

The Boston Globe

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Memo cites safety concerns at Pilgrim plant

NRC inspector notes staff 'overwhelmed'; sees poor maintenance and bad practices

By Travis Andersen
GLOBE STAFF

Staff at the Pilgrim Nuclear Power Station appear to be "overwhelmed" and struggling to improve performance at the facility, which has a poor safety record and is set to close in less than three

years, according to an internal memo from a federal regulator made public on Tuesday.

The memo, authored by Donald Jackson of the Nuclear Regulatory Commission, indicated that inspectors had found a "safety culture problem" during their ongoing re-

view, along with problems with maintenance, engineering, and the reliability of equipment at the 44-year-old plant.

Jackson's memo was inadvertently sent to an environmental advocate, who forwarded the message to the Cape Cod Times. The newspaper posted the memo online Tuesday.

Jackson is leading a team of NRC investigators who began re-

viewing operations at the plant in November, as required by law because of the facility's low safety rating. The power station is scheduled to close permanently in May 2019.

"The plant seems overwhelmed by just trying to run the station," Jackson wrote, adding that staff members are reportedly working to improve conditions at the site and there is "a lot of positive energy."

NUCLEAR PLANT, Page A16

Prosecutors seek relief for young witnesses

For victims of sex abuse, courtroom can be another location to feel unsafe

By Maria Cramer
GLOBE STAFF

The 10-year-old girl sat at the witness stand, fiddling with a soft pom-pom ball she had found in a sewing kit. Her head down, her voice barely above a whisper, she could bring herself to look up only once — when the prosecutor asked her if the neighbor accused of molesting her when she was 6 years old was in the courtroom.

The girl glanced up at the defense table, pointed to the 63-year-old man seated there, and quickly looked down. Suffolk Assistant District Attorney Brenna Flynn gently asked the child what the abuse felt like.

"It hurt," she said softly.

The case, heard last summer, ended in a mistrial after the jury was unable to come to a unanimous decision on the most serious charge, statutory rape of a child. The girl, who was on the stand for nearly three hours, did not want to testify again in a second trial.

On Oct. 31, prosecutors were forced to tell the judge they could not move forward with the case. The man accused of molesting the child was allowed to walk out of court that day.

Such an outcome in child sex abuse cases is not unusual in Massachusetts, Flynn said. But other states have found ways to make testifying less terrifying for children.

Some allow children to testify out of the courtroom, using a closed-circuit camera, or allow

TESTIMONY, Page A11

Their indefensible hope

They had found a way, against all odds. To a cure; to something like happiness. Was it asking too much to think it could last forever?

STORY BY BILLY BAKER
ILLUSTRATIONS BY TONIA COWAN
GLOBE STAFF

NO one had tried this before. They needed to build a drug company, out of nothing and in no time. Pat Lacey and Meryl Witmer had to raise money from donations and summon a complex working enterprise, licensed and equipped to make the pills that were saving lives.

The only easy part was coming up with the company name: Kids Cure Pharmaceuticals.

It was already December. Dr. Giselle Sholler's clinical trial would exhaust its small stockpile of the drug, DFMO, in just three months, the day February turned to March.

They worked feverishly and at all hours and told no one outside their circle what they were up to, even the parents of children now taking the drug. They worried the parents might panic and that their former supplier, a firm called CPP, might try to stop their new venture if it caught wind of it.

Pat, whose son Will had been saved by DFMO, worked the phones in Braintree, casting his net for donors to help raise the \$2 million they needed to finance the company. It was vastly more than he'd ever

WILL, Page A12



The power of will
A narrative in five parts.

Chapter 5

Ever tough and loyal, O'Flaherty is Walsh's rock



JOHN TLUMACKI/GLOBE STAFF/FILE 2016

Eugene O'Flaherty left Beacon Hill to become the city's top lawyer.

The first of three profiles of the advisers closest to Mayor Martin J. Walsh as he embarks on his bid for reelection.

By Mark Arsenault
GLOBE STAFF

Eugene O'Flaherty tried hard to kill this story.

I'm too boring to be profiled. Haven't you anything more important to do? The former legislator known for blowups with the media argued his case all the way to the Globe's editor, with whom O'Flaherty once had a spectacular run-in, which we'll get to in a minute.

