive as compensation for not being able to sue. The money helped her mother buy a three-bedroom home in Jacksonville.

"I don't want to sound ungrateful for the things that NICA has done for us," Jennifer Pham said. "They have done things for us that have contributed to Justin's life in good ways."

But NICA has always been a passive participant in Justin's care, she said — aware of Justin's needs but offering to help only after the family had exhausted every other resource.

"Why do we have to beg for it?" Jessica Pham said. "We're not asking for any more than what they said he was going to get."

While NICA makes families use every other available payment source before the program will reimburse, Medicaid does the same thing. That makes for complications.

It meant the family had to ask Justin's doctors to write letters attesting to every item's medical necessity, secure a denial letter from a Medicaid insurer and then appeal, which sometimes required a



Justin Nguyen, 24, is carried by his sister Jennifer Pham to his wheelchair as their older sister, Jessica Pham, reaches out to assist her. Their mother, Julie Nguyen, works on Justin's medical equipment in the background. Emily Michot, Miami Herald

hearing. The process was convoluted and could take months of follow-up and familiarity with complex bureaucracies.

NICA also insisted that caregivers, equipment providers and other vendors be compensated at the same rate that Medicaid pays, though the Florida Medicaid program's pediatric reimbursement is so low that some doctors refuse to accept Medicaid patients. Justin's records, for example, show a physical therapy group balked at the billing rate, requiring the Nguyen family to find another.

In December 2014, a federal judge said Florida's Medicaid reimbursement rate was preventing some needy children from getting care. A settlement between the American Academy of

Pediatrics' Florida Chapter, which had filed suit over the payment rates, and state health administrators was intended to improve reimbursement — and quality of care.

'JUSTIN WAS CHEATED'

In October, Herald reporters told Jennifer Pham that her mother could be paid for watching Justin — and that it was a long-standing policy. Pham, a law school graduate, checked it out herself and confirmed it was true.

She wept.

It was one of many things the family says it knew nothing about, benefits ranging from \$30,000 in home renovations to accommodate Justin's disabilities to \$500 a year in therapeutic toys that could have been reimbursed. And that they could have been reimbursed for trips to and from the doctor and hospital.

Some of those provisions are in the 38-page benefits manual, some not. Nguyen, never fluent in English, could not have read the book, and her daughters were in first and second grade when Justin was accepted into NICA.

On Dec. 7, NICA agreed to do what it could have done all along: pay Nguyen for 20 hours a day at \$15 per hour to care for Justin. NICA administrators also said they are "working with the family" to provide Nguyen four years of back pay, although the policy allowing payment for parents went into effect 18 years ago.

Jennifer Pham said she wishes NICA would do a better job communicating with families.

"I am grateful that Justin has lived all these years and NICA has supported him. But did we get the things we were promised for a lifetime of support? No."

Miami Herald

June 1, 2021



Alexandra Benitez, with her son Jay, says she was told that the program called NICA would take care of her son's medical needs. She wasn't told about the bureaucratic maze that came with NICA coverage.

Florida protected OBGYNs from paying for their mistakes. They handed taxpayers the tab.

By Daniel Chang and Carol Marbin Miller

Every other month, Jay Alexander Benitez would be hospitalized with pneumonia or other respiratory infections that stemmed from the profound brain damage he suffered at birth. “It was heartache,” the boy’s mother, Alexandra Benitez, said. “Being in the hospital scared him.”

Jay’s pulmonologist said that regular therapy with a nebulizer — a machine that delivers vaporized medication to the lungs to improve breathing — might prevent some of those illnesses. But Benitez said she was forced to wait months before the treatments could begin.

A Florida law passed in 1988 had prevented the Benitezes from filing a malpractice suit to recoup the costs of their son's care but promised that a no-fault fund would pick up the tab.

Alexandra Benitez soon learned that the no-fault fund, the Birth-Related Neurological Injury Compensation Association, or NICA, would pay for nothing — not until she had first gone to Medicaid, an insurance program loathed by many of Florida's poorest residents for its cut-rate reimbursements and propensity to fight claims large and small.

When Jay's pulmonologist recommended the nebulizer machine to loosen mucus in his lungs, Medicaid said no. The family needed extra feeding tubes for Jay's gastrostomy, a procedure in which a port is inserted directly into the stomach to provide nutrition. Medicaid said no. Jay's doctor prescribed a "stander," an adjustable frame that could be used to develop muscle strength in the boy's legs. Medicaid said no.

NICA would not cover any medical care for her son until she could prove that Medicaid had already denied the claim and show a signed doctor's letter verifying that the child really needed whatever she was requesting — not just breathing treatments, but also diapers, syringes, anything.

"They make the family jump through all these hoops. Just to get what children are entitled to," said Benitez, who lives in Lakeland, just east of Tampa Bay. "Hardship, that's what it is."

This is the story of how Florida lawmakers stripped parents of the right to sue over births gone catastrophically wrong, created a no-fault program funded by fees paid by doctors and hospitals to cover those claims, made hundreds of millions investing those funds in the markets, accumulated \$1.5 billion in assets and then offloaded much of the costs of care onto taxpayers.

That left parents like the Benitezes to grapple with Medicaid's arcane rules, a shortage of doctors willing to accept Medicaid patients and frequent denials of claims.

About 125 of the 215 brain-damaged clients, some of them now adults, currently in Florida's NICA program qualify for Medicaid, and they are required to seek help first from the taxpayer-funded safety-net plan. Those with private health insurance coverage also must ask their insurer to pay for care.

After decades of enforcing this last-to-pay policy, NICA faces an existential reckoning.

Florida legislators approved a bill of sweeping reforms for the program after the Miami Herald and the nonprofit newsroom ProPublica began publishing an investigative series in April documenting parents' frustrations with NICA. Gov. Ron DeSantis has yet to sign the bill.

And a federal lawsuit alleges that by telling parents to go to Medicaid first NICA is causing them to commit fraud by filing a false claim with Medicaid when NICA was supposed to pay instead.

Both Medicaid and NICA consider themselves a “payer of last resort,” meaning they pick up only what insurance and other “third parties” do not. But in reality only one program can be last in line to pay, and that — as explicitly stated in federal law — is Medicaid, the whistleblower lawsuit says.

A federal district judge in Fort Lauderdale rejected an effort by NICA to throw out the suit, a decision the program is appealing.

When asked in a Sept. 25, 2008, deposition what would happen if Medicaid were to stop covering care for people in the program, NICA Executive Director Kenney Shipley replied: “It would make NICA insolvent.”

Neither NICA nor the Agency for Health Care Administration (AHCA), which administers Medicaid in Florida, would provide figures for how much Medicaid has spent over the years on children enrolled in NICA. But an analysis AHCA performed for NICA in 2020 casts doubt on Shipley’s dire prediction.

Agency records for the period from January 2009 through Sept. 20, 2017, show AHCA paid at least \$35.8 million to provide care through Medicaid for 122 people with NICA coverage. That equates to less than \$5 million per year.

Still, federal law is clear that without a specific exemption, which NICA does not have, Medicaid must pay last, said Sara Rosenbaum, a health law professor at George Washington University and adviser to Congress on federal Medicaid payment and access policy.

“I’m not understanding why [Medicaid] has not come down on them like a load of bricks,” Rosenbaum said. “There’s something upside down about this whole arrangement.”

HELPING DOCTORS, BILLING TAXPAYERS

Florida lawmakers created NICA to reduce malpractice insurance premiums for doctors by shielding them from lawsuits for birth injuries that result in profound physical and cognitive disabilities, usually due to oxygen deprivation.

Obstetricians pay \$5,000 a year for coverage under the program, an amount that hasn’t been raised in 33 years and would be nearly \$12,000 in today’s dollars. All other licensed Florida doctors pay \$250 a year. Hospitals chip in \$50 per live birth.

In return for barring parents from suing, NICA compensates them with a one-time payment and a commitment to cover a lifetime of “medically necessary” care for the injured child.

But parents whose injured children are enrolled in NICA and qualify for Medicaid based on their income say Florida stripped them of the right to sue and replaced it with essentially the same medical treatment that every other poor and disabled child is entitled to in the state. In Florida, Medicaid rates below the median for quality of care when compared with other states.

“They said our son was going to be taken care of. All his medical care would be taken care of,” Benitez said of NICA. “Then, every little thing my son needed, we had to fight for it.”

The bill adopted by Florida legislators in April attempts to make life easier for families like the Benitezes. The legislation raises the one-time benefit to families from \$100,000 to \$250,000, boosts the payment when a child dies from \$10,000 to \$50,000 and requires for the first time that at least one member of the NICA board of directors be the parent of a child in the program.

A proposal to raise the \$5,000 OB-GYN dues and the \$250 annual fee for all other doctors by up to 3% a year, starting in 2022, was shelved.

Lawmakers left for a later date the issue of whether NICA can keep sending families to Medicaid first for their care.

During hearings, Florida lawmakers proposed adding a statutory requirement that NICA repay Medicaid for the care it has provided to children since the program began and going forward. NICA’s administrators beseeched them not to do it.

“I would just plead with you not to take action that could potentially cost hundreds of millions of dollars to the NICA program, potentially put it in financial jeopardy, and really derail where we’re trying to go with all of these positive benefits,” said Steve Ecenia, general counsel for NICA.

“This amendment causes us great concern and we would ask you not to adopt it,” said Ecenia, who is also a lobbyist for one of Florida’s largest for-profit hospital chains, HCA Healthcare.

The proposal was dropped.

NICA did not respond to a question about Ecenia’s characterization given that Florida data show Medicaid has spent less than \$5 million a year on these children over a recent nine-year stretch.

In the final bill, lawmakers directed Florida’s Medicaid agency to tally the “extent and value” of NICA’s potential liability for Medicaid spending and make recommendations about whether the state should recover those funds.

Whatever the Legislature does, NICA’s reliance on Medicaid may be doomed because of the lawsuit filed in Fort Lauderdale federal court.

NICA asked that the case be dismissed, raising a defense in court filings that the program is a state agency that cannot be sued.

In a 14-page order issued Sept. 18, U.S. District Judge William P. Dimitrouleas rejected the argument, finding that NICA is not a state agency and that federal and state laws make NICA legally responsible for paying health care claims before those costs can be passed on to taxpayers. NICA has asked the Eleventh U.S. Circuit Court of Appeals in Atlanta to reverse Dimitrouleas' ruling.

In a 2019 email, Shipley, NICA's executive director, acknowledged the risk that a judge might rule the program must pay first, with Medicaid serving only as a backup. She called this the "Sword of Damocles," referring to the myth of the king who had to sit beneath a sword hanging by a thread.

The only other program like NICA, in Virginia, was forced to stop sending children to Medicaid for their care in 2018 and paid millions of dollars back to the federal government after being sued by the same whistle-blower who filed suit in Florida.

'ALWAYS DENYING ME'

As Alexandra Benitez drifted in and out of consciousness during her son's chaotic delivery, she tried first to console her husband. Everything will be OK, she said, "because we are in the hospital after all." Bleeding heavily from what she later learned was a tear between her uterus and her baby's placenta, Benitez later bargained with her doctors.

