

Spotlight

Yale
NewHaven
Health

Yale New Haven
Hospital

NEWSLETTER FOR OUR DONORS, VOLUNTEERS, AND FRIENDS

WINTER 2019

Penelope (left) and **Nicole** (right) discovered they shared a love for donuts and pizza. Now they also share Nicole's liver! "I felt Nicole was a kindred spirit," says Penelope's Mom. "The perfect liver to be in Penelope!"

MIRACLES
YOU HELP MAKE
POSSIBLE

Nicole donated part of her liver, and saved a little girl's life

Thanks to your generosity, they are both doing great!

It's just over a year since five-year-old Penelope Hansen's liver transplant. But the story of Nicole Freidenfelds's life-saving gift—a portion of her liver—began long before Penelope was born.

Nicole's path to liver donation Nicole's father was dying of liver failure in 2010 when she heard a story on the radio about a miraculous-seeming medical procedure: living liver donation. It was too late for her dad, but the idea that you can donate a portion of your liver to save a life made a powerful impression on Nicole.

As the daughter of someone with liver disease, she saw the lifesaving potential of liver donation. And as a professional biologist, she was fascinated by the liver's amazing ability to regrow to full size and functionality in both the donor and the recipient. After her father passed away, living liver donation was always at the back of Nicole's mind.

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Early in 2017, she decided the time was right to become a donor, even though she didn't have a particular recipient in mind. She called the Yale New Haven Transplantation Center and volunteered to be an "altruistic donor," choosing to make a gift of life anonymously to a complete stranger.

Penelope's path to liver transplant

AmberJean and Shawn's first child, Penelope, was born in 2013. In the happy days leading up to the birth, they had typical parent-to-be worries, like... what should she sleep in—a onesie or pajamas?

That changed in a hurry. Shortly after Penelope was born, her doctor suspected that something wasn't right about her liver function.

"The doctor used the words *liver transplant*," says AmberJean. "After that, I couldn't hear anything else." Penelope was diagnosed with biliary atresia, a disease that damages the liver and can lead to liver failure and death.

Penelope would need a new liver. The goal in the short term was to keep her as healthy as possible.

She endured many months of painful symptoms—a swollen belly, enlarged spleen, stomach bleeds, and shortness of breath—to name just a few. But by age three, her doctors at Yale New Haven Children's Hospital felt she couldn't wait any longer. In early 2017, she was put on the national waiting list for a liver from a deceased donor.



That's Penelope on the right with her mom, AmberJean (middle) and Nicole on the left.

That's when their paths intersected

The wait for an organ from a deceased donor can be dangerously long—sometimes too long. The wait for a living donor transplant, however, is usually much shorter. It doesn't work out for everyone, but AmberJean and Shawn hoped it would work for Penelope. So they waited.

A few months later, the Transplantation Center notified

them of a living donor match.

On August 23, 2017, Nicole and Penelope were wheeled into adjacent operating rooms. A perfectly sized segment of Nicole's liver was removed, carried a few steps next door, and transplanted into Penelope. The transplant was a complete success.

"Penelope looked better immediately after the surgery," says AmberJean. "It was a remarkable difference. I felt I could finally breathe for the first time!"

Penelope will always require routine medical monitoring, but as AmberJean says, "We know she'll need a lifetime of follow-up, but that's the point—she's going to have a whole lifetime!"

Nicole's life is forever enriched too. "I would do it again in a heartbeat. What I got out of it, this feeling of helping someone, is something I now have for the rest of my life."

Thank you to all our wonderful donors—financial and organ—for helping make near-miracles possible! ♥

Living donation: Did you know....?

- ... Kidney and liver patients who receive a living donor organ can be transplanted much sooner—sometimes years sooner!—than they would from the deceased organ list
- ... Anyone in good physical and mental health over the age of 18 can be a living donor candidate
- ... The pediatric patient one-year survival rate for liver and kidney transplants is 100% at Yale New Haven Transplantation Center
- ... Most living donors tell our caregivers that the experience was so wonderful, they wish they could do it again!

“Sign up to be a donor!

Don't take it with you—save lots of lives!” AMBERJEAN, PENELOPE'S MOM

Did you know that **22 people die every day waiting for an organ?** You can change that by becoming an organ donor.

Visit givetoynhh.org/organ-donation to register or learn more.

What a difference a year makes!

Last year, Erin barely had the strength to cheer for riders from her wheelchair. This year she rode 25 miles in the Closer to Free Ride.

September 9, 2017: After her double mastectomy, Erin Matthews had to remain at Smilow Cancer Hospital longer than she expected. She'd managed to stay strong and upbeat through her frightening cancer diagnosis, 16 weeks of chemotherapy, and the prospect of surgery. But when she found herself stuck in the hospital for two extra weeks due to surgical complications—more precious time away from her two sons—she began to struggle with despair.

She was confined to a wheel chair and couldn't breathe without the help of a suction machine. Even so, her doctor urged her to go down to the sidewalk outside the hospital and cheer for the Closer to Free riders during the Smilow Salute, a hallmark of the ride each year.

