

LOOKING FORWARD

(Don't Look Back. You're Not Going That Way!)

INTRODUCING A NEW LTFU STUDY NEWSLETTER

This is the first issue of Looking Forward, a new LTFU publication, in which we'll feature stories about survivors like you.

These individuals are engaged with life and "looking forward" to each new day. We'll also bring you stories about "Community Partners" people and institutions who are making a

difference by providing concrete help and services to survivors in their area or nationwide.

Did you know that you are one of more than 24,000 childhood cancer survivors who take part in the Long-Term Follow-Up Study?

You may have been in the study since it began in 1995. Or, you may have joined more recently as part of a new group of survivors diagnosed between 1987 and 1999.

Either way, many of you have asked for a publication like this. We hope you enjoy this first issue!



Billy is holding a southern stingray.

Unstoppable Billy Rivard

Billy Rivard teaches high school biology in Mendon, Michigan. He's a recent graduate of Western Michigan University in Kalamazoo.

In 1996, at age 5, Billy was diagnosed with acute lymphoblastic leukemia (ALL). After relapsing in 1999 he received a bone marrow transplant (BMT). "I caught a virus during the transplant and was in the hospital for four months!"

he recalls. In 2012, Billy found out that he would need a kidney transplant, too. "My uncle donated a kidney for me. No one in my immediate family was a match for the transplant because my blood type had changed from A to O as a result of the BMT!"

Billy's mom Linda is a nurse who is also a cancer survivor. She manages a survivorship clinic at Advocate Health Care in the Chicago area. She says that despite having so many issues Billy takes great ownership of his follow-up care: "He has been a great teacher for me in how to handle life after cancer."

Billy loves teaching. "It's a great profession to be in especially after going through cancer treatment," he says. "I'm able to use many real-life examples from my experience that show how important science is. My goal is to inspire somebody to be a doctor

or researcher and figure out a way that nobody ever again will have to go through what I did.

Billy's favorite hobby is fishing. "And because of that I have a huge passion for the environment. I also think that being sick has made me realize how important a healthy environment is for everyone's health."

To pursue both interests, Billy is involved with an organization called the Coastal Marine Education Research Academy (CMERA), in Clearwater, Florida.

"We go out and tag sharks and sting rays as well as studying other marine life such as sea turtles.," Billy says. "This is probably my favorite thing I have ever been a part of."

With his complicated medical history, Billy has to stay on top of his health. In discovering his passions, he has found plenty of reasons to do so!



Julia with her daughters Mia (left) and Grace.

Community Partners:

Julia Stepenske & SurvivorVision®

Julia Stepenske is a childhood cancer survivor whose experience helped decide her career path. She was diagnosed with non-Hodgkin lymphoma in 1989 at age 15. She was treated on a clinical trial at Children’s Memorial Hospital in Chicago and her cancer went into remission.

“In college, I decided to make it my life’s mission to help childhood cancer patients in any way possible, so I went into nursing,” Julia says. She worked first as a pediatric oncology nurse at the hospital where she was treated, later moving to work at a survivorship clinic. Through her professional work Julia saw an opportunity to help in other ways. With a group of her friends she created a foundation called SurvivorVision that provides funding for programs to help childhood cancer survivors thrive and meet their goals.

100+ day packs and textbook scholarships

SurvivorVision partners with participating hospitals to provide gift packs to bone marrow transplant patients to acknowledge their 100th day after transplant. The 100th day is a major milestone for BMT recipients. The packs include gifts such as a t-shirt, a waterbottle, a notepad for journaling, and a commemorative bead from the children’s charity “Beads of Courage.”

The foundation also sponsors scholarships to cover the cost of college textbooks. The scholarships are open to all childhood cancer survivors. An application form is available on the foundation website:

survivorvision.org/about-us/our-programs/

“As a bedside nurse working with transplant patients I realized that Day +100 was a really big deal and not every hospital did special

For more information,
please contact us at:
1-800-775-2167

On the web: LTFU.stjude.org
Email: LTFU@stjude.org



things for the kids on that day,” Julia says. “Also, I was blessed to have a textbook scholarship in college and figured why not start one, so we did.”

While pregnant with her second child Grace, Julia’s cancer unexpectedly returned 19 years after it went into remission. Fortunately, she was diagnosed and treated quickly thanks to advances in cancer treatment and to being cared for at a childhood cancer program that helped her navigate life after cancer. “Being connected to a specialized survivorship program saved my life,” Julia says. “I wish that all survivors could have an opportunity to get their follow-up care at a dedicated survivorship clinic.”

As a two-time cancer survivor, Julia cherishes her time with her family. “We do everything together,” she says. “We cross-country ski and bike as a family. And we celebrate everything—birthdays, holidays, weekly events like pizza-and-a-movie night, board game night, we make time to do things together.”

LOOKING FOR A VOLUNTEER OPPORTUNITY?

We learned about Imerman Angels from Billy Rivard who has signed up with the program. This organization matches people who have been affected by cancer and are seeking support with a volunteer mentor who is the same age, same gender, and has faced the same type of cancer. Their website has

information about how to become a mentor “angel” as well as information about other volunteer opportunities:

imermanangels.org/give-support/

Is there a “Community Partner” in your area that you’d like to see featured in a future issue of Looking Forward? Please submit your suggestions on our website:

ltfu.stjude.org