"I told them to forget about me," Benitez said. "Just take my son, and save him."

Born with a severe brain injury, Jay Alexander Benitez was approved for NICA coverage in December 2001.

Alexandra Benitez, now 48, said she was told that NICA would cover a lifetime of care for Jay but not that she would have to get denials from Medicaid first.

"This was a constant thing, because my son always needed something," Benitez said.

Medicaid, like NICA, did cover nursing care. Initially it agreed to pay for eight hours daily, allowing Benitez time to sleep, cook or clean the house. To remain eligible, Benitez had to reapply every six months and meet the low-income requirements.

If a family's bank account crept over \$2,000, Medicaid would terminate the nursing care for exceeding the program's low-income requirements. Currently, a Florida household of three cannot earn more than \$29,207 a year to qualify for Medicaid. Denials, delays, reductions in care and terminations can be appealed.

For years, the Benitez family lived on a razor's edge of poverty, one roof leak or car repair away from ruin.

"They were always denying me," Benitez said.

Benitez said she wishes NICA knew how Jay's profound disabilities affected the entire family and how dedicated she and her husband were to his well-being.

"He was a happy soul," Benitez said. "Even though his body was in constant pain he would fight through it."

Jay died at home on Jan. 29, 2015, after suffering a massive seizure. He was 15. Benitez said she did whatever she could to make Jay's life better. Having to slog through repeated requests, denials and appeals with Medicaid before NICA would pay depleted her.

"When you have a child you have hopes and dreams. You see them in the future. You don't look forward to burying your own child," she said. "It's a hard, long road. A long fight. ... My son's life, my family's life, was not easy at all."

PERPETUATING POVERTY

Although NICA and Medicaid cover a limited amount of in-home nursing care — and NICA even pays parents to watch their own children — some families are forced to patch together caregiving plans with nurses who don't show up for work, sleep on the job, relocate unexpectedly or simply leave midshift, records show.

Pat Wear, who helped oversee a disability advocacy group in Florida before becoming commissioner for mental health and developmental disabilities in Kentucky, said low reimbursement rates are "at the heart of" Medicaid's — and therefore NICA's — inability to provide reliable, let alone high-quality, in-home nursing care.

"There's a direct correlation between the reimbursement rates and quality of care," said Wear, who is now retired. "Generally speaking, you get what you pay for."

Even when NICA covers expenses that Medicaid won't, it is NICA policy that the program will pay at the same reimbursement rate as Medicaid — which critics say ensures that the quality of care seldom exceeds what Medicaid can provide.

Florida's Medicaid program spent less per enrollee to provide care for people with disabilities than almost any other state, ranking 44th out of 50 states in 2018, the most recent year reported in federal data.

In 2014, a Florida federal judge found that Medicaid's low reimbursement rates relegated impoverished children to an inferior health care system.

Dr. Rex Northup, a retired critical care specialist who headed the Florida Panhandle region of another taxpayer-funded program, Children's Medical Services, testified before the judge at the time. He described how some Pensacola families on Medicaid had to travel almost 350 miles to the University of Florida's Shands Hospital in Gainesville to find a specialist willing to treat a medically complex child — not because the specialty was that rare, but because many doctors simply weren't willing to accept Medicaid reimbursement rates.

Medicaid was "supposed to provide care equal to other insurance," Northup said. Except in extremely rare cases, it didn't, he added.

U.S. Circuit Judge Adalberto Jordan found that Florida's Medicaid reimbursement rates were so low that children in the state's program did not have adequate or reasonable access to medical and dental care as required by federal law. The case settled, with health regulators vowing to improve reimbursement rates and access to care. (Jordan was elevated to the Eleventh U.S. Circuit Court of Appeals while the lawsuit was pending.)

As part of the settlement, Florida's Medicaid agency instituted an incentive plan that raised reimbursement rates for pediatricians who met certain requirements. Some are now paid the Medicare rate for elders, which is higher.

NICA administrators reject the claim that any children in the program who are insured by Medicaid are given inferior health care.

"NICA families receive care from some of the best, most specialized doctors in the United States — and no doctor has refused to care for a NICA patient, in Florida or elsewhere, due to reimbursement rates," the program said in answer to a series of emailed questions from the Herald. "Not one."

"If they, for some reason, do not accept a specific reimbursement rate for medically necessary and reasonable treatment, then NICA will pay whatever is necessary to make sure its families do not incur out-of-pocket expenses."

NICA case management logs, obtained by the Herald under Florida's public records law, are filled with references to parents calling the program, sometimes in tears over losing their jobs, and falling deeper into poverty, because of nursing-care issues:

- Mother "states that there is no way she can work because nursing care is not dependable and many times she has to go to work and then come home to care for [her child] as well or can't go to work at all because nurses don't show up."

- “Nurses are calling off frequently and mother is having a hard time performing her job from home.”
- “Mother called, lots of problems with keeping a nurse, one left for a different job, one sleeps on duty and parent did not want her back.”

That mother called NICA to complain that her “husband had to come home from work to take care of [their] child. Work told him he was missing too much time re sick child, if he left don’t come back.”

Later — the exact dates are redacted — the log noted the father’s employer followed through with the threat. “Last week, father was let go because he had to go home to care for child.”

The log noted the father could be paid \$15 an hour to give care to his disabled child when he’s forced to leave work. But if the father quit his job for good or was fired, his caregiving pay from NICA would drop to \$10 an hour.

SHOWDOWN IN FEDERAL COURT

NICA’s current legal reckoning is being driven by the parents of a severely disabled boy named Cody Arven. In July 2015, they challenged the policies of the Virginia Birth-Related Neurological Injury Compensation Program. It was the model for NICA.

There are some differences between the two programs. Florida’s soon-to-be-expanded board of directors consists of doctors, hospital representatives and insurers. Virginia’s board already includes two members who represent people with “special needs,” as well as a plaintiffs’ attorney. In Virginia, parents have up to 10 years after a baby’s birth to file a claim, compared with five years in Florida. And while Virginia does not offer a one-time \$100,000 award, it pays lost wages annually to the injured child once he or she turns 18. The pay is equal to 50% of the average private, non-agricultural wage. The benefit amounted to about \$29,000 in 2020.

In their federal lawsuit, Veronica and Theodore Arven, the latter now deceased, accused Virginia’s birth injury fund of illegally dumping its costs on taxpayers through Medicaid. Cody Arven was accepted into the Virginia fund after his 2003 birth left him severely disabled.

In 2018, the Virginia program settled by paying \$20.7 million to the U.S. government and agreeing to stop shifting costs to Medicaid in the future. For filing the whistle-blower lawsuit, the Arvens received \$4.1 million of that.

That same month, Virginia’s program started buying private health insurance for all of its covered children who had relied primarily on Medicaid, said George Deebo, the director. Deebo said the change caused about a 20% increase in spending for the program.

“It changed the order of how we pay for services,” he said of the settlement. “Essentially, we reversed position with Medicaid.”



Cody Arven, the child who took on Virginia's version of NICA and is now, through his mother, suing Florida's.

Florida NICA took notice.

“This is a terrible outcome,” one of the Florida program’s lawyers, Paul R. Monsees, wrote in a January 2019 email to Shipley and NICA’s general counsel. “What is to stop” a family from filing such a whistle-blower suit in Florida? Monsees asked.

Three months later, on April 25, 2019, the Arvens did exactly that. Under a federal law, any person can bring a civil lawsuit against companies or people who allegedly defraud the U.S. government.

Whistle-blower lawsuits are initially sealed so potential wrongdoers aren’t tipped off and complaints can be investigated. The Arven lawsuit was unsealed in September 2020 when Dimitrouleas rejected NICA’s attempts to dismiss it.

Although the issues are similar to Virginia, the stakes are higher. Florida’s NICA program has accepted more claims — 433 compared with about 255 for Virginia.

Virginia’s fund holds \$500 million, about one-third of NICA’s assets.

‘STEALING FROM MEDICAID’

Florida and federal law require AHCA to claw back payment whenever Medicaid covers medical services that could have been paid for by a so-called third party, such as a health insurance plan or NICA.



'What happened to Fatema shouldn't have ever happened,' said Allyson Williams of her daughter Fatema Shakir, who suffered severe brain damage at birth and died at age 9. Courtesy of the family.

The few exceptions to this rule are named in state and federal guidance and include state health agencies and federally designated benefits, such as the Indian Health Service, the Ryan White HIV/AIDS Program and the Women, Infants and Children program.

NICA is not on the list of exceptions — despite requests to state lawmakers and state and federal health regulators from NICA's attorneys to be included.

When the Herald asked AHCA for records showing whether the agency has made any attempts to recover any money from NICA, the agency refused to answer, citing the pending federal lawsuit.

But while NICA's attorneys failed to persuade AHCA to alter its policy on Medicaid liability, they have argued successfully thus far in state courts that NICA has no obligation to repay Medicaid.

Administrative law judges who preside over NICA petitions and claims at the Florida Division of Administrative Hearings have ruled repeatedly that the program is not liable for Medicaid spending.

That's what happened in the case of Fatema Shakir, who entered the world when no one was looking. No doctor or nurse was in the delivery room, and her mom, Allyson Williams, was so numbed by pain blockers that she didn't realize she had given birth in her hospital bed. Fatema, severely brain damaged, was found under the covers with no heartbeat.

Although revived that day in June 2007, Fatema would be left with profound brain damage rendering her unable to eat or breathe without tubes.

"What happened to Fatema shouldn't have ever happened," Williams said. "That shouldn't have ever happened."

Fatema's parents fought NICA compensation at first, arguing that there was no doctor present when she was born brain-damaged on June 3, 2007. Staying out of NICA might have enabled the parents to pursue a malpractice suit they filed in 2008.

But the NICA statute only requires a participating doctor — one who paid the \$5,000 annual premium — to have provided obstetrical services any time during labor, delivery or resuscitation immediately after birth in order for the case to qualify for compensation.

In August 2013, Fatema’s parents abandoned their suit and accepted NICA benefits. As the case dragged on in administrative court, and Fatema’s needs grew more intense, Williams said she felt pressured to accept NICA and was relieved to get help no matter where it came from. Williams was a single mom, unable to keep a job, she said, with other young children at home.

“It wasn’t Fatema’s fault, but I couldn’t work because she had all these doctors’ appointments, and if she got sick, she couldn’t go to [out-of-home daytime nursing care], and that just took a lot.”

But the month after Williams had accepted NICA, Florida’s Medicaid program slapped Fatema’s parents with a \$1.4 million lien for Medicaid benefits that covered Fatema’s long stay in the neonatal intensive care unit after delivery and her subsequent care.

Nearly four years later, Fatema died at the age of 9 on April 15, 2017. Her father, Muhammad Shakir, died later that year.

Prior to Fatema’s death, Williams asked an administrative judge to order that NICA pay off the lien. The judge said no, stating that NICA was not responsible for past expenses paid by Medicaid. Williams appealed the denial to Florida’s First District Court of Appeal, which affirmed the administrative judge’s decision.

