

Spotlight

NEWSLETTER FOR OUR DONORS,
VOLUNTEERS, AND FRIENDS

WINTER 2017

Yale
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THANK YOU DONORS, RIDERS, & VOLUNTEERS

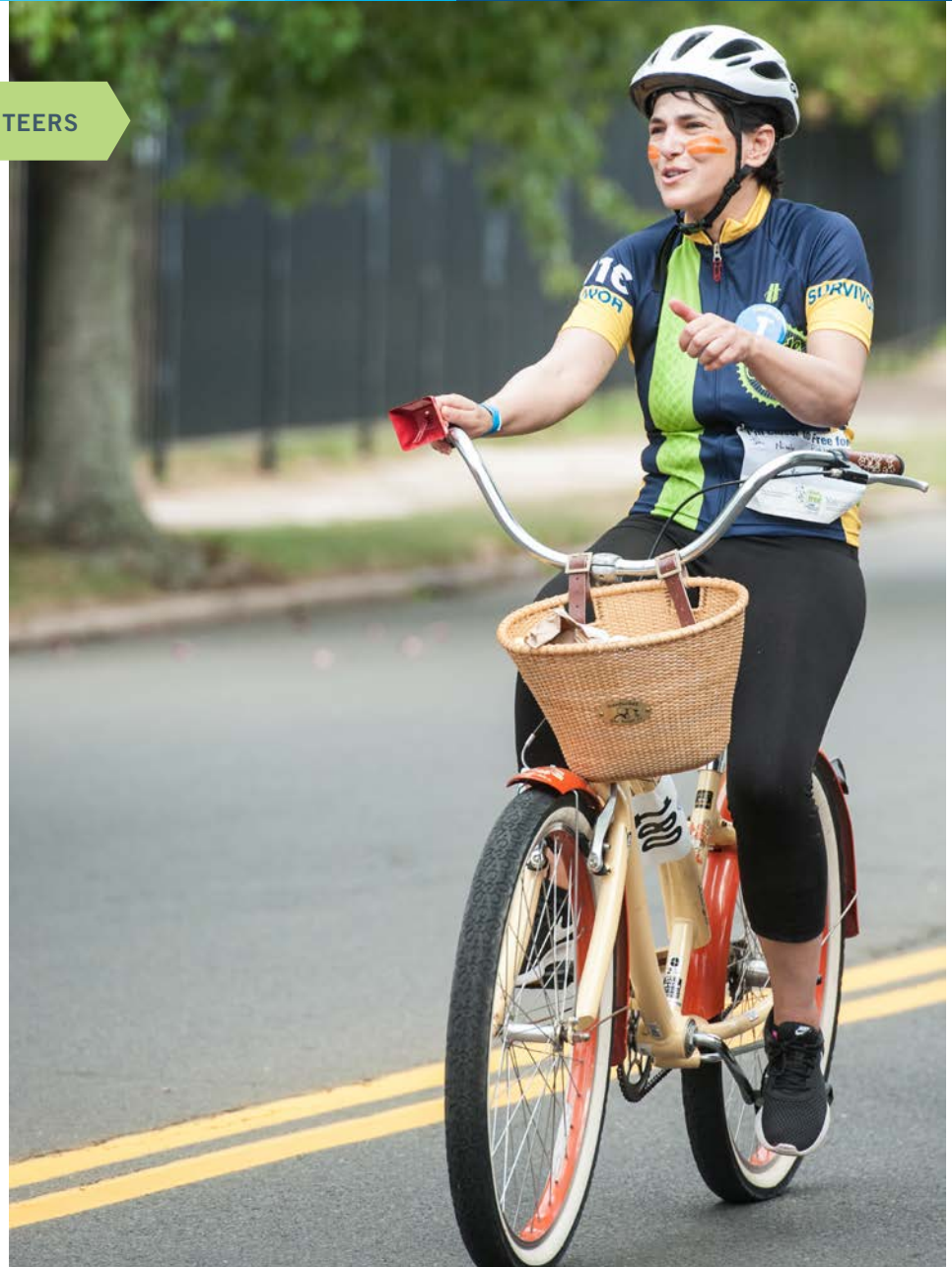
Because of you, Debra crossed the finish line

In September 2015, during the Closer to Free Ride, Debra was fighting cancer at Smilow Cancer Hospital. This past September—just a year later—she rode for Closer to Free and crossed the finish line with her family by her side.

