THE LITE PROGRAM

Fall/Winter 2019



# The Lighthouse

#### LITE NITE RETURNS

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### "COPING WITH EMOTIONAL ISSUES AND STRESS AFTER TREATMENT"

The annual LITE Survivor and Family Education Night (LITE Nite) was held this year on June 28, 2018 at the Rutgers University Conference Center and Inn in New Brunswick, New Jersey from 5:30pm to 8:30 pm. LITE Nite is both an opportunity to provide education regarding management of long-term/ late effects related to pediatric cancer treatment and a celebration of survivorship. Attendance at LITE Nite is free of charge for all attendees and includes a buffet dinner. Sponsorship of the event was through a grant from the National Children's Cancer Society (NCCS) and financial support from the Pediatric Hematology/Oncology Division, Rutgers Cancer Institute of New Jersey.

The title of this year's LITE Nite was, "Coping with Emotional Issues and Stress after Treatment: Anxiety, Depression, and Stress Through the Life-Course." These topics were chosen based on results from the 2018 LITE Nite satisfaction surveys and feedback from adolescent and young adult pediatric cancer survivors. Two faculty members of Rutgers Robert Wood Johnson Medical School presented. Ronke Babalola, MD, MPH, Child and Adolescent Psychiatrist and Assistant Professor of Pediatrics, spoke on, "Anxiety and Depression in Childhood Cancer Survivorship." Katie Devine, PhD, Clinical Psychologist, Population Science, focused her talk on, "Stress: What It is, How it Affects Survivors and How it Changes Over the Life Course." Our Survivor Panel completed the evening. The panel of four included a parent and three young adult survivors. Panel members shared their personal experiences managing the emotional impact of treatment and survivorship, including coping with their own anxiety and depression past and present. The discussion between the panel and the audience was vibrant, compassionate, and nurturing. Siblings and other parents in attendance added to the discussion of how survivorship is experienced by all family members noting that how it is spoken of and processed can transform over time to a positive future focus. The group developed their own recommendation that it would be beneficial for adolescent and young adult (AYA) survivors to have structured recreational gatherings specific to their age group to increase social support. A request for these types of activities has been made to a local pediatric cancer foundation that is now considering adding an event for AYA survivors. In keeping with tradition, the celebration ended with the gift baskets "raffle" where upon registration, each survivor is given a number of free tickets for donated gift baskets that range in interest for all ages.

The LITE team would like to thank the members of the panel and the audience for their generosity in sharing and supporting each other as well as continuing to teach us about real-life pediatric cancer survivorship. We are seeking survivors and family members' suggestions for next year's LITE Nite. So far, sibling survivorship and update on late effects are the two most mentioned topics. If you would like to add a topic or vote for one already mentioned, please email Sue Stephens at stephesu@cinj.rutgers.edu.

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What is a Survivor?

**S** trong willed

**U** nique

R esilient

V igilant

**I** nteresting

V ery special

**O** utstanding

R esourceful



# "Managing Your Health" Program Helps Young Adults Take Charge of Their Healthcare"



As childhood cancer survivors become young adults, there are lots of new responsibilities — going off to college, starting a job, living on their own, and perhaps even starting a family of their own. Also during this time, they become responsible for their own healthcare, including your survivorship care. Many young adult survivors of childhood cancers find it difficult to navigate the complex adult healthcare and insurance systems. A research team led by Katie Devine, PhD, and the LITE team - Margaret Masterson, MD, Dawn Carey, RN, MSN, APN, and Sue Stephens, LSCW - developed the "Managing Your Health" program to empower young adults to feel more confident in managing their survivorship care and getting the healthcare services they need.

In our initial research study, we found that young adults in the program improved their confidence in managing their care and took greater responsibility for survivorship care tasks. Participants told us that talking with a peer mentor was especially helpful. As one participant said, "Speaking with a mentor was a huge positive...there is something to be said about speaking to someone who understands, who's been through the same thing as you."

Last year, Dr. Devine was awarded a grant from the National Cancer Institute to enhance the online educational modules and test the new and improved Managing Your Health program. The 6-week program involves completing online educational modules about how to manage your health and the healthcare system, as well as being matched with a peer mentor — another young adult survivor who knows what it's like to take responsibility for managing your health and can provide some tips and support while you do it. Several young adult survivors from the LITE Program helped us develop the new online modules. We also recently trained nine peer mentors to be ready to work with new participants.

Thank you to all the survivors who have participated! It is only with your support and involvement that we are able to develop programs like this to benefit more young adult survivors of childhood cancers. For more information, email Dr. Devine at survivorhealth@cinj.rutgers.edu.





#### Healthy Holiday Tips

- · Bring a healthy dish to the party (vegetable platter w/ low-fat dip, salad, fruit salad).
- · Don't go to the mall hungry, or on an empty stomach. This lead to impulse eating at the food court or snack kiosks.
- · Pay attention and keep track of what you eat. Download an app for your cell phone.
- · Weigh yourself a few times a week over the holiday season or pay attention to how your clothes are fitting. This will allow you to adjust/correct bad eating habits sooner.
- · Do not skip meals and eat before going to a party. Limit the number of high calorie foods (fried foods, cheese, dips) you put on your plate.
- · Keep arms-length away from the buffet and snack table. Choose wisely and fill your plate with vegetables, fruit, and lean meats first.
- · Pop a mint into your mouth when you start to feel full to curb additional snacking/noshing.
- · Keep healthy snacks at the office (fruit, raw vegetables, low fat granola bar), so you are less tempted by holiday treats piling up at the office.
- · Manage portion sizes, use smaller plates.
- · Control your environment make holiday treats harder to get to and not in constant sight.
- · Keep up with exercise no matter how busy you get.

The holiday season does not have to cause unwanted weight gain.

Lori Magoulas, PhD, RD



## Reminder...... Get your FLU Shot

Ways to prevent getting the FLU:

- 1. Get the flu shot
- 2. Stay at least 3 feet away from people who are coughing and sneezing
- 3. Keep hands away from face and mouth
- 4. Wash hands regularly
- 5. Avoid sharing drinks
- 6. Get sufficient rest
- 7. Eat healthy diet
- 8. Avoid kissing significant others who are sick





# **RUTGERS**

Cancer Institute of New Jersey



#### **RUTGERS HEALTH**

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#### WELCOME

# Karen Long-Traynor, PhD

I am excited to join Rutgers Cancer Institute of New Jersey and be involved with the LITE program as a clinical psychologist. As you know, advances in pediatric cancer have significantly increased survival rates, but treatments used may lead to "late effects." While many survivors have few complications after treatment, some may experience psychological and neurocognitive difficulties. These may include depression, post-traumatic stress, learning difficulties, or memory problems.

I offer evidence-based therapies, including cognitive behavioral therapy (CBT) and Acceptance and Commitment Therapy (ACT), to address the unique mental health concerns that are encountered by survivors. Treatment may involve a single session or a longer therapy, depending on the needs of the individual. In addition to therapeutic services, I offer neuropsychological testing which assesses areas such as academic functioning, memory, intelligence, executive functioning, and mood. These evaluations can be used to gain necessary academic accommodations or services.

If you have questions or would like to set up an appointment, please contact me at 732-235-5696 or email me at kl886@cinj.rutgers.edu