Ronald Gilbert, an Orlando attorney who represented Williams, said that after his client accepted the NICA benefits, AHCA never enforced the lien. Williams did not pay the lien, Gilbert said, and there is no record that NICA paid it.

“The lien went away, which is just stealing from Medicaid, in my opinion,” Gilbert said, “particularly if the NICA program has [\$1.5] billion in financial reserves.”

Fatema continued to rely on Medicaid after being accepted into NICA. Williams said she does not recall who paid for Fatema’s care — NICA or Medicaid — but that the costs were covered. She said both NICA and Medicaid treated Fatema fairly, but that she would have preferred to sue for her daughter’s injuries.

“No amount of money in the world can replace the amount ... my daughter should have been awarded,” said Williams, who is now 42.

Federal regulators say they have not issued any legal opinions, letters or other written guidance with respect to NICA or the Virginia Birth-Related Neurological Injury Compensation Program.

Rosenbaum, the health law professor at George Washington University, said programs like NICA are in theory beneficial, but only if you “take the step of aligning it with Medicaid policy.”

If DeSantis signs the legislative reform bill adopted by lawmakers in April, then the state’s Medicaid agency will begin a review of NICA’s potential liability. The legislation requires AHCA to deliver a report of its findings by Nov. 1.

Miami Herald

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Tiffany Tomkins

Mom devoted her life to her disabled son. A hospital said she was using him to make money

By Carol Marbin Miller and Daniel Chang

Ashley Lamendola was still a teen when medical staff at St. Petersburg General Hospital delivered the awful news that would change her life forever: Her newborn son, Hunter, had suffered profound brain damage and would do little more than breathe without help.

“It was like an atomic bomb went off in my life,” she said.

Lamendola believed the hospital was partly responsible for Hunter’s birth injuries. But Florida is one of two states that shield doctors and hospitals from most legal actions arising from births

that go catastrophically wrong. Lamendola filed a lawsuit against St. Petersburg General anyway, and when it appeared she was gaining traction, the hospital advanced an extraordinary argument.

It suggested that Hunter's mother was not acting in her son's best interest and that a critical decision about his future care should be put in the hands of an independent guardian and a judge. Lamendola, attorneys said, was pursuing her own self-interest by refusing to participate in the quasi-government program that compensates the families of children injured at birth.

Under the program, known as the Birth-Related Neurological Injury Compensation Association, or NICA, the state provides \$100,000 upfront and pays for "medically necessary" care for the child's lifetime. In exchange, parents give up their right to sue hospitals and doctors, lawsuits that can result in judgments or settlements in the tens of millions of dollars.

By choosing to "pursue her own speculative, complicated civil lawsuit" rather than permitting her son to accept his "vested" NICA benefits, Lamendola was trying to profit from Hunter's injuries, St. Petersburg General attorneys argued in a court filing. They underscored the words "her own."

Had she accepted Hunter's inclusion in NICA, "the Mother would be unable to pursue her own civil lawsuit, seeking her own separate monetary damages for the Child's injuries," the lawyers added.

"You carry a child for nine months, and then you finally get to hold them — eventually in my case," said Lamendola, who was employed as a customer service rep at an AutoZone when she gave birth. "And you take care of their every want and need, and you put a child before you. I mean, once you have a child, there is no more you. It's them. It's us. It's that baby that needs you and needs everything from you."

"I didn't understand how somebody who wasn't me could know what he wants and needs. I knew every sound, every movement, every seizure that he had," Lamendola said. "And to think that somebody thought they knew better than me. It was wild to me."

The battle between parents like Lamendola and hospitals like St. Petersburg General can seem like a gross mismatch: Lamendola was a single mom who made \$10.50 an hour and lived with her mother. HCA Healthcare, which owns St. Petersburg General, is one of the nation's largest for-profit hospital chains, with 180 hospitals, 280,000 employees and revenues of \$51.5 billion in 2020.

For hospitals facing stunningly high settlements or verdicts, NICA, the state's no-fault program, is a valuable legal tool — a club to bat away expensive lawsuits. At the cost of \$50 per live birth, hospitals can protect themselves from multimillion-dollar judgments.

Paolo Annino, who heads the Children’s Advocacy Clinic at the Florida State University College of Law, said attempts to restrict a parent’s authority through the appointment of a guardian are unusual: In child welfare disputes, for example, parents must be found unfit by a judge before being stripped of their right to decide what’s best for their children.

“What we have here is a scenario where there’s no allegation of offending parents at all,” he said. “The parent is, with very few exemptions, the one who makes the child’s health care decisions.”

NICA came under fire this month after a series of reports by the Miami Herald and the investigative reporting newsroom ProPublica. Families complained that the \$100,000 grant — unchanged since 1988 — is inadequate, and that payments for medical procedures or equipment are routinely slow-walked or denied entirely. After the articles were published, state leaders professed outrage and promised a comprehensive fix to the program.

Here is how NICA works: After a baby is born brain damaged, parents can file a lawsuit against the hospital and doctor. The defendants then can ask the judge to pause the suit and order the parent to file a NICA claim. That petition is heard in a separate venue by an administrative judge, who then decides if the case is “compensable.” Ultimately the administrative judge determines whether NICA applies or if the parents can resume their lawsuit.

To qualify for NICA, in addition to having physical and cognitive impairments, a child must weigh at least 2,500 grams (5.5 pounds) at birth and be delivered in a hospital. When children don’t fit those criteria, parents retain the ability to sue.

For the roughly 440 Florida children covered by NICA over the past 33 years, some of them now deceased, the program wasn’t really a choice. It was a mandate, with a few exceptions.

One exception is when OB-GYNs fail to pay a \$5,000 annual assessment. Nearly one in four licensed obstetricians statewide do not pay. Another is when a hospital doesn’t pay its \$50-per-birth fee.

Parents can also argue that they weren’t properly notified by their hospital or doctor of their participation in NICA with enough lead time to choose another provider. When parents like Lamendola attempt to invoke these exceptions, the fight can become fierce — and expensive.

Both the hospital and Lamendola’s obstetrician, Christina Shamas, declined to discuss Hunter’s case with the Herald.

One of the hospital’s lawyers, Jay Spengler, wrote in an email to the Herald that, for children who qualify for NICA compensation and coverage, “it is something that should be carefully considered, as it provides a child affected by severe birth-related neurological injuries a lifetime of necessary and reasonable medical services.”

In a deposition, Shamas defended her performance that day, saying that, as the “difficult” delivery progressed, she believed Hunter would be born just as quickly at that point with a vaginal delivery — and the aid of a vacuum device — as he would a C-section.

Though Hunter’s heart rate declined significantly several times during the 80 or so minutes right before he was born, the fetal heart monitor also showed that it accelerated again, too, she said.

“This does not necessarily mean a compromised baby,” Shamas said.

Shamas also said that Hunter’s heart rate would improve when nurses administered oxygen to his mother, repositioned her in bed and gave her fluids.

Shamas said she took all the necessary steps to ensure Hunter was born healthy.

FLOPPY, SILENT, ALIVE

It’s unclear how often lawyers representing doctors and hospitals accuse the parents of brain-damaged children of selfishness in an effort to force them to accept NICA benefits. Requests for guardians can occur anywhere in a family’s legal journey: administrative court, trial court or appeals court.

Richard Milstein, a past president of the Dade County Bar who has been appointed guardian ad litem in hundreds of disputes, said he was aware of no statutory provisions governing the appointment of guardians in NICA cases.

Generally, judges have discretion over whether to appoint a guardian, though Milstein said judges often rely on guardians to be their “eyes and ears” on matters involving litigants who can’t make decisions for themselves.

But when hospitals and doctors “question the wisdom” of parents making decisions about their children, “it is an offensive concept,” said Michael Freedland, a Broward attorney who represented Lamendola.

“It should send chills down the spine of every parent out there who is caring for a perfectly healthy child, or one who has special needs,” he said.

In its review of 1,238 NICA claims at the Division of Administrative Hearings, the Herald examined in detail 10 such cases but did not find any in which a guardian recommended a family be required to accept NICA compensation.

In one case, an Alachua circuit judge appointed a guardian ad litem to represent the interests of Nazyrah Jones, an Ocala child who suffered permanent brain damage when her heartbeat

“essentially flat-lined” during delivery on May 13, 2008, a lawsuit alleged. Nazzyrah’s guardian wrote in a 2011 report that “it would be in Nazzyrah Jones’ best interests that this case proceed as a medical malpractice lawsuit.”

A Central Florida hospital told Ninoshka Rivera, too, that it knew what was best for her son, Kevin Terron-Otero. And that what was best was NICA.

Due to oxygen deprivation, Kevin was born floppy and silent, but alive, on Nov. 4, 2009. The hospital and doctors thought it was a classic NICA case, though Rivera wanted to seek compensation through a lawsuit. As the process played out, the hospital asked an Osceola County circuit court to appoint a guardian to weigh in.

In a court brief, the hospital said it was concerned about the well-being of the child, fretting over “the staggering potential for loss to this child” if Rivera persisted.

The judge did appoint a guardian, but the guardian did not recommend that Rivera’s son be forced into NICA, freeing her to sue.

Rivera settled with the hospital’s insurer for \$1 million. She is still in litigation with three doctors and two medical practices that have denied wrongdoing, court records show.

Luis Jimenez and Priscilla Franco experienced a similar fight.

The couple’s 2016 NICA petition was filed “under protest,” arguing that NICA’s lawsuit ban was unconstitutional. For its part, NICA determined the injuries to their child compensable in March 2017.

The parents continued to resist, alleging in August 2018 that son Dallas received substandard care in a manner that was “willful and wanton.” That’s another exception, though rarely used, to escape NICA.

In this case, it worked, enabling the parents to pursue their lawsuit in Miami-Dade circuit court. The hospital then asked the judge to appoint a guardian, with the familiar argument that the parents had demonstrated a conflict of interest with their son by turning down NICA’s guarantees. That request was rejected.

The malpractice litigation remains pending.

And when Sandra and James Shoaf spurned NICA’s one-time \$100,000 payment and fought to pursue their malpractice suit, a hospital pointed out that their two-year separation — divorces are common among the parents of severely disabled children — left their daughter, Raven, especially vulnerable to her parents’ self-interest. The family was allowed to reject NICA



Raven Shoaf. Courtesy of family.

benefits, and the hospital where Raven was delivered eventually settled with the family for \$13 million, insurance records show.

Lucinda Finley, a University of Buffalo law professor whose expertise includes tort and equal-protection law, said accusing parents of seeking to profit from their children's injuries is a form of emotional abuse — compounded by the fact that parents and their children are the victims of someone else's potential negligence.

"Simultaneously devastating and enraging, infuriating," Finley said. "I can imagine the parent saying this hospital whose doctors are responsible for killing or seriously injuring my child now has the audacity to say I don't care about my child."

She added: "These are not parents who are suddenly seeking to improve their lifestyle. These

are parents who are suddenly faced with the crushing financial needs of seriously disabled children."