When he couldn't stop the story, the attorney who heads the City of

Boston's law department sat for an interview that fairly well confirmed what many say: 1) Gene O'Flaherty is pretty intense, and 2) he's passionately loyal to his longtime friend, Mayor Martin J. Walsh.

Consider the nondescript nature photo on display in O'Flaherty's City Hall office. It is actually a picture of the Garden of Gethsemane, a copse of olive trees in Jerusalem where the Gospels say Jesus Christ was betrayed.

"The picture reminds me of the travesty of betrayal," said O'Flaherty, explaining why he keeps it. "It serves as a reminder to me to stay loyal so as to never feel the

O'FLAHERTY, Page A8

Antiboycott groups pay for state officials' trips to Israel

By Frank Phillips
GLOBE STAFF

Governor Charlie Baker and Massachusetts lawmakers are touring Israel this month on trips financed by groups opposed to a growing anti-Israel boycott movement, which is at the center of a legislative fight on Beacon Hill.

Baker, whose trip is being financed by the Combined Jewish Philanthropies, is leaving Thursday for a six-day economic development tour. A dozen House members are on a separate 10-day trip paid for by the Jewish Community Relations Council.

Both trips come as the JCRC is campaigning for legislation on Beacon Hill that would ban the investment of state pension funds in companies that boycott Israel. The group receives financial support from the

CJP.

The trips have sparked sharp criticism from peace activists and pro-Palestinian advocates who have pushed the boycott because of Israel's stance toward Palestinian people. But the Jewish groups insist that trips are meant to foster eco-

The trips have sparked sharp criticism from those who have pushed the boycott because of Israel's stance toward Palestinians.

TRIP, Page A7

In the news

A strong earthquake killed nearly 100 people in Indonesia's Aceh province and left thousands homeless. A4.

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Suggested retail price

\$1.50

\$2.00 outside Metro Boston

\$2.50 in Florida

Reebok will move its corporate headquarters and 700 jobs to the Seaport, the latest business to relocate to the Innovation & Design Building. C1.

With Senate approval and President Obama on board, the path is clear for the 21st Century Cures Act, but it may take years for the changes it calls for to be implemented. C1.

The opening of seven new stations on the MBTA Green Line extension has been delayed to 2021 and the project still needs to clear several hurdles. B1.

A man and his 9-year-old son were found dead in Acushnet, apparently from carbon monoxide poisoning. B1.

Pearl Harbor survivors gathered to mark the 75th anniversary of the attack. A2, B3.

"Boston Winter" opened on City Hall Plaza days after being postponed by weather. B2.

Musician Kristin Hersh credits an experimental treatment for PTSD for her newfound health and says it has changed her relationship with her art. G1.



Give fleece a chance

Thursday: Some sun, cooler. High 42-47. Low 28-33.

Friday: Much colder, blustery. High 36-41. Low 20-25.

High tide: 5:23 a.m., 5:45 p.m.

Sunrise: 7:01 Sunset: 4:11

Complete report, B11.



MANUEL BALCE CENETA/ASSOCIATED PRESS/FILE 2016

ON THE TEAM — Retired Marine General John F. Kelly, who has Boston connections, is reportedly President-elect Donald Trump's pick for homeland security secretary. Oklahoma Attorney General Scott Pruitt will be the choice to head the EPA. A2, B1.



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Their indefensible hope

► **WILL**
Continued from Page A1
tried to raise before.

Witmer, a New York hedge fund manager with connections and business experience, took the job of finding and assembling the building blocks of a drug manufacturing operation, while, in Grand Rapids, Mich., Sholler navigated the road to winning FDA permission to use the new pills they planned to manufacture. None of their other work would matter if the agency didn't sign off, and Sholler had warned everyone: Things do not move fast when you're dealing with the government.

FDA permission would require a massively detailed application, and Sholler's days were already booked tending to the ever-growing number of children with neuroblastoma in her trial. At night, she and her program manager, Genevieve Bergendahl, hammered away at the hundreds of pages of explanation and data. In between, Sholler squeezed in dinner with her own girls, who were now 9 and 12. When they had each

turned 8, she said a silent thank you. That's the age past which kids almost never develop neuroblastoma.

Days raced by quickly, but by the end of December, it felt like they were making real progress. It helped that they had started with an incredible turn of fortune.

