

THE ADOLESCENT LEADERSHIP COUNCIL LIFTS UP TEENS LIVING WITH CHRONIC ILLNESSES

Stephanie Beaudry often refers to her son, Matthew, 15, as “one in a million.” And he truly is. Matthew was successfully treated at Hasbro Children’s Hospital for pineal blastoma—a rare and aggressive tumor in the brain’s pineal gland—not once but twice. He was first diagnosed when he was seven months old and again at age four.

But being “one in a million” can be difficult when you’re a teen trying to fit in with your peers. Matthew is now cancer-free but still deals with after-effects, including stunted growth, thyroid deficiency, and vision and hearing loss. And last year he underwent his fifth brain surgery for a tumor that, fortunately, was non-cancerous. It’s a lot to deal with, especially combined with the typical challenges of high school.

His friends at the vocational technical high school he attends in Fall River can’t relate to the challenges he faces. But his friends at The Adolescent Leadership Council (TALC) at Hasbro Children’s Hospital sure can.

“It’s a community that’s always there for me,” Matthew says.

Founded in 2005 by then-resident physician Gary Maslow, donor-funded TALC is a support and mentorship program for 13- to 18-year-olds who have a chronic illness. TALC hosts monthly meetings on the first Thursday of every month, as well as social events, leadership retreats, and an annual summer camp. Meetings include collaborative activities and group discussion led by medical residents from The Warren Alpert Medical School of Brown University.

“The teens are able to talk about their illnesses in a safe place,” says program director Erin Scott, LCSW.

Before he became involved with TALC, Matthew was struggling with his self-esteem and feeling different.

“He said, ‘Why is it always me?’” Stephanie recalls. “He felt like he was being singled out for medical issues the other kids at



Matthew Beaudry

school didn’t have. Through TALC, it was nice to see him realize he’s not the only one. There are a lot of kids out there going through hard things, and they need to share their stories with each other.”

TALC is open to teens with various types of chronic illnesses, including diabetes, sickle cell anemia, lupus, and digestive diseases. While they may not be able to relate to every aspect of each other’s illness, common themes come up, including fitting in socially, managing chronic pain, and dealing with stereotypes.

“Without programs like TALC, I think it really leaves these kids open to issues with stress, bullying, anxiety, and depression, along with what they’re going through medically,” Stephanie says.

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— Erin Scott, LCSW

TALC members also benefit from mentorship from students from area colleges, who are living with chronic illnesses as well. The mentors model the successful transition into young adulthood and share experiences related to everything from navigating the medical system to self-advocacy.

“The college students are able to offer a different kind of support than we can as medical professionals,” says Matthew Willis, MD, who serves as a faculty advisor for the program, along with Francine Pingitore, PhD, RN.

Dr. Willis adds that the opportunity to form relationships is especially important for participants.

“A lot of these kids are under-socialized because of the limits of the chronic illness,” he says. “When I hear from parents, they often say that TALC has been the single most significant program that their children have participated in, in terms of physical and emotional development.”

Parents can get involved by attending their own meeting, which occurs at the same time as the teens’. Patient parent Jennifer Felizzola says the arrangement has helped her daughter, Izzy, who has spina bifida, cope with separation anxiety, among other things.

Jennifer adds that the parent group offered her “validation and the opportunity to relate to other parents.”

Stephanie has also felt supported by the parent component of the program. But she’s most grateful for the changes she’s seen in Matthew. For many years, he coped with the aftermath of cancer without an outlet like TALC. Recently, though, with support from the program, as well as individual therapy, his self-esteem has improved “by leaps and bounds,” Stephanie says.

“The other day he said, ‘you know Mom, maybe I go through this because I’m strong, and maybe another kid wouldn’t be able to handle it the way I do,’” she says. “And that’s because of TALC.”

For more information, go to www.lifespan.org/TALC

A NEW TALC TRADITION



Hair and makeup. Fancy outfits. A night on the dance floor. Thanks to the generosity of the Dunkin’ Joy in Childhood Foundation, the teens of TALC were treated to something extra-special last year: their own prom at Hotel Providence. The event offered an opportunity for members, some of whom didn’t make it to their own school’s prom, to socialize and celebrate in style. It was so successful that it’s happening again this year—with a Cinco de Mayo theme this time.



HEALING ARTS SUPPORT PATIENTS' WELL-BEING

The teenager's hospital room was filled with signs of healing in the form of brightly hued paper cranes, suns, and wreaths taped all over the walls.

During her months-long inpatient stay in Hasbro Children's Hospital Integrated Care unit, Julie's 15-year-old daughter unexpectedly discovered a passion for the art of origami. Offered through the hospital's Healing Arts program, paper-folding instruction provided the teen with a therapeutic outlet.