JUST KEEP PUSHING

An emergency C-section might have saved Hunter Lamendola from being deprived of oxygen and suffering permanent brain damage — and spared his mom from a lifetime of hardship, Lamendola said in her lawsuit. She said she had urged her obstetrician, Shamas, and the nurses who delivered Hunter on June 27, 2012, to initiate a Cesarean section. Her mother, grandmother and aunt all had required C-sections to give birth.

Lamendola, then 19, soon began to suspect that Hunter was in danger, she testified in an August 2016 deposition. Nurses repositioned her several times, "propped" her up with a pillow and administered oxygen. They said they "couldn't see the baby" on a fetal heart monitor, she said.

"I was worried about Hunter," Lamendola said in the deposition.

"Every time I said I wanted a C-section, it seemed like nothing was done about it," Lamendola said. "So I didn't feel like I was really heard."

9. If NICA's Summary Order on Compensability is granted, the Mother will have a conflict of interest with the Child. By rejecting the Child's vested NICA benefits, the Mother would be able to pursue her own speculative, complicated civil lawsuit on behalf of both the Mother and the Child. However, by accepting the Child's vested NICA benefits, the Mother would be unable to pursue her own civil lawsuit, seeking her own separate monetary damages for the Child's injuries.

The nurses, Lamendola said, were “dismissive” of her — at one point telling her to “just look at this smiley face on the wall and forget about” her pain.

When Lamendola asked again and again for a C-section, she was told to keep pushing, she said.

“Dr. Shamas said, ‘You need to continue pushing. You need to push with all your might,’ ” Lamendola recalled in her deposition. After Hunter emerged, Lamendola gushed blood. “Blood went all over the room,” she said. “It flung everywhere.”

Hunter was transferred quickly to the neonatal intensive care unit at All Children's Hospital — now Johns Hopkins All Children's — also in St. Petersburg. Lamendola did not get to touch her newborn son or catch more than a glimpse of his face behind a plexiglass incubator on wheels.

The emergency medical team from All Children's that had rushed in to transport Hunter from the St. Petersburg General Hospital delivery room asked repeatedly if Lamendola had seen him.

“They said, ‘We want to bring him by your bed, so you can see him just in case it's the last time,’ ” Lamendola recalled in an interview, choking back tears.

Lamendola said St. Petersburg General's hospital staff moved her to a room beyond the nursery to spare her the sound of bawling babies and joyful moms.

Nurses taped a picture of Hunter to the wall, Lamendola said.

A day passed before Lamendola could see Hunter again — at All Children's — then a week before she could hold or touch him. All Children's scheduled a meeting in a conference room adjacent to the neonatal intensive care unit, with a large wooden table surrounded by empty chairs, and a television cart and white board off to the side.

The first indication of where the meeting was going: a box of tissues on the table. The second: The hospital had arranged for a pastor to be present.

Hunter's intensive care doctor broke the news. Hunter had sustained "global brain damage."

"All the baby books don't talk about that," Lamendola said in an interview.

"Everything that I had planned or hoped. I didn't know what could or would be possible, at that point."

Hunter is blind. He cannot talk. He has reflux and cannot swallow. And he suffers almost daily seizures.

Lamendola filed the malpractice suit against Shamas and St. Petersburg General on April 24, 2013. The lawsuit was halted in July. Lamendola also was ordered to file a NICA petition.

On March 11, 2014, NICA told an administrative judge that Hunter's injury was compensable. But the following August, the judge, Susan Belyeu Kirkland, ruled that Lamendola could reject NICA benefits because St. Petersburg General had failed to give her proper notice of its participation in the program.

Such notice can't be given when a mother is already in labor and unable to choose another doctor.

"The policy of St. Petersburg General Hospital was to provide the NICA notice only when the patient [arrived] at the hospital and is admitted as an inpatient for delivery of her baby," the judge wrote. In other words: too late for a mom to find another hospital.

The ruling opened a door for Lamendola to exit NICA. St. Petersburg General promptly moved to shut it.

With the dispute back in Pinellas circuit court, St. Petersburg General asked for appointment of the guardian, arguing Lamendola could take millions of the hospital's money — and then walk away from her son when he got older.

"The child is vulnerable given the Mother's limited duty to only support the Child until the age of majority," the hospital wrote. The court pleading underscored the word only.

Vivek Sankaran, director of the Child Advocacy Law Clinic at the University of Michigan Law School, noted that the hospital itself had a conflict of interest, since it would be off the hook legally and financially if Hunter became a NICA client.

“The law is clear that someone does not get to substitute judgment unless there is proof that you have fallen below a more objective standard of harming your child in some concrete, identifiable way,” Sankaran said. “It can’t simply be ‘we disagree with your assessment of what’s best for your child.’”

“The law builds in protection for us to disagree on matters of child rearing,” he added. “That’s what the constitutional decisions have always held.”

St. Petersburg General, through its insurer, would ultimately pay Lamendola \$9.5 million to settle the case — after spending nearly \$1.2 million fighting her, insurance records show. Shamas’ insurer paid another \$250,000 to the family — after spending \$400,000 in litigation.

According to her attorney, Freedland Lamendola is not allowed to discuss the settlements.

DEVOTION AND PEDIASURE

Now 8, Hunter’s typical day begins at 6:30 a.m., when his mother prepares his breakfast: Pediaisure, a liquid mixture of vitamins, minerals and protein, pumped directly into his stomach and small intestine through a plastic tube.

At 9 a.m., Lamendola gives Hunter his meds. About a half-dozen of them, sometimes as many as nine. At 9:30 a.m., she disassembles Hunter’s wheelchair and loads it into the car for occupational therapy at 10, followed by feeding therapy at 11 a.m. Lunch is at noon — more Pediaisure in the pump — followed by 30 minutes in a contraption that builds muscle in Hunter’s paralyzed legs. Then a half-hour listening to the television, which blindness prevents him from seeing.

Lamendola’s mother takes care of Hunter when Lamendola is at work.

Hunter is more like a patient than a little boy, said Lamendola, who is more of a caregiver than a mom.

“It’s hard to be a mom now, because I have to be a therapist. I have to be a nurse. I have to be a doctor. I have to be everything that I should not have to be for him,” Lamendola said in a deposition. “I have to be a secretary to make all the appointments and cancel appointments when he’s sick.”

Hunter now has a little brother, Levi, who is a toddler.

“He is like a little Mama Bear to him,” Lamendola said in an interview. “When Hunter has a seizure, he rushes over and holds his arm and checks on him. When his feed runs out, starts beeping, he runs over and points at it to tell us to turn it off. He’s very protective of Hunter.”

Before the birth of her second child, Lamendola insisted that her new obstetrician agree in advance to a C-section. And she found a doctor who didn't participate in NICA.

"Since I had Hunter — and I'm basically his advocate, and I am basically his words — I have learned to speak up for myself and say whatever I have to say," Lamendola said. "I honestly don't care anymore if I'm nice about it. I'm going to say my truth."

Miami Herald

December 29, 2021



Dan and Jennifer Bookhout with their family, including their daughter Arwen at the center. COURTESY OF THE BOOKOUT FAMILY

Accused of refusing aid to disabled kids, a Florida agency responded — by hiring a PR guru

By Carol Marbin Miller and Daniel Chang

Dan Bookhout was accustomed to fighting over almost everything in his dealings with Florida's Birth-Related Neurological Injury Compensation Association, the program underwriting care for his severely disabled daughter, Arwen. The program's "no, no, no culture," he said, was "exhausting."

So Bookhout thought it seemed "fishy" when administrators offered, without a fight, to buy or lease a nearly \$30,000 robotic device to help his then-5-year-old walk. And when administrators asked for his help to promote the device to other parents.

What Bookhout didn't know at the time was that the program was being investigated by the Miami Herald and the nonprofit newsroom ProPublica for its stinginess with parents — and NICA administrators, aware of that fact, apparently wanted to get out ahead of what they expected to be tough findings.

NICA turned to a public relations firm to build goodwill and try to change its public perception.

Nearly \$200,000 was earmarked for a PR contract with Sachs Media at the same time as NICA was rejecting parental requests for wheelchairs, therapies and in-home nursing. Although the CEO of Sachs Media says the firm's work helped usher in reform in its own way, parents and lawmakers say the contract represents one more questionable decision by NICA's past management.

The PR contract made sense at the time to NICA's administration, given the questions it was receiving from the Herald.

"The Miami Herald has been conducting an investigation into NICA for several months, submitting numerous requests for public records and interviews," Ryan Cohn, a Sachs executive vice president, wrote in a December 2019 proposal to NICA. "We see this as the path forward to win in the court of public opinion and to protect your mission and the future of the organization," he said in an email to which the plan was attached.

The public relations firm helped NICA place a glowing op-ed in a Tallahassee newspaper and shepherded a second story about NICA's offer to buy robotic gait trainers for children who couldn't walk. Along the way, NICA gave the public relations firm something it had refused to give to the families themselves: the contact information for other families in the program.

For decades, families of Florida children born with catastrophic brain injuries wanted to connect with each other — for ideas and strategies, for advice on equipment and therapies, to buck each other up amid crises or just to vent. NICA administrators refused to share their names, citing the federal patient privacy law called HIPAA, which keeps individuals' medical information confidential.

"It was an intentional effort to keep families separate," said Bookhout. "Isolating us was a way of consolidating power."

In the end, state lawmakers insisted that administrators do what families demanded — listen to parents, and change. The Legislature expressed outrage and demanded an overhaul after a series of stories was published by the Herald and ProPublica.

A crucial byproduct of that transformation is that NICA families are now finding each other, able to talk to each other, to support each other — and are being heeded by the newly reconstituted NICA board, which for the first time includes a NICA parent and an advocate for

people with disabilities. The parents have created a Facebook group to share experiences. NICA is hiring an ombudsman and is considering creating a parents' council.

At the NICA board meeting this month, the newly appointed board chairman told parents: "You have been heard."

Ron Sachs, the founder and CEO of Sachs Media, said the contract was never merely about "buffing" NICA's image with families, policymakers, the public and reporters. His staff interviewed a "handful" of parents in the program to make their concerns known to administrators — hence the need for the names of NICA parents, which NICA made him promise not to share. His goal — in addition to improving the program's messaging — was to foster positive change, he said.

And Sachs said it succeeded by improving NICA's website and benefits handbook and helping leaders communicate better. The firm also championed NICA's effort to increase its initial payment to parents from \$100,000 to \$250,000 — a centerpiece of the legislative reform package.

"They're a better organization now," Sachs said.

Sachs' staff fell short of some of their goals, he said, because NICA was like every other large organization: It has lawyers, government relations staff and a board of directors.

"Our job is to give them our best advice and counsel, but we can't obligate them to enact them," he said. "We did not have the ability to wave a wand and have things go our way. We could not singularly make anything happen."

Kenney Shipley, NICA's executive director until she resigned this summer, declined to speak with the Herald and ProPublica.