There are only two companies in the world that manufacture the raw ingredients for DFMO. One of them was locked in an exclusive arrangement with CPP for the US market. The other was a European company, and when Meryl Witmer heard the name of the company she felt a jolt of excitement. I already have a business relationship with them, she said. And you're not going to believe this. I'm meeting them tomorrow.

She quickly struck a deal, then fronted the cash to get the raw ingredients on a ship and heading across the Atlantic. She also managed to find a Florida company that could turn the chemicals into a drug — and promised a quick turnaround when executives heard who the drug was for.

Pat had also had a run of luck, finding a

wealthy donor moved by his story to write a check for \$1 million. With that anonymous gift in hand, he'd gone to the fund-raisers at Sholler's hospital in Grand Rapids and challenged them to raise enough to match it. On Christmas Eve, Sholler called him at home. The match had been met. The same week, Sholler and Bergendahl finished the FDA application and submitted it.

Much had been done in a very short time. It seemed possible, even, that they were slightly ahead of schedule, and as the New Year arrived they allowed themselves a faint, and unspoken, belief that they might make it in time.

The feeling didn't last long.

Ready to explode with frustration, Sholler hurried to her office at the hospital in the January morning cold. It had been three weeks since she'd filed the application — three precious weeks — and there had been no real movement at the FDA.

The previous day she'd finally had a quick call with agency officials, but she left the conversation feeling like they failed to appreciate the urgency of the situation.

If that wasn't enough, the ship carrying the chemicals they needed had arrived at the Port of Miami several weeks before, but customs had held up the shipment. Without the raw materials, they were nowhere.

And so Sholler arrived at her office at the hospital that morning ready to light a fire. She picked up her desk phone and punched in the number of the FDA project manager assigned to her application in Maryland.

The phone rang on the other end of the line. It kept ringing, then went to voice mail.

The next morning the FDA manager called back and listened while Sholler confided everything — the fight with their drug supplier and the need for speed.

To Sholler's relief, the woman on the other end of the phone seemed to understand.

She laid out a long checklist of things that had to get done. If Sholler could deliver on her end, the case manager told her, she would do everything she could to clear a path at the FDA.

Later that day, Meryl Witmer called, ecstatic, with the news that customs in Miami had released the shipment, and a truck was already headed west across the Everglades, carrying the precious chemicals to the manufacturing facility on the Gulf Coast of Florida.

The logjam was broken at last, but the weeks they'd lost had cost them dearly. The manufacturing company still had to run a batch of pills and submit them for time-consuming testing for purity and safety. Only when the drugs had passed that test would the FDA consider clearing the way for children in the trial to take them.

The manufacturer promised to work quickly, and a few days later, on Jan. 20, it sent photos to Witmer of the first batch of pills. The DFMO was then moved into laboratory control rooms to be exposed to varying levels of light and humidity. It would take weeks to see if the drug remained stable or whether mold or harmful microbes would grow. The testing had to be rigorous. It couldn't be hurried.

Three weeks passed, and they were still waiting on the test results when an e-mail arrived from the FDA. The agency said the ap-

DISPATCHES FROM A NIGHTMARE

Pat Lacey created a blog and wrote almost daily about his son Will's battle with cancer

WHEN REAL LIFE EXCEEDS YOUR DREAMS
JUNE 26, 2015

There is so much I could say and write about today. I went back to find an appropriate photo on this website from when Will was starting kindergarten and quite frankly I became overwhelmed revisiting what I wrote at the time. I can't believe how hard life was — for such an extended period of time — and it makes me even more grateful that where we are now is such a better place. Living long enough to attend his first day of kindergarten was a hope and dream we had.

And while Will has had so much taken away from him — and has had to endure more than his fair share — we are

living the life right now that we could only dream about back then.

I'm going to share an excerpt from 2008 below to sum it all up — because I don't have it in me to revisit all those emotions right now. And besides I need to get busy creating a new set of "impossible" dreams to one day hope that I can see my children achieve.

"When Will Will Lacey die?" — Anonymous
November 2008

... We have no more idea when Will is going to die than I would know when I'm going to die. In Will's case, I know that he will not live as long as his peers but what I don't know, what no one knows, is when (or how).



