

Lynbrook family hopes to give dying child a lifetime of memories

February 23, 2013 by DENISE M. BONILLA / denise.bonilla@newsday.com



disease, physical regression and then death, typically between 15 months and 3 years old. Because the disease is so rare and strikes so young, there are no firm statistics on the number of Type A NPD cases. But experts believe Quinn is one of only four children in the country who have the disease.

Determined to give her as many experiences as they can, Quinn's parents Eileen and Brett, both 34, have created a list of places, activities and encounters they feel everybody should experience in life. Quinn's List has grown to more than 30 entries, everything from being kissed by a puppy to going to Disney World.

Quinn Linzer rests her head against her mother's shoulder as her family winds through a maze of elaborate dollhouses and exotic stuffed animals at Manhattan toy mecca FAO Schwarz.

There is a sense of urgency for the parents of the 9-month-old from Lynbrook.

They have just months to give their daughter a lifetime.

Quinn has Niemann-Pick Disease Type A, an incurable [genetic](#) disorder that causes brain

Their hope, Eileen said, is to give Quinn a life of quality while giving the couple and their sons, Colin, 5, and Reid, 3, "memories that involve Quinn and not just pictures of her." advertisement | [advertise on newsday](#)

Living the list

Eileen looked for guidance in how to deal with the disease in blogs written by parents of children with Type A NPD. She found some parents used their precious time searching for treatments. Others took their child on whirlwind adventures. The Linzers decided on an approach somewhere in the middle.

Eileen emailed family and friends and asked: What does every child, every woman, every American need to do in their lifetime? The result: Quinn's List.

In just a few months, Quinn's parents have crossed off quite a few things -- apple and pumpkin picking, attending [Jets](#) and [Mets](#) games, riding in a convertible. Quinn wore a wedding dress when Eileen had a miniature version of her own dress made for a blessing ceremony for the baby in November. On Jan. 1, Quinn was made an honorary member of the Coney Island Polar Bears when one of Eileen's cousins held her as the cousin waded up to her knees in the Atlantic.

"We're doing them as it fits in," Eileen said. "We're attempting to do as much as we can before next summer. We don't know how long we're going to have her or what condition she'll be in then."

Brett said the couple is "not concerned with making sure every single item is crossed off." Some of the best moments have been quiet and intimate, like playing peek-a-boo or having a lick of ice cream.

The Linzers acknowledge Quinn's List is as much for them and the boys as it is for her.

"We get out of it whatever we can," Brett said. "Obviously, there's a self-serving aspect to it. But I don't think sitting at home would be any better for her."

A shocking diagnosis

Eileen, who recently quit her job with a publishing company in Manhattan, and Brett, who works for a small, family-run manufacturing business in [Cedarhurst](#), had two high-spirited sons, Colin and Reid, and Brett had been content. But Eileen felt their family was not yet complete. So after she agreed to cut back her work hours, the couple decided to have another baby.

Not long after Quinn's birth in May, problems arose.

She barely ate and what she did eat came right back up. At 2 weeks old she was losing weight and becoming lethargic. She underwent tests and doctors began to offer theories, including that Quinn might need a kidney transplant.

"All the worst-case scenarios weren't that bad, looking back at it," said Brett. "A kidney transplant sounded awful then. Now it would be a miracle if that could be an option."

A liver biopsy was performed. As they waited for results, Eileen, as always pragmatic and in-control, searched online for answers, wanting to prepare herself. Brett, by nature laid-back and optimistic, avoided the Internet, afraid of becoming overwhelmed by the possibilities.

On Quinn's 3-month birthday the couple was summoned to the [New Hyde Park](#) office of their pediatric gastroenterologist.

"Even while we were sitting there, Brett and I were laughing and joking about how we would never let her live this down, how we'd heckle her as a teen for all that we went through in the first few months of her life," Eileen said.

Then the doctor told them: Quinn had liver disease consistent with Niemann-Pick Disease Type A.

Brett didn't know what that meant. Eileen began to cry.

Making a tough decision

The couple had known Brett's Ashkenazi Jewish heritage put him at risk for being a carrier of the disease's gene mutation. It turned out Eileen -- who is of Irish descent -- is a carrier as well, with a mutation doctors said they've never seen.

In Type A NPD, the body lacks an enzyme called acid sphingomyelinase (ASM), which helps metabolize a certain lipid, or fat, found in every cell of the body. With a deficiency of ASM, the lipid builds up inside cells causing massive growth in the body's organs -- mainly the liver, spleen, lungs and brain, said Melissa Wasserstein, medical director for the International Center for Types A and B Niemann-Pick Disease at [Mount Sinai Medical Center](#) in Manhattan.

Symptoms vary, but Type A can cause loss of motor skills, brain deterioration and [blindness](#). There is no treatment other than pain management, Wasserstein said. Research is limited. "There's nothing that's ready for human trial," she said. "It's an unbearable situation for families to be in."

Eileen and Brett learned researchers at [Duke University](#) were doing [stem cell](#) transplants in patients with some types of NPD, helping create ASM. The transplants have never been done with Type A patients. Still, the couple made the trip to the [North Carolina](#) school. "It was a glimmer of hope no one else had for us," Brett said.

But when they found out the transplant would not take effect until after Quinn turned 1 year old -- past the point when mental decline typically begins -- Eileen stopped cold. "The worst thing would be extending her life but have her be worse at the end," she said. "No one needs to live through that, her included."