'CULTURE OF SECRECY'

The Florida Legislature created NICA in 1988 in response to pleas from obstetricians, who claimed their rising medical malpractice premiums were driving them from the market. The law precludes parents from suing when their children are born with severe disabilities from oxygen deprivation or spinal injury. In return, NICA was to provide "medically necessary" and "reasonable" care for the rest of a child's life.

Many parents say, however, that NICA focused more intently on growing its nearly \$1.7 billion fund than meeting the needs of its clients and their families. As the Herald and ProPublica reported this year, parents have had to fight over big-ticket items like wheelchairs and vans, and little things, too, from drugs to blenders that make food accessible to children with daunting disabilities.



Kenney Shipley, who headed Florida's Birth-Related Neurological Injury Compensation Association since 2002, resigned after the Miami Herald/ProPublica series led to a legislative overhaul and reconstitution of the NICA board.
COURTESY: NICA

When parents complained about NICA's arbitrary denials or its exhausting approval process, they were often met with more resistance. One family was even tailed by a private investigator hired by NICA. Sometimes, administrators suggested families who disagreed with the program's denial of treatment or services hire lawyers and appeal to Florida's administrative courts, parents say. At times, NICA spent considerably more in legal fees fighting parental requests than it would have cost to provide the care.

"NICA barricaded itself as an organization, keeping its spears outward," Bookhout said. "Their culture of secrecy [was] their knee-jerk reaction — their go-to."

NICA's deployment of the Health Insurance Portability and Accountability Act, or HIPAA, as a defense against helping families find each other was unnecessary, the program now acknowledges. The names of families in the program, along with addresses and other

information, have been available via the Division of Administrative Hearings for three decades — just like records at other courthouses or their websites.

As the Herald investigated NICA, administrators continued to reject requests from parents. They wrote checks to Sachs Media.

Using Florida's public records law, the Herald acquired hundreds of pages of emails and other records that opened a window onto NICA's effort to paint a flattering self-portrait.

Ron Sachs knows the PR terrain in Florida politics well. He has represented a who's who of private, nonprofit and government institutions, including The Florida Bar, the Florida Chamber Foundation, Alliance for School Choice, Disability Rights Florida, and the Florida departments of Children and Families, Veterans' Affairs, Transportation and State, as well as the state Office of Insurance Regulation and the Fish and Wildlife Conservation Commission.

State agencies have agreed to pay Sachs Media nearly \$1.5 million in recent years, in addition to three contracts involving the Department of Corrections and the Department of Environmental Protection that do not disclose a contract amount.

As part of the Jan. 7, 2020, NICA contract, Sachs was to provide “reputation management,” “strategic counsel and guidance,” “message development,” “thought leadership,” “media relations” and “op-eds and letters to the editor.” Sachs also was to redesign NICA’s website, something parents had been requesting for years.

Sachs began representing NICA that month, and ultimately was paid \$199,200 over two years to persuade lawmakers, advocates and journalists that program administrators were doing everything they could to help children with severe brain damage and their parents. The contract ends Dec. 31, 2021.

About the time Sachs began representing the program, NICA parent Elizabeth Midland had about \$500 in the bank and a 1-year-old daughter at home. Midland’s daughter, Jolee, has severe spastic quadriplegia, the result of a catastrophic brain injury. NICA was fighting over everything, Midland told the Herald: medication, therapy, a wheelchair, renovations to make her driveway wide enough for the SUV the family bought to accommodate a wheelchair.

“We had to refinance our house to get that taken care of,” she said. “NICA wouldn’t help.”

NICA, Midland wrote to her daughter’s Fort Walton Beach pediatrician in a Jan. 16, 2020, email, “is being a pain in my rear for reimbursement for ANYTHING.”

Meanwhile, NICA was gearing up its effort to convince the public that parents were happy with the way they were being treated.

“We are gonna rock for you!” Sachs wrote to NICA’s director, Kenney Shipley, nine days before Midland wrote to her daughter’s doctor.

‘WHAT A GREAT VOICE TO SUPPORT US’

One of the pieces Sachs’ firm placed was a guest editorial that his team arranged. It was signed by Jack Levine, a Tallahassee children’s advocate who in 2020 received the Lawton and Rhea Chiles Advocacy Award.

“We’ve been working with child advocate Jack Levine on an op-ed about how NICA is one of Florida’s best examples of a fiscally sustainable program benefiting at-risk families,” Cohn, the executive VP, wrote in an email to Shipley 11 days before the op-ed was published. “Once finalized, we plan to submit it to the Tallahassee Democrat.”

“What a great voice to support us!” Shipley replied.

lyana@sachsmedia.com
Subject: Re: Contract Attached

Thanks so much, Kenney and Steve. We're gonna rock for you!

In email, public relations executive Ron Sachs promises to 'rock' on behalf of Florida's agency serving children who suffered brain injuries at birth.

The Sept. 12, 2020, column was entirely favorable. "As our state policymakers look ahead, they must seek ideas that help at-risk families now and that remain fiscally sustainable in the future," the column said, calling NICA "a shining example" of a "little-known program smartly created by state officials more than three decades ago."

In an interview with the Herald, Levine said he was approached to write about NICA by Sachs, whom he's known since at least the 1990s, when Sachs was a spokesperson for then-Gov. Lawton Chiles. "So I did a little bit of reading and a little bit of thinking about how it was relevant to the Florida budget picture."

On Tue, Jan 7, 2020 at 5:23 PM Kenney Shipley
<kshipley@nica.com> wrote:

Thank you Ron! We think you rock already!

In response to Ron Sachs' email, NICA administrators say they appreciate his efforts to improve the agency's image.

"I've got a 40-year relationship with Ron Sachs and his company, so we work very cooperatively together," Levine added.

Levine said he was not paid by Sachs to publish the piece, and that it reflected his own thoughts. "I'm the drafter," he said, "and it went under my name."

Records obtained by the Herald, however, show parts of Levine's op-ed appear to echo a February 2020 set of "primary talking points" drafted by Sachs' staff.

From the talking points: "NICA's creation helped to stabilize Florida's medical malpractice insurance market, reducing malpractice insurance premiums and ending an exodus of obstetricians from the state."

From Levine's op-ed: "NICA helped stabilize Florida's medical malpractice insurance market, reducing malpractice insurance premiums and ending an exodus of obstetricians from the state."

From the talking points: "The fund has been bolstered by strong investment policies, and NICA has not raised provider assessments since 1988."

From Levine's op-ed: "Astoundingly, NICA has never raised those assessments since its creation in 1988 — thanks to strong investment choices that have bolstered the NICA fund."

In a followup interview, Levine acknowledged that he received "background information" from Sachs that helped him write his column.

NICA emails obtained by the Herald show Sachs also arranged for a story about NICA to be published in Florida Politics, a web-based news organization devoted mainly to campaign, election, lobbying and government policy news — and read by influential people in Tallahassee. The story concerned NICA's decision to offer robotic "exoskeleton" suits to participating children with severe cerebral palsy, a neurological condition that results in physical, and sometimes cognitive, impairments.

The story followed an article that appeared in Runner's World, which celebrated the achievements of two disabled children who walked the equivalent of a three-mile virtual race with the aid of a sophisticated gait-trainer device produced by Trexo Robotics of Toronto. (Sachs was not involved in that article.)

One of the two youngsters was Arwen Bookhout, daughter of Dan Bookhout, whose family lives in Elkton, near St. Augustine.

Arwen was born on July 11, 2015. Her umbilical cord had become compressed during delivery, leading to severe oxygen deprivation. She was accepted for NICA compensation in February 2019.

In the beginning, the Bookhouts were grateful for what NICA offered. The program paid hospital and medical bills, and it took much of the pressure off a young couple coping with a life-shattering event. "We were thankful we could breathe again and get on with our lives," Dan Bookhout said.

But relief gave way to frustration when NICA constantly quibbled over payments. Eventually, the couple would seek forgiveness after the fact, rather than permission, by buying what Arwen needed and fighting over reimbursement later. That was the Bookhouts' strategy when they contacted Trexo about leasing or buying a robotics suit.

The Bookhouts paid a \$1,000 deposit, and Arwen's robotic device arrived in early March 2020, Dan Bookhout said. He recalls being shocked when he first broached the subject with his NICA case manager. He expected a donnybrook. Instead, the case manager not only offered to get the suit for them and reimbursed the deposit, but also wanted to discuss hooking up other families, too.

"I'm writing to ask you for permission to share Arwen's story ... with the Trexo equipment on our website," Shipley wrote in an Aug. 12, 2020, email. "I think it would be helpful to other families."

"We were flabbergasted," Dan Bookhout said. "The lack of pushback was shocking."

As the devices arrived in the homes of NICA children, so too did NICA's requests to parents to feature their children in a story. "The Lakeland Ledger is interested in running the story if any of the children live in Polk County," one Sachs employee wrote to Shipley on Aug. 20, 2020. "Do you have any NICA families in Polk County?"

A month earlier, Shipley had told her lawyers that NICA and Cohn, from Sachs Media, were discussing "doing a story on this new type of equipment that we are authorizing and paying for. I think it's a great story," she added.

That story was published by Florida Politics on Aug. 24, 2020. It featured an 11-year-old boy whose Trexo device had arrived six days earlier. The child had taken 126 steps with the exoskeleton suit that first day, the story said, "a huge milestone."

A day later, one of NICA's lawyers wrote an email about the article: "Great work Sachs team."

'A SEA CHANGE'

By the summer of 2020, Dan Bookhout said, things seemed strange at NICA. He and his wife had been speaking with administrators only by email, to create a record when requests were denied. But here was Shipley and her staff offering to buy or lease pieces of equipment that cost nearly \$30,000.

"It was such a sea change in their typical mode of operation," he said.

This past April, Bookhout began to understand what had been happening inside NICA that may have prompted Shipley to open the program's checkbook. After the Herald and ProPublica began publishing their investigation, lawmakers demanded an overhaul of NICA. Its entire governing board resigned. Shipley, the executive director, quit under intense criticism.

The legislative overhaul marked the most significant change in NICA's 33-year history.

And, for the first time, parents were speaking with each other — and to lawmakers, and to a new, larger board of directors that now included a NICA parent and an advocate for children with disabilities.

Sachs said he and his wife had lost family members, including his brother, in recent months, and they understand the value of sharing their pain with others who are struggling with similar emotions. "Connecting people who experience loss is a helpful thing to the healing process," he said.

NICA, Sachs added, "was created to do good. And now, because of all the reviews, internally and externally, they are in a position to do better.

Miami Herald

June 22, 2021



Florida Chief Financial Officer Jimmy Patronis, who oversees the NICA program, praised the passage of a bill reforming it. Wilfredo Lee AP

DeSantis signs into law bill overhauling safety net for families with brain-damaged babies

By Carol Marbin Miller and Daniel Chang

Gov. Ron DeSantis has signed legislation overhauling the controversial Florida program that provides lifelong care for children born with catastrophic brain damage, approving the most far-reaching reform in the program's 33-year history.

With DeSantis' signature Monday night, parents who participate in the Birth-Related Neurological Injury Compensation Association, or NICA, will get an immediate \$150,000 cash benefit, and the pledge of Florida lawmakers that they will no longer have to fight with

administrators for wheelchairs, medication, therapy and other services for their severely disabled children.