BACK TO SCHOOL
SEPT. 8, 2016

Will turned 12 a few weeks back and started 7th grade yesterday.

Today marks three years since Will last took any tumor-directed medicine.

We gave Will his last dose of DFMO in January of 2013 and then held our breath for three months as we waited for his scans to show if his tumor was dormant — and indeed it was.

And while it certainly has been a three-year period filled with a new set of unique challenges, obstacles, and setbacks, I am also aware of how incredibly fortunate my family is.

And while no one knows what the future holds, my experience as a dad has me more attuned to the reality that smooth sailing is never the status quo. As a result, the key for me is striking the right balance so that I can try to fully absorb all of the incredible gifts that life is holding out before me every day.

plication would be fully in order, once the safety test results were in. After that, the FDA would have 30 days to make a decision.

It was Feb. 12. Sholler and her team didn't have 30 days. They had 16.

It was time to think about a fallback.

Sholler and Bergendahl scoured the inventory of DFMO at each of the 29 hospitals now participating in the study, looking for surpluses that they could ship to hospitals where there were more patients than pills. That might eke out a little more time. Bergendahl lined up the special couriers and expensive packaging needed to safely ship DFMO from one part of the country to another.

Sholler checked in with her hospital's lawyers, who had continued to negotiate with CPP for more drugs. Talks had gone nowhere.

Pat talked about a last resort — going to the media. If it looked like they weren't going to make it, he would try to publicly shame CPP into supplying more. They were coming nearer to that point when Witmer finally got word that the testing in Florida was complete and that their pills had passed with flying colors. Sholler rushed the results to the FDA. It was Feb. 17.

Now it was all waiting and worrying. Eleven days on the calendar was just eight working days. It seemed impossible to believe that a sprawling, deliberate bureaucracy like the FDA could do anything in so short a time.

At home in Braintree, Pat checked in with Sholler and Witmer every day, and every day there was nothing to report.

He felt trapped. The winter's record blizzards had dropped eight feet of snow. Roofs were collapsing. Schools were closed. The kids had been home almost every day for a month.

He worried over Will. The boy had outrun death for 10 years now, but was still recovering from the after-effects of a brain hemorrhage, possibly caused by his many harsh cancer treatments. He had regular appointments with a physical therapist. At the end of each session, Will would sit nervously while the therapist talked to Pat and Dina about his progress, then meekly ask the question: Hockey?

Not yet, was always the answer.

A mountain of fund-raising work awaited Pat at the office he was now renting for his charity, BeatNB, a few blocks from his house. He'd gotten a good deal on it; it was above a store that sold tombstones. Some snowy mornings, the only way to get there was to strap on his boots and venture into the empty streets.

When he made the trek one day in late February, he arrived to see that plows had barricaded the door with a mountain of snow. He spent hours digging. Finally inside, he checked in with Sholler and Witmer again.

Anything?
Nothing.

More online

To see this story online, with more photos, illustrations, and an audio version, go to bostonglobe.com

Bergendahl sat on her couch in the dark, staring at the TV, hoping it would silence her brain and let her sleep.

It was late on Friday the 27th. They had heard nothing, and with the deadline now upon them, Bergendahl had spent the day on the phone with Sholler and the clinical sites. The mood had been grim. First thing in the morning, she would start the process of dispensing their last pills, shuttling them to the hospitals that most needed them.

She checked the time. It was nearly 11. Bergendahl turned off the TV and told herself to go to bed. Before she did, she picked up her cellphone and saw something new in her inbox that made her sit up. It was an e-mail from their case manager at the FDA. Heart racing, she opened it and quickly dialed Sholler, who answered the phone already screaming.

"Did you see it?" Bergendahl yelled.
"Yes!" Sholler yelled back. "We did it!"

The following morning, the first batches of DFMO made by Kids Cure Pharmaceuticals left Florida, bound for hospitals around the United States. When the shipment arrived at Sholler's clinic in Grand Rapids, the doctors and a small group of hospital staff gathered around to watch a young girl named Delaney Doyle receive the very first dose.

The toddler paid no attention, absorbed in a cartoon on her iPad, as her mother fed her a spoonful of applesauce containing a crushed up pill. Sholler snapped a picture and sent it to Pat.