IN MARCH 2015, Debra Boardman checked into Smilow Cancer Hospital. It was her daughter's 12th birthday. Just two days earlier, she had received a terrifying diagnosis of acute myeloid leukemia—a potentially fatal blood cancer.

“You always think, it couldn't happen to me. But when you actually hear that word—cancer—it just feels as if your whole world is crashing down,” she remembers. “We just cried and cried.”

Her first treatment was a powerful course of chemotherapy. The drugs knocked out her immune system completely—so she had to stay in the hospital for 28 days to prevent life-threatening infections.



Just a little farther ... Debra approaches the Closer to Free finish line

That was just the first of a painful series of treatments, tests, and procedures that lasted many months. There was follow-up chemo that made her dangerously sick, landing her in intensive care. There were endless, anxious days waiting for test results. Most fright-

ening of all, Debra had to have a risky stem cell transplant.

And there were long periods of loneliness in the hospital, with Debra desperately missing her daughters, Emma and Molly, and her husband, Michael.

continued inside ➤



Members of Debra's team—which she named the **Never Never Never Give Up** team—included her family and many friends

“I rode to show people that they can have hope. That there was someone who saw the ride and said, ‘Next year I want to do that. Next year life will be different.’”

Fortunately, the compassionate care she received at Smilow, thanks to generous donors like you, made it just a little easier to bear. “Everyone there—the doctors, nurses, cleaning crew, aides—was incredible,” says Debra.

“I am grateful for all of them, every day of my life. It’s very tough to get ripped out of your whole life, away from family and into the hospital. They became like a second family.”

From hospital bed to fearless fundraiser

Early this past summer, her cancer in remission, Debra was driving to the clinic for a checkup. She looked up and saw a billboard for the Closer to Free fundraiser bike ride.

“I wanted to do it. I threw the idea out to my family, and they said, ‘Yes! We can do this!’”

Debra, Michael, and the girls put together a team and signed up for the 10-mile ride. Emma, age 13, would ride the entire course herself. Molly, age 9, pedaled behind her dad in a bike trailer. Good friends joined the team. And together, they raised over \$9,000 for cancer research and care.

“It meant the world to me,” says Debra. “A year ago, I was not in any condition to ride. Here I was, a year later, having built up the strength and stamina I needed to complete the ride. It felt like such a personal victory!”

But perhaps even more important was the sense of purpose she felt riding for all the other people who have been touched by cancer.

“I had one particular friend who didn’t make it—I rode for him,” she says. “I rode for people who helped me, people who’d been through what I went through

– 2016 –

Closer to Free by the numbers

1,450
Riders

125
Survivors rode—like Debra

148
Teams

132
Members on the largest team

3
Members on the smallest team

519
Volunteers

72,628
Total miles ridden

\$2.5 million
Raised for cancer research and care

and answered all my questions. I rode for the wonderful doctors, nurses, and staff at Smilow. And I rode for the people who are still there now, fighting for their lives.”

Last August, Debra celebrated the first anniversary of her transplant. “To say you hit the one-year mark is incredible,” she says. “And I absolutely plan to ride again next year!” ♥

A disease that affects much more than the body

We need your help to launch the Sickle Cell Support Fund

IF YOU DON'T HAVE SICKLE CELL disease (SCD), it's nearly impossible to understand its devastating impact.

Jomo Marsh, a 22-year-old student and gymnastics instructor, is one of more than 100,000 Americans with SCD, a hereditary blood disorder. “You feel so alone when you have an SCD crisis,” he says. “Family, friends, co-workers—they can’t understand. There’s no way to help.”

