

LOOKING FORWARD

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

A NEWSLETTER FROM THE LTFU STUDY

A Circle of Giving

Catherine St. James, 25, of Teaneck, New Jersey, is making career plans. She recently graduated from Seton Hall University, majoring in anthropology, and is thinking of pursuing a Master's degree in Public Health.

Catherine's interest in Public Health began after she was treated for a brain tumor as a teenager. At age 14, she was diagnosed with craniopharyngioma, a type of brain tumor that involves the pituitary gland.

Shortly before she was diagnosed she began to have serious headaches. A competitive soccer player, Catherine thought the headaches might be from heading the soccer ball. But she was also unusually short for her age. Her parents took her to see an endocrinologist, who ordered an MRI that revealed the tumor in her brain.

Just before she started her freshman year of high school Catherine had surgery to remove the bulk of her tumor. She was also treated with radiation. After treatment she wanted to find a way to help other cancer and brain tumor survivors.

"Before I got sick, I wanted to be a teacher but I got interested in Public Health in college," she says, "especially the area of patient education. It seemed like it could be a way for me to use my experiences, and the things I noticed during treatment, to make things smoother for people who are going through some of the same things that I went through."

About a year after her surgery, Catherine and her family learned about the Children's Brain Tumor Foundation (CBTF). The foundation offers a host of services for brain tumor survivors and their families. CBTF counselors assisted Catherine as she began exploring career paths in Public Health. The foundation also helped her obtain an internship at a medical device company that makes equipment for brain surgeons.

In return, Catherine has volunteered at the foundation, putting together care packages for patients. She's also shared her story as a guest speaker at some foundation events. "We have a nice give-and-take," Catherine says. "They help me and I help them!"

Catherine has had to deal with some significant side effects of treatment. "Fatigue is a big issue," she says. "If I'm active for two or three days, it seems like I have to take two or three days to recover. It's frustrating to be so tired!"

Despite the fatigue, she leads a busy life. Through CBTF, she connected with Camp Mak-a-Dream, a camp for cancer survivors, located in Montana, which hosts a "Heads Up" conference for young adult brain tumor survivors. The conference provides survivors an opportunity to meet and make friends with others



who are facing similar life challenges.

Catherine attended the Heads Up conference in June, 2016. Her favorite activities were the evening fireside chats, where participants gather to talk and share their feelings, thoughts, and experiences. She also loved the camp's beautiful surroundings. "Coming from the New York City area," she says, "I loved the chance to breathe the fresh mountain air for five days!"

Catherine hopes to attend a future Heads Up conference as a mentor to provide emotional support for future campers—planning once again to give back for what she has received.

Photo: Catherine St. James, *right*, with her sister at a Children's Brain Tumor Foundation event



Community Partners: **CAMP MAK-A-DREAM**

Located in western Montana near Missoula, Camp Mak-A-Dream has been providing medically supervised, cost-free camp experiences for cancer patients and survivors since 1995. The camp offers sessions for children, teens, siblings, young adults, and families. Anyone whose life has been affected by cancer is welcome.

Activities at the camp range from hot-tub soaks and movies to zipline and mountain hiking. In addition to such serious fun, the camp also offers cancer survivors the opportunity to



make life-long connections with other survivors.

Camp director Beth Jones says, "People form bonds here like nothing we

see outside the camp world." Beth first encountered the camp as a volunteer when, as a member of the Missoula Children's Theater, she helped put on a workshop for campers. "It was a powerful experience seeing how people at the camp support each other," she recalls. "When an opportunity opened up, I decided I wanted to become a part of it permanently!"

HEADS UP CONFERENCES

Camp Mak-A-Dream offers a special program for brain tumor survivors—the Heads Up conferences for teens and young adults. The conferences are a collaborative effort with the Children's Brain Tumor Foundation. CBTF partners with the camp to develop conference programming. The foundation also helps with staffing and with travel expenses for participants.

According to Beth, the Heads Up conferences combine all the fun of camp plus workshops

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please contact us at:
1-800-775-2167
<https://LTFU.stjude.org>
Email: LTFU@stjude.org



to help survivors learn to manage the long-term effects of their disease and treatment. "We schedule daily workshops on various topics, including educational and employment issues and social relationships. We also have small group and fireside chats where participants can share their thoughts and feelings about things that are important to them."

Each conference is held once a year and lasts about a week, and each session has space for about 50 participants. Many return year after year. Experienced campers can apply to serve in a variety



of leadership positions, including as mentors, who offer peer to peer support to other participants.

As noted, all camp sessions, including the Heads Up conferences, are cost-free to participants. A limited number of travel scholarships are available for first-time campers. For more information, or to apply to attend a camp session go to:

<http://www.campdream.org/>



Children's Brain Tumor Foundation

Catherine St. James and her family continue to receive a lot of support from the Children's Brain Tumor Foundation (CBTF). The foundation provides support at every stage of the brain tumor experience, including a Survivor and Bereave-

ment program. They also provide parent and survivor mentors, educational advocacy, career development and employment programs, social and social skill groups, and regular online chats for parents and survivors. More info at: www.cbtf.org

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: <https://lftu.stjude.org/>