The family had no idea — no one outside Sholler's tight circle knew — how close they'd come.

Eight months later, on a damp and cloudy November morning, Sholler and a dozen others gathered in a small hotel conference room at the Sheraton Silver Spring in Maryland.

There was nervous energy in the room, like a study group cramming before the final exam. Soon, they would all get in cars for the short trip to the sprawling campus of the FDA.

Having won the battle to keep control of her trial, Sholler was now going to try to do something even more difficult. She aimed to persuade the FDA that a randomized trial of the kind CPP had insisted on was unnecessary. There was, she believed, a better way, a path that would keep kids from having to go through the horror of a relapse just to prove that DFMO works better than a placebo. She would rely on historical data and not on living children.

Sholler would have 10 minutes to make her presentation. It was almost time to leave.

Seated around a long table, she and her team rushed through the final preparations. Pat was there, as were Witmer and Bergendahl. A handful of parents had flown in to be there, too. Lisa Riniolo, a mother from Buffalo, had a tattoo of her late daughter, Melina, visible on her forearm. Kyle Matthews had flown up from Tampa. He lost his son Ezra to neuroblastoma and was preparing to leave his job to work full time for BeatNB. A half-dozen oncologists who were offering the trial had also come to testify, including Sholler's

attending physician at Hasbro Children's Hospital in Providence, where, all those years before when she was a medical resident, the death of her first patient, Tyler, had set her course in life.

Let's go through it one final time, Sholler said, glancing at a clock on the wall.

She projected the first slide and started once more on her script, describing children taking DFMO and finding new life.

"They are happy, playful, going to school. They do not require transfusions. They are growing and thriving. This is incredibly different from previous therapies."

She raced through the presentation, speeding up as she got to the final slides and time ran short. Then she came to the end and a catch took hold in her throat.

"At Helen DeVos Children's Hospital," she said, then stopped.

"At Helen DeVos Children's Hospital," she began again, "we have not had a neuroblastoma patient relapse in 3½ years."

"We cannot go back to what it was like before."

A hush swept around the room. Pat nodded his head. Lisa Riniolo bowed hers.

The presentation went well, but the FDA still wanted a lot more data. Sholler opened a new, nearly identical trial that February. If her results held, the FDA said it would take a second look at her proposal.

It was a decision she could live with because it meant that for now, every child who wanted DFMO would be able to get it.

In addition to the DFMO trial, she already had several new ideas in the works, including a huge project using genomic analysis to tailor medications for individual tumors. She had learned that curing this cancer wasn't one battle, but many. They were all long, and they were all hard.

She opened more test sites, including overseas — a hospital in Beirut, another in Marseille, France — and she spoke at conferences around the world.

But every day, new children were getting diagnosed. And always, there were children who did not make it.

Sometimes she reached a point when it felt like she couldn't handle it anymore. She wondered what it would be like to escape to a new life, a life where there were no children with cancer needing her help. But the thought never lasted for long. She thought often of Tyler, the first child she could not save, and of Will, the first one to live. They had lit a path in her mind, from what was to what might be.

On a recent trip to Kenya, where she was volunteering in oncology wards, she stopped for a second when she noticed her daughters in a field, playing soccer with some of the children from the hospital. She took a photo and posted it online. She called it "happiness." It was, she reminded herself, what she was working for.

One golden evening this summer, Pat walked out onto the front porch of his house in Braintree and sat on the steps next to Dina.

It had been so long since they'd had a night like this, with no obligations. No fund-raisers, no appointments.

For 11 years, every day had been lived on

A LIFE IN SNAPSHOTS



Will celebrated his 12th birthday on Cape Cod in August this year.



LACEY FAMILY PHOTOS

He continued the family tradition by topping this year's Christmas tree last month.

the edge. It seemed hard to even remember what it had been like when they first moved into this house, the house where Pat grew up and where he and Dina had sat in the living room joyfully watching their baby son, imagining their future together.

This was not that future. But it was good. Maybe as good as it gets, Dina said.

From inside the house came the shrieks and muffled thunder of their three children playing. The screen door slapped open and Will, all 12 years and 5 feet of him, clomped onto the porch and down to the lawn and dragged a hockey net into the street. The light had grown soft, and they watched as Will raised his stick and began firing shots at the net.

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