Two or three times a year, Jomo suffers an SCD crisis. His red blood cells cramp up into a crescent shape that makes them clump, hindering their flow through blood vessels. The resulting pain is so intense, he feels as though his bones have fractured throughout his body. His last crisis put him in the hospital for a month.

And yet, Jomo has been relatively lucky. He hasn’t experienced some of the more dangerous consequences of SCD: anemia, infections, fatal organ failure, tissue damage, and strokes.

SCD crises strike without warning

And they can last for weeks at a time, making it difficult to stick to any routine—including employment.

“Employers like to be flexible, but at the end of the day, they need dependable workers,” says Jomo. “When you have SCD, you can’t control what happens. Sometimes it leads to losing your job. Soon you are struggling to buy food for your kids or pay for your medication—keep the electricity on.”



“Sickle cell disease is a battle, and if you’re not fighting, you’re losing,” says Jomo.

“Since it’s genetic, it affects multiple generations. It can have a devastating impact on the well-being of entire families.”

There is no cure for SCD

Until a cure is found, those who have the disease will have it for life. They can do nothing but try to stay as healthy as possible—while they wait for the next crisis to strike. “You never know what’s going to set it off,” says Jomo. “I’m always waiting for the other shoe to drop.”

Jomo is studying for a degree in exercise science—focusing on how to improve health with physical activity. “My goal,” says Jomo, “is to help lighten the load of people with SCD.”

Please help our patients fight their battle against SCD. Donate generously to the new Sickle Cell Support Fund.

That’s why Jonathan Spodick, a clinical social worker at YNH’s adult sickle cell program, asks your help in launching the YNH Sickle Cell Support Fund. The fund will help SCD patients in crisis to pay for food, medications, clothing, transportation, and utilities.

Jonathan and the dedicated staff of his department often find themselves reaching into their own pockets to help patients make ends meet. But their generosity doesn’t go nearly far enough.

“You can’t find a disease where people have greater needs,” says Jonathan.



Did you know?

You can help a patient manage the hardships of a life with Sickle Cell Disease.

Make your gift now to launch the new Sickle Cell Support Fund.

Please use the enclosed form to make a gift today, or give online at givetoynh.org/scdfund.

THANK YOU FOR CARING

Your generosity helps moms get through the toughest time of their lives

RONALD MCDONALD HOUSE (RMH), just steps away from Yale New Haven Children's Hospital, is a home away from home for the families of pediatric patients receiving medical treatment. *Judy Pasqualoni, a marketing manager for the specialty centers at Yale New Haven Children's Hospital, made it her mission to help the moms of these kids get through the toughest time of their lives. Here's her story, in her own words.*

Just before Valentine's Day 2013, I was volunteering with my staff at the Ronald McDonald House. I saw how terribly sad and lonely most of the mothers there were. And I wondered what I could do to make this difficult time just a little easier.

I decided to make little "spa baskets" to give as Valentine's Day gifts—one for each of the 12 moms staying there. They included things like pretty soaps, hand

cream, shampoo, and a notebook and pen. I wanted to make the mothers feel that they weren't alone, that someone was thinking about them.

The house manager at RMH told me the mothers were absolutely overwhelmed when they received them! So I knew I had to make more. My co-workers chipped in generously to help purchase the spa items. And whatever I couldn't get from others, I put in myself.

That was three and a half years ago, and over 200 baskets have been delivered since! Now every new mom who comes to RMH finds a gift basket waiting for her on her bed.

I'm thrilled that we were chosen to be in the Yale New Haven Children's Hospital Wish Book again this year! I know I can count on our generous donors to help.



It's time for the Wish Book!

We hope you received your copy a few weeks ago. Please give generously again this year. **Our kids need you!**

Use the giving slip enclosed in your Wish Book, or give online at ynhhwishbook.org.



YOU are the reason we love to come to work every day!

Happy New Year & Thank You for helping so many patients in 2016!



From the YNHH Office of Development