That's on top of the \$100,000 the law previously provided, which had not been increased since the program's inception. Families said that original amount fell far short of providing what's necessary for a severely disabled child.

The law, which takes effect immediately, follows an investigation by the Miami Herald, in conjunction with the investigative newsroom ProPublica, that found NICA had generated nearly \$1.5 billion in assets — largely through the investment of assessments paid by doctors and hospitals. At the same time, families complained, administrators frequently delayed or denied medication, therapy, equipment and nursing services to parents struggling to pay their bills.

In many ways the reform bill was a rebuke of NICA's leadership, which had for decades run the program with little transparency. Parents said the program denied claims and made it difficult for them to access care for their children with severe and permanent brain damage. In one 2013 email obtained by the Herald, NICA's director wrote that the program was "not here or funded to 'promote the best interest' of the children."

The new law says otherwise: One provision requires that "the association shall administer the plan in a manner that promotes and protects the health and best interests of children with birth-related neurological injuries."

A statement issued by the program Tuesday said NICA "wholeheartedly supports and appreciates what Florida lawmakers have done this year to help our organization enhance benefits for our families."

Parents and guardians of children in NICA said they were glad to see the governor approve the changes, but some also wondered why it took years for the state to address the program's inadequacies.

"It feels good to be acknowledged, not just acknowledged but that they're trying to make things right," said Jennifer Pham, whose younger brother, Justin Nguyen, was accepted into NICA in 1998.

Pham, whose family's story was reported by the Herald, said her family had reached the point of desperation after years of fighting with program administrators to get what Justin had been promised.

"Why do families have to go through so much to get change," said Pham, 31, whose family lives in Jacksonville. "I feel like anytime anything good happened with NICA it was because my family was at the edge. We were at rock bottom, and then they wanted to help out."

For most of its history, NICA operated in obscurity. Lawmakers created the program to manage the care of children born with severe physical and cognitive disabilities as the result of oxygen deprivation or spinal cord injury at birth.

Families were steered into the program by a 1988 law — one of only two in the nation — that severely restricts the parents of certain brain-damaged children from suing their obstetrician or the hospital where their child was born. NICA was created to protect obstetricians from ruinous legal judgments for some of the most expensive medical mistakes, thereby lowering malpractice liability insurance premiums.

The reform legislation was passed unanimously by both chambers of the Legislature in response to the Herald and Pro-Publica stories, called Birth & Betrayal.

Parents said they were often treated with indifference and contempt by administrators who, they believe, cared more about their investment portfolios than the lives of frail and disabled children. Administrators hired a private investigator to tail one boy's parents after they appealed NICA's refusal to pay for therapy.

Yamile "Jamie" Acebo of Pembroke Pines — whose hardship was detailed in a Herald story — said the help her daughter, Jasmine Acebo, received from NICA often was delivered grudgingly, and late, if at all.

"They were just trying to nickel-and-dime me," Acebo said of her experience with NICA. "It's like it was their savings account — like it was theirs and they were not really doing anything to help people."

But Acebo said she's happy that future NICA families will get more freely what she had to fight for. "Finally something is going to get done," said Acebo. "They are finally going to do the right thing. A lot of these families are struggling, and should not have to struggle."

Among other provisions, the new law will give families the means to fully cover funeral and burial expenses if a child in NICA dies. Acebo said she couldn't afford both a coffin and funeral when 27-year-old Jasmine died in 2017. She said she had had to cremate her daughter, though her faith frowns upon the practice. "Let me tell you," she said, "I had to scrape and scrounge, and people had to give me money for my daughter's funeral."

With DeSantis' signature, "on top of grieving a child, they won't have to worry, 'Where am I going to get money to bury my child?'" Acebo said of parents still in the program.

Because her involvement in NICA ended with the death of her daughter, Acebo will not receive the added \$150,000. But she will receive the enhanced death benefit, \$50,000 for death expenses, not the \$10,000 the law previously allowed.



Justin Nguyen is surrounded by his mother, Julie, and his sisters Jennifer and Jessica Pham as they celebrate his 12th birthday. Every one of Justin's birthday is a big celebration in the family as they say they never know how many more years Justin will be with them.

Chief Financial Officer Jimmy Patronis, whose agency oversees NICA, said in a prepared statement Monday night that the legislation “fundamentally reforms” the program, which lawmakers created in response to complaints from obstetricians that their medical malpractice premiums were becoming prohibitively high.

“This law represents a major paradigm shift,” Patronis said. “As of now, NICA must be fully engaged in the overall well-being of these families and children. Overall, these families are going to get more relief, and it is our job to ensure the board is holding NICA accountable and seeing these reforms are implemented.”

In addition to the increase in the one-time payment and the enhanced death benefit, the law provides:

- A \$10,000 annual mental health benefit for families.

- Representation on the board of directors by a NICA parent and an advocate for disabled children, and a six-year term limit for all board members.
- An increase in the lifetime “housing assistance” and home modification benefit from \$30,000 to \$100,000. ▪ Money for wheelchair-accessible vans and a “reliable method of transportation” for the life of children in care.
- A code of ethics for administrators and board members.
- An appeal process at the Division of Administrative Hearings, where NICA petitions are filed, for families to dispute NICA denials.

The statement issued by NICA said, in part: “We are eager to provide these new benefits and have already begun implementing the new language and protocols envisioned in the legislation. Our 17-person team is committed to meeting all statutory deadlines and will do everything we can to give NICA families the support they need in navigating the claims process.

“We recently launched a more user-friendly website and are revising the Benefit Handbook to make it easier for families to understand the benefits their child may be eligible for and how to access those benefits.”

In a prepared statement, one of the legislative sponsors said the law “will help ensure so many struggling families get the help and care they deserve.”

“As a mother of two, I know there is nothing more important than ensuring your child has the proper care they need to live a long healthy life,” said state Rep. Traci Koster, a Safety Harbor Republican, and the law’s House sponsor. “This legislation brings needed changes to the NICA program and improves services that they provide.”

Sen. Danny Burgess, a Zephyrhills Republican, co-sponsored the legislation in the Senate. “The NICA program has been in need of reforms for quite some time now and this legislation is an important step in the right direction,” Burgess wrote.

He added: “On behalf of all of the NICA families who have struggled, this is a light at the end of a very dark tunnel.”

Sen. Lauren Book, a Plantation Democrat who co-sponsored the legislation in the upper chamber, said “no family should have to beg for the treatment and supplies their children need while a quasi-governmental agency puts up roadblock after roadblock.”

The law, Book told the Herald, “will provide some much-needed relief for these families and put some measures in place to hold NICA accountable.”

“But our work is far from over,” she added, pointing out that House Speaker Chris Sprowls initiated an investigation into NICA during the recent lawmaking session.

“We know there is much to be done,” she said.



Jennifer and Jessica Pham, ages 6 and 7, had to grow up fast when their brother came home from the hospital tragically disabled. The sisters say the help — and information — they got from a state program was welcome but insufficient.
By Emily Michot | Daniel Chang | Carol Marbin Miller

Facing fierce criticism, head of Florida's troubled program to aid brain-damaged kids quits

By Carol Marbin Miller and Daniel Chang

On the eve of what was expected to be a contentious board of directors meeting, the head of Florida's compensation program for children born with catastrophic brain injuries has abruptly resigned.

Kenney Shipley, who has overseen the Birth-Related Neurological Injury Compensation Association, or NICA, for nearly two decades, announced her resignation in a letter Wednesday. It takes effect Jan. 4, 2022, though Shipley intends to claim accrued leave time after an interim director is appointed.

“I feel grateful and honored to have been able to serve the very special families that I have worked with over the years,” Shipley, who was paid \$176,900, wrote in her letter. “Many have been my heroes and taught me what real strength and character are.”

“I plan to cooperate and be available to assist the organization in any way that would be beneficial,” Shipley added.

Shipley, a former insurance adjuster, had been facing intense criticism since April when the Miami Herald, in partnership with the investigative newsroom ProPublica, began publishing a series of stories about the program, created by the Florida Legislature in 1988 to immunize obstetricians from the financial consequences of catastrophic births.

Under the NICA statute — one of only two such laws in the nation — parents lost the right to sue their doctor or hospital under certain circumstances when their child was born with severe brain damage from oxygen deprivation or spinal injury. In exchange for that loss, parents were promised “medically necessary” and “reasonable” medical care for the life of their children.

The investigation by the news organizations, called Birth & Betrayal, detailed how NICA had amassed nearly \$1.5 billion in assets while administrators often refused requests large and small — for medication, medical equipment, wheelchairs, therapy and in-home nursing for children with breathing tubes. The series showed administrators spent thousands in legal fees to avoid spending hundreds for care.

After the series published, Florida lawmakers passed sweeping legislation to reform the program, delivering new benefits and protections to the more than 200 Florida families with children covered by NICA, including mental health services, representation on the board of directors and retroactive compensation of \$150,000 for parents whose children are still alive and in the program. Gov. Ron DeSantis signed the legislation into law in June.

Alex Sink, Florida’s chief financial officer from 2006 to 2010, said she is encouraged by the changes at NICA. Sink had criticized the program as a “scam” and accused NICA’s leaders of having misplaced priorities that emphasized the financial growth of the program over meeting the needs of families.

“It gives me hope that maybe these people who are supposed to represent us in Tallahassee occasionally have a conscience,” Sink said. “It’s a long time coming. ... It really is a new day for NICA.”

Sink added: “This new board has the opportunity to bring in a CEO who does the job. The job is to put the needs of these families first.”

Shipley’s departure occurs at a crucial moment: The program’s governing board of directors was expanded from five to seven at the same time the members of the previous board, dominated by representatives of the healthcare and insurance industries, quit amid a new provision setting term limits. The reconstituted board, which for the first time includes a NICA parent and an advocate for children, holds its inaugural meeting Thursday at 1 p.m.



Alex Sink

Aside from the new law, NICA also must contend with an angry Legislature and intense oversight from Florida’s chief financial officer, Jimmy Patronis, whose office is conducting a “market conduct operational audit” to determine “the extent to which NICA’s claim-handling practices comply with [the program’s] statutory mandate.”



September 15, 2021

Jim DeBeaugrine, MPA, Interim Chair
NICA Board of Directors
1778 Vineyard Way
Tallahassee, FL 32317

Dear Chair DeBeaugrine:

It is with mixed feelings that I am offering my resignation as Executive Director of the Florida Birth-Related Injury Compensation Association (NICA). If agreed by the Board, my final day will be January 4, 2022, but I plan to take leave as soon as a new Interim or Executive Director is appointed by the Board. I will be available to overlap or help manage day to day activities and assist in transition until January if it would be helpful. I plan to cooperate and be available to assist the organization in any way that would be beneficial.

I am advising you of this now so that you have time to appoint a search committee if that is the direction that works best, or otherwise identify a candidate to replace me. We had planned to set another meeting in October to approve the operational documents and the annual report that is required to be presented to the Legislature on November 1, 2021. The Board could also vote for an interim or new Executive Director at that meeting.