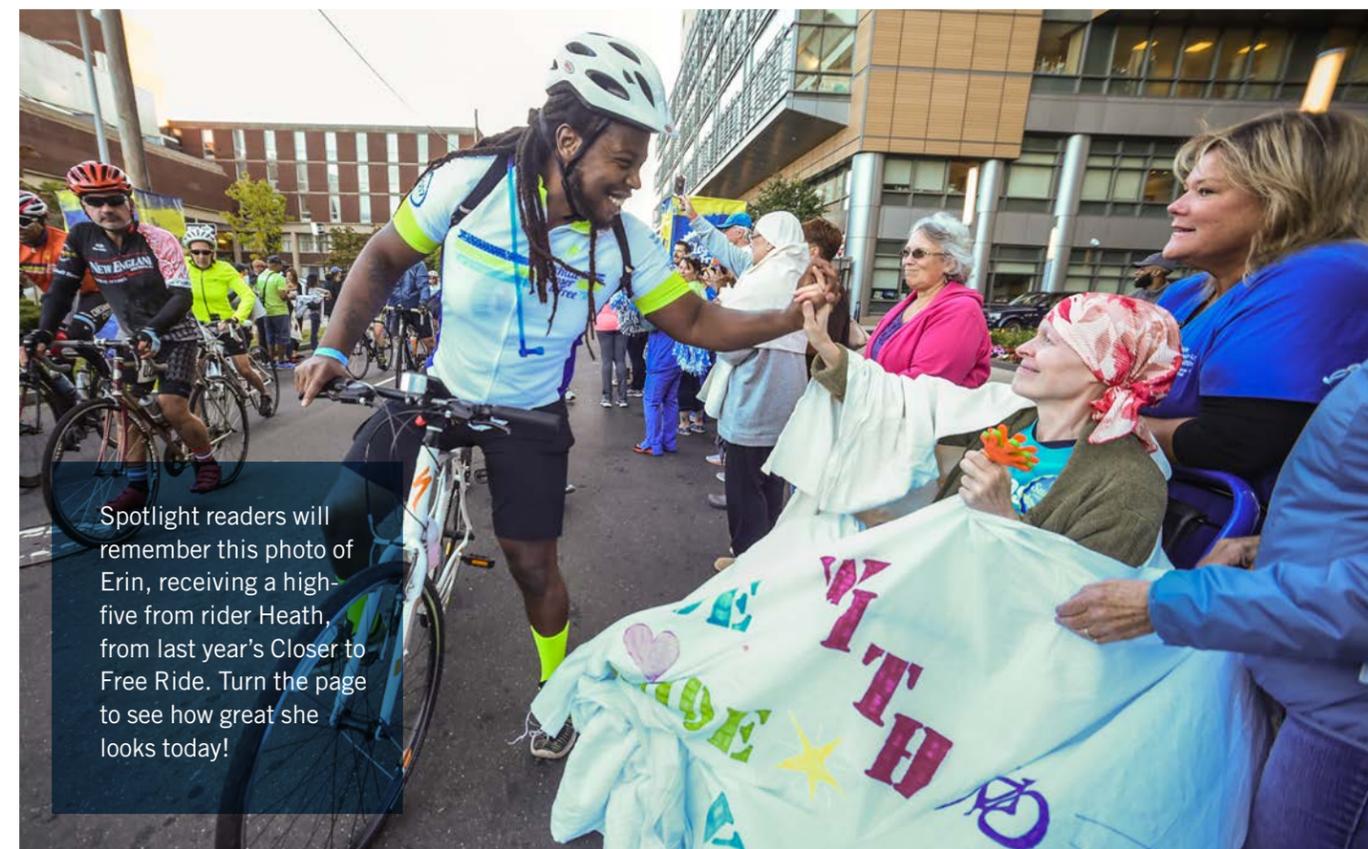
She didn't know much about Closer to Free. So she was amazed when she saw more than 1,700 people riding their bikes past patients outside Smilow Cancer Hospital with greetings,

good wishes, and an outpouring of hope and love.

"It was as important a part of my recovery as any medicine or surgery," she remembers. "There were hundreds and hundreds of people out there, and I felt they were riding for me so I could get better, lifting me up in that moment when I couldn't even breathe on my own."

Sitting in her wheelchair, she vowed that she would do the same for the next patient who needed lifting up.

(keep reading Erin's story...)



Spotlight readers will remember this photo of Erin, receiving a high-five from rider Heath, from last year's Closer to Free Ride. Turn the page to see how great she looks today!



Closer to Free 2018 shows a dramatically different Erin. After receiving the Closer to Free bike, she's ready to ride 25 miles with her two boys.

THANK YOU

YOU made it all happen!

1,853 Closer to Free riders raised **\$3.3 million** for Smilow Cancer Hospital.

Want to know what the Ride is really like?

Visit rideclosertofree.org/CTFVideos to see a short video of highlights from this year's Ride—and be prepared to laugh, cry, and be amazed at the display of heart, spirit, and generosity.

Thank you riders, donors, and volunteers!

September 8, 2018: This year, she traded that wheelchair for a bike.

Each year before the Ride begins, an especially inspiring rider/cancer survivor is honored as the recipient of the Closer to Free bike—a symbol of strength and courage that is signed by riders and displayed in the lobby of Smilow during the following year.

This year, that bike went to Erin. She held the bike and raised her fist with enthusiasm and determination as her two boys smiled up at her and

the crowd cheered. Then Erin and her sons hopped on their bikes and rode 25 miles for Closer to Free.

“Like every rider, I was in tears as I rode by the patients outside Smilow,” she says. “That’s what’s so special about Closer to Free. You’re doing it for the patients and they’re right there. It becomes such an important part of their life and their survival. It gives them a moment of strength, despite whatever they’re going through.”

Erin and her boys are already signed up for next year's Ride—and they would love to see you there, too!

Register to ride!

Join us at the **2019 Launch Event** on March 7 at Stony Creek Brewery in Branford, 5–8 PM. Find more information and updates at: rideclosertofree.org. ♥



She's not out of the woods yet.

Erin still needs your support! To fight off the chance of a recurrence, she is participating in a clinical trial. Your donation makes life-saving research and clinical care possible for Erin and countless others. **You can help them stay Closer to Free with a generous gift.**

Donate at:
givetoynhh.org