"We got a lot of comments, like 'wow, we've never seen a room like this before,' and that brightened her mood," Julie says. "It also became a social thing, where she would give pieces to other children and staff. I'm so grateful that my daughter had this experience as part of her hospital stay."

Origami is just one of many creative activities patients can engage in through the philanthropy-funded Healing Arts program. Children throughout the hospital, including those waiting in the emergency room, can try painting, dance, yoga, tape art, and other art and mindfulness activities.

Healing Arts play an especially important role on the Integrated Care unit, which addresses the needs of children and adolescents struggling with complex and co-occurring psychiatric and medical diagnoses like eating disorders, pain syndromes, and diabetes. Patients often have long stays of up to a year and may struggle with sharing their feelings.

"Through our services, kids have a way of expressing themselves outside of traditional talk therapy," says Healing Arts Coordinator Kyle McDonald. "The arts and various forms of creativity offer another language for them to process difficult feelings and emotions. We have seen some amazing results."

Immersion in singing, drawing, and movement can also ease the anxiety, fear, and boredom that can come up in the hospital setting. "Through her experience with Healing Arts, my daughter was able to take away some positive memories from her hospital stay," Julie says.

IS YOUR KID A PICKY EATER?

Rejecting foods is common among toddlers and young children. Fortunately, Celeste Corcoran, MD, is here to help with the following tips. Dr. Corcoran directs the Healthy Eating Active Living Through Hasbro (HEALTH) Clinic at Hasbro Children's Hospital, which provides lifestyle treatment for children to improve their overall health. She specializes in caring for children and adolescents who are struggling to be at a healthy weight.



1 SERVE AS A GOOD ROLE MODEL

Children mimic what they see, so it's important for parents to fill their own plates with a variety of healthy foods, including fruits, vegetables, grains, and lean protein.

2 BE PATIENT

Sometimes it takes 12 or more times of presenting a new food to a child before they will even try it.

3 GET CREATIVE

Disguise the look and taste of vegetables by combining them with other foods. For example, make a smoothie with a banana, frozen blueberries, spinach, Greek yogurt and a dab of honey. Another idea: throw some shredded zucchini or carrots into a meatloaf.

4 SEEK HELP, IF NECESSARY

If the behavior becomes extreme, it's best to talk to your child's pediatrician. In some cases, picky eating may reflect a sensory or swallowing issue that is best addressed through a medical evaluation.



For more information, scan the QR code

COMMUNITY FUNDRAISING EVENTS MAKE A BIG DIFFERENCE

Few things are more inspiring than seeing supporters come together in creative ways to support Hasbro Children's patients and their families. The hospital welcomes gifts from outside fundraisers of all styles and sizes. And even kids can make a difference. For example, 8-year-old Theo raised \$1,000 this past summer at his second-annual lemonade stand. Hearing about kids with COVID and other illnesses from his mom gave him the idea to take action.



Theo's lemonade stand

Sometimes whole communities come together year after year to make a dramatic impact. One such example is Johnston Memorial Cancer Events, which hosts golf tournaments and other fundraisers throughout the year to support the hospital's oncology patients. The group made up of several families who have been impacted by cancer, has raised more than \$350,000 for the hospital to date. They have made a new pledge of \$100,000 to fund pediatric cancer research at Hasbro Children's. Thank you JMCE!

The Washington County Fair and partner Rockwell Amusements have been raising funds for Hasbro Children's through their event since 2018. After taking two years off due to the pandemic, the fair resumed in August 2022, and the organizers supported Hasbro Children's with their most generous donation to date—more than \$40,000. They collected donations from attendees and also made individual contributions. And each night of the fair, they invited a patient to tell their story on the band stage.

In December, the Aquidneck Friends of Hasbro group, led by Karin Dillahey, spread holiday cheer through its "mailbox brigade." In exchange for a donation to the hospital, volunteers adorned the mailboxes of residents in Newport, Middletown, Tiverton, Portsmouth, and Jamestown with greenery donated by Middletown's Sweet Berry Farm, and festive handmade bows. This year's spirited event raised \$5,000.

Facebook fundraisers are also a great and easy way to get involved. This is just a small sampling of events that can happen with a little creativity and a desire to help!

To learn about how to host your own fundraiser, go to giving.lifespan.org/Hasbro/fundraise.



Johnston Memorial Cancer Events



Washington County Fair and Rockwell Amusements



Mailbox Brigade

Caring for Kids, a publication of the Rhode Island Hospital Foundation, is published for the friends and supporters of Hasbro Children's Hospital. For more information, please contact the Development Office at 401-444-0394.

giving.lifespan.org/Hasbro



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