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1 of 1



Patronis also appointed his consumer advocate, Tasha Carter, to represent families in disputes with NICA administrators over care and services.

But even after lawmakers appeared to reproach Shipley by including a statutory provision requiring the program to operate “in a manner that promotes and protects the health and best interests of children,” Shipley continued to anger both parents and regulators.

Though the Legislature had imposed no conditions on NICA families receiving a \$150,000 cash supplement, Shipley at first insisted that parents sign a “perjury statement” — an attestation, required by Shipley for all invoices, that the signer was not committing fraud — before they could claim the benefit. The statements, which invoked the specter of criminal prosecution, infuriated some parents.

In a June 21 email obtained by the Herald, Carter told Shipley that “to require the parents and legal guardians to sign a Perjury Statement in order to receive the award creates stipulations that are not in law. Would NICA withhold the disbursement of the parental award if a parent or legal guardian refused to sign the Perjury Statement?”

Carter asked Shipley to “immediately discontinue the requirement” and to notify families that the perjury statement was no longer required.

Shipley did not publicly address the concerns from Carter. Before the change in the law, NICA alleged that it required families to sign such statements “after unfortunate instances of some claimants falsifying documents and misrepresenting payments when seeking reimbursement.” But it would not provide specifics when asked by Herald reporters.

The board’s interim chairman, Jim DeBeaugrine, said Wednesday that the new board is prepared for the work ahead, which includes recruiting a new executive director, creating a new agency culture that emphasizes service to parents and begin implementing the mandates of an entirely new governing statute.



Jim DeBeaugrine

“We have our work cut out for us,” he said.

“Everybody who has accepted an appointment to this board understood that going in,” said DeBeaugrine, a former director of the Florida Agency for Persons with Disabilities who also has been a longtime caregiver for a disabled family member. “I’m confident we are going to be up to the task ahead.”

“It’s a very important job,” DeBeaugrine said of the next leader. “It will be the executive director of an organization with \$1.5 billion in investments. More important than that are the lives we are supporting. The families. We want to get it right.”

One of the families the new board will be supporting includes the mother and two sisters of Justin Nguyen, a 24-year-old Jacksonville man who was left with profound brain damage at birth.

“My brother has been in the NICA program for 24 years — probably as one of NICA’s oldest participants,” said Justin’s older sister, Jennifer Pham, 31, who has helped manage Justin’s care since his childhood. Pham said Shipley was “negligent in fulfilling her duties and obligations while leading and managing NICA.”

“The future looks brighter for the next day,” Pham said, “but we still have a long way to go to correct the program.

“I hope that the next director is more involved with and passionate about NICA families and the needs of their loved ones. And I also hope the events that unraveled concerning NICA over these past months serve as a wake-up call to the Florida government and watchdogs. How much do families have to suffer before they’re heard?”

NICA parent Ashley Huffman of Jupiter, whose 7-year-old son, Malcolm, is in the program, also was pleased to learn it would soon be under new management. “We need someone fresh who actually cares about the quality of our children’s lives. Too many mistakes and too many families have suffered needlessly under her watch.

Miami Herald

October 22, 2021



The Polaroid photo that was shown to Jamie Acebo as she recuperated from her difficult delivery. Emily Michot, Miami Herald

‘These findings boggle my mind’: Audit savages Florida program to aid brain-damaged kids

By Carol Marbin Miller and Daniel Chang

Case managers at Florida’s \$1.5 billion compensation program for catastrophically brain-damaged children didn’t consult specialists to determine whether medications, therapy, medical supplies and surgical procedures were “medically necessary” to the health of children in the plan.

They relied on Google instead.

The Birth-Related Neurological Injury Compensation Association, or NICA, arbitrarily decides who may be compensated for care — and how much. Administrators developed no system for resolving disputes with angry parents, discouraged parents from appealing denials to an

administrative court, and didn't maintain a system for storing and tracking denials or complaints.

Those are some of the findings of an audit performed by the Office of Insurance Regulation, which oversees the industry for the Florida Cabinet.

"As a father of two, some of these findings boggle my mind and raise basic questions, such as why is a program of this size doing record-keeping with CD-ROMs?" the state's chief financial officer, Jimmy Patronis, wrote in a letter to NICA's board chairman. "Why are denials not documented? Plus, is there any process for figuring out whether a procedure, or a piece of equipment, is medically necessary or not?"

"Too often, government can operate like a heartless bureaucracy," wrote Patronis, "and we cannot allow NICA to function with indifference. These families deserve nothing less than Florida's full compassion and support."

Patronis requested the audit in April after the Miami Herald, in partnership with the nonprofit newsroom ProPublica, published a series of stories detailing how NICA has amassed nearly \$1.5 billion in assets while sometimes arbitrarily denying or slow-walking care to severely brain-damaged children.

The report confirms the series' findings, which NICA in April said failed "to provide a completely accurate portrayal."

As a whole, the audit describes in mostly clinical terms a closed, callous, capricious system that left the parents of sometimes profoundly injured children with no recourse or options when their requests for help were rebuffed.

NICA administrators placed "barriers, burdens and time restrictions" on reimbursement that aren't in state law, the report said.

For example, parents can override the need for prior authorization when seeking emergency medical care. But NICA told auditors that "it must first be demonstrated that a participant family member 'benefited from' or noticeably 'progressed' as a result" of such treatment to be reimbursed — a condition state statute doesn't require.

And even if a child in the program was determined to be eligible for a treatment or therapy, family members sometimes were required to "contact NICA before committing to the purchase," because failing to do so might "jeopardize the amount of reimbursement," the audit said.

NICA's power to arbitrarily approve or deny care was sometimes spelled out explicitly in guidelines. The program's Benefits Handbook says that when a family requests a benefit

outside of the child's separate insurance plan, or outside Florida, "NICA alone determines, in advance, whether it will elect to pay for those benefits, even if the treatment, evaluation or surgery is medically necessary," the audit said.

One of the most curious findings concerns NICA's method for determining whether requests for care were medically necessary, and therefore eligible for reimbursement. If any such system existed at all, it involved consulting the Internet, not qualified medical professionals.

"NICA stated the case managers and the case manager supervisor often use Google to research and determine medical necessity," the report said.

When medical necessity is still in dispute, the report said, judgment ultimately rests with "the executive director, who makes determinations regarding medical necessity regardless of the fact that she has no medical training or credentials."

Jamie Acebo of Pembroke Pines, whose daughter Jasmine spent 27 years in the NICA program, said NICA's administrator referred her to websites to justify spending decisions — at one point directing her to a company selling air mattresses that were inferior to the one her doctor had prescribed.

"She would send me pictures from Google." A previous mattress — necessary to prevent Jasmine from developing dangerous pressure sores — "didn't even get to a year," said Acebo, whose story was detailed in the Herald and ProPublica series.

The Legislature created NICA in 1988 to satisfy the demands of obstetricians, who insisted their medical malpractice premiums were too burdensome. The statute forbids the parents of certain brain-damaged infants from suing their doctor or hospital. In exchange, the law promises a lifetime of "medically necessary" and "reasonable" care.

Days after the Herald and ProPublica series published, the Legislature unanimously passed a sweeping reform of the 33-year-old program. It promised \$150,000 in immediate cash assistance to every NICA family, up to \$10,000 in annual mental health coverage, and \$100,000 for handicap-accessible home renovations for each family currently enrolled. The law also set aside \$40,000 in additional death benefits for parents whose children died, ending their enrollment in NICA, retroactive to the program's inception.

The legislation directly addressed the concerns of lawmakers, and Patronis, that NICA appeared to view parents as an inconvenience to its main mission of protecting doctors and insurers: For the first time in the program's history, Florida law explicitly requires that the program be administered "in a manner that promotes and protects the health and best interest of children with birth-related neurological injuries."

Gov. Ron DeSantis signed the legislation into law in June.



Kenney Shipley. Courtesy of NICA.

One version of the bill required NICA to hire an ombudsman to advocate for families unhappy with their treatment, but the measure was removed in the lawmaking session's waning days as a handful of lobbyists for the program and insurance industry sought to water down the law's scope.

The Office of Insurance Regulation audit explicitly recommends that NICA appoint such an advocate.

In the weeks following the legislation's passage, all five members of NICA's Board of Directors, which had been controlled by doctors, hospital administrators and insurance industry representatives, resigned. They were replaced with a seven-member board that, as the new law requires, includes the parent of a NICA child and an advocate for people with disabilities.

The program's director, Kenney Shipley, abruptly resigned on Sept. 15, the day before NICA's newly appointed board met for the first time. "I feel grateful and honored to have been able to serve the very special families that I have worked with over the years," Shipley wrote at the time.

In an Oct. 18 letter to the board's new chairman, Jim DeBeaugrine, accompanying the audit, Patronis said the Herald's "stories of parents, and their children, going through challenges in dealing with NICA were clearly symptomatic of a flawed program. That's why we needed [the Office of Insurance Regulation] to take a look at the nuts-and-bolts of how NICA operates to determine where shortcomings existed."

The results, he wrote, "reaffirm" complaints from current and former parents in the program — some of whom came forward for the first time recently in the wake of the series, and the legislative changes it wrought.

He added: "These are very basic elements of running a program of this type, and NICA was unable to provide auditors with acceptable answers."

Patronis called the audit, and its 15 separate recommendations, a "roadmap" for redirecting the program to "the right course."

Auditors also concluded that the recommended changes were needed if NICA is to be in compliance with the new mandate to manage the program in a manner that promotes the health and best interests of children accepted into the plan.

DeBeaugrine — who formerly served as director of the state Agency for Persons with Disabilities, and represents children with special needs on the board — has been asked to oversee the program’s reinvention. In an interview with the Herald, he also called the audit a blueprint for reform.

“We are taking that report and its recommendations seriously,” he said, adding the audit will help incoming board members “navigate and implement” the calls from parents and lawmakers to transform the program.

Instead of devoting much additional time to decrying how the program lost its way, DeBeaugrine said, board members should heed the audit’s recommendations for fixing the problems. “This gives us some good ideas for how to move forward,” he said. “It points out some areas of improvement. We will be referring to it quite a bit.” The overhaul of the Florida program known as NICA accelerated with the appointment of Jim DeBeaugrine, long active in the field of disability rights, to the board.

At the next NICA board meeting, DeBeaugrine said, he will recommend the board appoint an interim director to carry out the changes.

“She tendered her resignation,” he said of Shipley. “We are going in a different direction. Taking these reports, I think it just makes better sense to start that process once we get different management in place.

“I feel like we have a blank slate,” he added.

Even after lawmakers, advocates and the state’s top financial regulator placed the program under intense scrutiny, administrators had difficulty explaining many of NICA’s practices.

For instance, the report said administrators were unable to document how many families were eligible for the \$150,000 added benefit called for by lawmakers: The program said 215 families were entitled to the supplement, but detailed payments to the parents of 221 covered children — not 215.