Brett wasn't so sure. A doctor had used the word "might" when speaking of prolonging Quinn's life, Brett said, and he clung to the word. Ultimately, Brett said he didn't want to put Quinn through the procedure and "give up what good times she has left for that chance."

The fact the Linzers agreed didn't make the decision to leave Duke any easier.

"To say 'no thank you' was still incredibly difficult," Eileen said. "It was shutting that final door."

The couple returned to [Long Island](#) feeling helpless.

"You wish it was just a matter of money," Brett said. "Even if it was a million dollars, I'd find a way to scrape it together somehow. But no amount of money can find a treatment for her."

Including her brothers

Quinn lays on an exercise mat while physical therapist Sylvene Blissett gently stretches one of the baby's legs across her body. At 14 pounds, Quinn is lagging in her physical development. Blissett's goal is to build up Quinn's muscles so she can sit upright.

Blissett visits the Linzers twice a week, as does feeding therapist Leslie Faye Davis. Davis, a speech language pathologist, also is trying to help Quinn speak. "We'll push for progress for as long as we can go," she says, turning toward Eileen. "I want her to hear 'ma, ma, ma.' "

The couple has limited Quinn's therapies. "We don't want her entire life to be centered around this," Eileen said. "If she can swallow better and play better and just generally have a better time, then we'll do it."

Colin and Reid are made a part of the therapies and offer suggestions for new foods Quinn should try. Next up: a [McDonald's](#) French fry.

Sometimes the boys get a little too ambitious.

One weeknight last month, the Linzers settle down for dinner. It's two weeks before Quinn's surgery to allow her to be fed through a tube inserted into her stomach.

As Eileen gives Quinn a bottle, Colin and Reid [dive](#) into their rice, beans and cheese. Colin offers to feed Quinn some of his dinner.

"It's got a lot of stuff she can't have," Eileen tells him. "We have to be careful, remember?"

Disappointment washes over his face. Then he remembers something and smiles.

"She's going to eat like [Spider-Man!](#)" he says, laughing.

When Colin had wondered how [Spider-Man](#) eats through a covered mouth, Eileen seized the opportunity to lessen his fears about Quinn's surgery. She told him [Spider-Man](#) eats through his stomach, just like Quinn will eventually.

Every day the couple fields questions from the boys about Quinn. Innocent phrases such as "when Quinn grows up" can be unintentionally painful. Wanting to be upfront without revealing too much has been a delicate dance.

Asked by the boys about upcoming events -- such as Quinn's future birthday parties and school - Eileen reminds them that Quinn is a special baby and that "not everyone gets to do that."

But with the list, Quinn will get to do activities many adults have not experienced. Just before her surgery Eileen crossed off one more: having tea at the Plaza. And then another: getting a Mani-Pedi at a salon.

The list, said Eileen's brother John O'Gara, has produced unintended consequences.

"We were all focused on doing so much for Quinn," said O'Gara, who along with three other siblings has been raising money to help fulfill Quinn's List and to pay medical bills. "Then we started to realize she's been doing so much for us, how much she's been bringing to our lives." Now, hugs for loved ones last a little longer, he said, and "I love you" come a little more often.

Wasserstein sees the benefits for Eileen and Brett as well. "It's a beautiful thing to do for Quinn and hopefully it will help them deal with this, too," she said.

Eileen acknowledged, "The list keeps us focused on the little things. We don't have the time to fall apart now."

Hanging in

Two days after the Saturday visit to FAO Schwarz, Quinn was rushed to the hospital. She had

begun bleeding through her two-week-old stomach tube.

Quinn was in intensive care for five days.

"I so want the option of crawling under a rock," Eileen wrote on her blog, sitting at Quinn's side in the hospital. "Ignoring the obvious. Gaining access to a time machine and going back a month, two weeks, to Saturday. But I can't." Instead, she wrote, she and Brett are just trying to hang on.

"We're very lucky in that we are able to give her the best possible life," Brett said. "But when she was just a few months old, it seemed there was plenty of time. Now we're starting to feel the ticking of the clock a bit faster."

QUINN'S LIST

DONE

LOVE

Have tea at The Plaza

Visit FAO Schwarz

Ride in a convertible

Get ears pierced

Watch the chefs at Inatome hibachi restaurant

Sit on Santa's lap

Dip toes in ocean

Go apple picking

Go pumpkin picking

Wear a wedding gown

Visit American Girl Doll store

Get a mani-pedi

Go to the circus

Go to a baseball game

Go to a football game

Sleep over at Uncle Brian's house

Take the Polar Bear Plunge

Vote

Play peek-a-boo

Dress up for Halloween

Have a slumber party

Go to the ballet

Taste ice cream

Be kissed by a puppy

STILL TO DO

Visit the Metropolitan Museum of Art

Be kissed by a butterfly

Swing on a swing, slide on a slide

Swim with dolphins

Visit the zoo

Picnic in Central Park

Ride on Nunley's Carousel

Visit the Land of Make Believe

Take a Circle Line cruise

Host a tea party

Drive a car

Fly a kite

Visit the Empire State Building

Watch sunset on the beach

Jump in a pile of leaves

Splash in a puddle

Play in the sand, build sand castles

Go to Disney World

Ride a horse

Play in the snow

See the Big Duck in Flanders

Go star gazing

Watch a sunrise

Go on family trip to Maine

Dress up like a princess

Dance with daddy

Visit Washington, D.C.

Source: Linzer Family Blog www.teamlinzer.com

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