The program hadn’t kept track of the families of deceased children, either, the report said, complicating the task of providing them the \$40,000 in additional death benefits under the new law. The previous benefit was \$10,000. Parents who lost a child before or after filing a petition for benefits were entitled to \$40,000 in additional death benefits under the new law. The legislation raises the death benefit from \$10,000 to \$50,000 for all new petitions.

The provision applies to 216 families of deceased children, the audit said. But NICA can’t find 50 of them. Another child appears to have been in foster care in Texas when he or she died, and attempts to identify and contact the child’s parents or guardians have been unsuccessful.

Acebo, whose daughter died in 2017, said the Herald's stories — and the audit that confirmed their findings — were important to her efforts at healing because “I never realized until the articles came out that other families were going through the same things.”

“There are families out there in the world who don't even know this has taken place,” she said. “After experiencing the death of a child, they won't even be able to get this money. To me, that is so unfair.”

The audit called NICA's system for storing and tracking claims “incomplete and unreliable.” Auditors, the report said, “were unable to ascertain the timely and accurate payment of claims” because records sometimes lacked documentation, contained erroneous labels, and inaccurate coding.

Administrators kept claims data in two separate categories, the report said, one for paid requests, another for claims that were denied. But the silo for rejected claims was essentially empty.

In addition to outright denying claims, administrators sometimes agreed to pay only a portion of an expense, the report said. The program “was unable to provide any documentation to support the imposition of these monetary limits” or that they complied with the law governing the program.

Record-keeping, the audit said, often was antiquated, uncentralized and unreliable. Auditors found “boxes of paper records” scattered throughout NICA's Tallahassee office. The program also kept records on compact discs, which “can erode over time.”

“The auditors noted a significant number of documents were missing from the claims system and, in certain cases, were uploaded after NICA received an inquiry from the auditors,” the report said.

The report said NICA spent hundreds of thousands of dollars on vendors without requiring a contract.

Some of the lapses identified by the auditors reflected failures to comply with the program's own Plan of Operation, including: the failure to develop a system for resolving disputes with parents, the failure to maintain an “up-to-date” claims procedures manual, and a schedule to ensure claims are processed and reimbursed in timely fashion.

When auditors requested a copy of NICA's claims manual, for example, they were given a document that is eight years old. Administrators told auditors the 2013 manual “was outdated and no longer in use,” the audit said, but noted the program never bothered to update it.



Delaina Parrish, born without the ability to speak or walk, is today able to communicate because of a machine that translates her eye movements into words. She recently graduated from the University of Florida. The machine came from the manufacturer, not from the Florida Birth-related Neurological Injury Compensation Association, or NICA. Notwithstanding her success, she and her parents say the program does too little to help others like her. Family photo

organization.”

The device that gave voice to her daughter was provided not by NICA but by the manufacturer.

For years, administrators visited the homes of families who were being enrolled in the program, and occasionally after that when it was necessary. But the visits ceased in 2017, the report said, and “no similar replacement outreach efforts to support participant families have been instituted since 2017.”

Acebo — who recalls being offered the chance to institutionalize Jasmine during one such home visit, an offer she rejected — said Thursday the audit was a vindication of her decision to tell her story, painful as it was.

Acebo said she never understood why NICA was hoarding hundreds of thousands of dollars while families like hers suffered. “These children are not going to get to be 50 years old. They’re not. Why not give them the best quality of life you can give them while they’re here? “I felt like finally someone listened to us,” she said. “Finally someone did something about it.”

NICA’s poor communication with families in the program was a central theme in the report, which quoted the mother of a now-23-year-old woman — whose story is reported in the Herald series — beseeching administrators to “help families” and not “put up brick walls.”

“Change needs to happen in the NICA culture,” the report quoted Patricia Parrish saying at an April 6, 2017, board meeting. The audit said NICA leadership “failed to record if or how” such complaints were resolved.

After reading the audit, Parrish — whose daughter Delaina graduated from the University of Florida, aided by a device that converts her eye movements into computer-generated words — said she was most struck by the lack of accountability at NICA — over the course of three decades, the administrations of multiple governors and financial regulators and both political parties. “The pain and suffering among parents was caused, in part, because there was no oversight,” she said.

“We have been let down,” she said. “They let every one of us down by not managing the oversight of this

She added: “Now they are going to have to be held accountable. That, to me, is the best thing in the world.”

Miami Herald

April 8, 2021



Jackie Amorim, whose 3-year-old daughter, Vera, was accepted into NICA in 2019, is grateful for the bill passed by lawmakers. But she also wants NICA to cover alternative therapies for children. Jackie Amorim

After 33 years parents of brain-damaged kids get to express disgust with Florida program

By Carol Marbin Miller and Daniel Chang

The parents of children born with catastrophic brain damage who were stripped of the right to sue were offered a measure of consolation Thursday for the first time in more than three decades: They were given the chance to speak.

About a dozen mothers and fathers addressed the administrators and governing board of Florida's Birth-Related Neurological Injury Compensation Association, or NICA, at a meeting held via the internet. Many of the parents said they had suffered silently for years as the program fought over benefits that could have relieved the considerable burden on the children and families NICA served.

Florida lawmakers created NICA in 1988 to immunize obstetricians from the consequences of births that go tragically wrong. Doctors had complained that high medical malpractice premiums were making it difficult for them to practice in Florida. The NICA law forbids parents from suing when children are born with catastrophic brain damage, and channels them into the NICA program for “medically necessary” and “reasonable” healthcare.

But starting in April, the Miami Herald, in partnership with the investigative newsroom ProPublica, published a series of stories showing that NICA had amassed nearly \$1.5 billion in assets while parents struggled to pay for such things as wheelchairs, feeding tubes, medical supplies, therapy and nursing.

The investigation, called “Birth & Betrayal,” detailed how NICA administrators sometimes spent thousands of dollars in legal fees to avoid spending hundreds to care for a disabled child. Several parents said they had been “nickel-and-dimed” by leaders who appeared more concerned with their financial ledger than the lives of children.

Though NICA’s board meetings have been open to the public, Thursday’s meeting marked the first time since the program’s inception that parents joined en masse to share their lived reality with its leaders.

“Dealing with NICA is extremely frustrating and stressful,” said Ashley Hammer, the stepmother of 19-year-old Brennan Hammer. “We didn’t get to choose the way our children were horrifically brought into this world. We fight every day to keep them alive and happy. We shouldn’t have to fight for the benefits which have been promised — and are owed to — NICA children and their families.”

NICA Executive Director Kenney Shipley, who announced her resignation Wednesday but was present at the meeting, offered Hammer \$2,500 in NICA funds last year to help defray the costs of a guardianship the family needed to protect Brennan when he reached adulthood. Hammer consulted a local attorney.

“After he laughed at me, he stated it was nearly impossible to complete such a guardianship within that budget,” she said.

But Shipley wouldn’t budge, she said, and the family paid \$7,500 out-of-pocket in legal fees. “Kenney stated, and I quote, ‘I should be thankful for the amount we did receive, as guardianships aren’t medically necessary,’ ” Hammer told the NICA board.

Hammer said that when Hurricane Irma struck in 2017, she asked NICA to cover the costs of a hotel room as the generator the program supplied could not even power air conditioning, causing the boy to have heat-induced seizures. “Brennan needed air conditioning,” Hammer said. “His life depended on it. Kenney denied our request, stating NICA already reimbursed a generator.”

“There is no monetary value you can put on what these children and families have lost,” Hammer said. “Nor can you put a value on what they have and will miss out on. My child will never walk, never talk, never fall in love. He will never marry. He will never have children — among other milestone celebrations most families get to experience.”

“I once asked Kenney, ‘At what point do you get off of your high horse and become an advocate for these children and their families,’ and her answer was ... ‘That isn’t NICA’s place. NICA is here to provide [protection] for doctors.’ ”

Thursday’s was the first NICA Board of Directors meeting since lawmakers — responding to the Herald’s and ProPublica’s reporting — overhauled the state law governing the 33-year-old program. Among other things, the Legislature provided \$10,000 in mental health benefits, required NICA to ensure participants have reliable transportation and set aside \$100,000 for families to make their homes accessible for special needs.

For the first time, the board — which previously had been dominated by representatives of the healthcare and insurance industries — included a parent served by NICA, Renee Oliver, and an advocate for children with disabilities, interim Chairman Jim DeBeaugrine. He is a former director of the state Agency for Persons with Disabilities and cares for a disabled family member.

“We are always reminded of why we exist,” DeBeaugrine told the board. “The family member who serves on the board will make sure we never forget that.”

The recreated board approved three policy changes Thursday that Shipley suggested: reimbursing families for home renovations they paid for out-of-pocket before the legislative reforms, continuing to pay families for caregiving while children are hospitalized, and expanding compensation for families that have difficulty with transportation expenses for a disabled child.

Jackie Amorim’s daughter, Vera Sophia Haggemiller, was born April 5, 2018, and accepted as a NICA participant in May of the following year. Amorim told the board Thursday that many parents depend on the salary NICA pays them to provide in-home nursing and caregiving, as caregiving demands forced them to abandon jobs and careers.

But when their children are hospitalized, the paychecks cease — even though hospitals rarely are able to provide the level of care such children require — leaving families in a financial hole. The policy effectively “penalizes” the families whose children are the most fragile, she said.

Children like Vera “cannot express pain, cannot call for help, and cannot push the call button” for a nurse, she said, making it impossible for families to leave their children behind in the hospital. “It’s traumatic to be in the hospital,” she said. “This is a horrific policy to me.”

But when Amorim and other parents asked for relief “we were just treated as if we were complaining.”

“So many of us didn’t want these lives that are so hellish on a daily basis,” she said.

Like other parents, Michelle Perez shed tears when she described the difficulty some NICA parents experience just submitting invoices and other paperwork. “It’s not just the time away from our families, but the time away from our [disabled] child,” she said. “And that’s not fair.”

“We’re looking to make these things easier, and more straightforward,” DeBeaugrine responded. “It’s a worthy goal of ours.”

The older sister of NICA participant Justin Nguyen, whose birth injury left him profoundly impaired, was visibly angry when she told board members that Shipley and NICA had “made our lives pure hell” during the two decades the program has served her brother.

“You need to find somebody who actually cares and is compassionate instead of using families,” 31-year-old Jennifer Pham said to the board.

She then addressed Shipley directly: “I’m damn glad to see you gone.”

Shipley, whose resignation letter praised the devotion of parents and caregivers, sat silently through the parental rebukes. She will keep her title while spending part of the next few months on leave. Her formal exit is in January.

Three parents of children who died said the state had victimized them all over again by excluding them from the \$150,000 supplement approved by the Legislature in April.

“I am overjoyed that parents are finally getting their voices heard, said Sherri Cruz, whose son, Mateo, lived for 15 hours before being pronounced dead on Oct. 26, 2018. “It is noteworthy,” she added, “the amount of people who do not feel they are being equally treated.

“This feels like a different victimization,” Cruz said.

Added James Johnson, whose son Cooper was born and died in June 2017: “We don’t get a chance to be a voice for our child.”