

News & Updates

March 2023 | Volume 14 - Number 3

Upcoming Activities

April 10, 2023 12th Annual Toiletry Drive Wish List

April 30, 2023 Letters of Intent MMCF/APHON Research Grants Learn More

May 21, 2023 14th Annual Walk Walk with Us!

About Us

Spreading Hope Through Psychosocial Support SM

Learn

Support

Help Make The Miracles Possible

EARLY INVESTIGATOR RESEARCH GRANT RECIPIENTS

Christina Amaro, Ph.D.





MATTIE MIRACLE

IMPLEMENTATION GRANT RECIPIENTS



Lydia Chevalier, Ph.D. Sherilynn Chan, Ph.

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On February 14, Mattie Miracle **donated \$42,000** to the American Psychosocial Oncology Society (APOS), to support our innovative psychosocial research grant program. The grants are designed to support the implementation of the <u>Psychosocial Standards of Care for Children with Cancer and Their Families</u>. **Mattie Miracle is committed to funding research that produces clinical tools and models that can enable the implementation of the Psychosocial Standards of Care at treatment sites around the country.**

APOS coordinates and administers our grants and we are honored to be connected to this outstanding professional association. Twelve strong Letters of Intent (LOIs) were submitted and six were invited to submit a full proposal. Each proposal was reviewed by three experts in the area of the proposal.

The following areas were scored:

- Significance to psychosocial oncology and the implementation of the pediatric Standards of Care
- Scientific Merit
- Innovation
- Appropriateness of Methods
- Qualifications of the investigator (research team) to conduct the study

Supporting Innovation

Donate

CFC #59853

Giving



It's not just about the medicine!™ Based on the above criteria, we wish to congratulate the **recipients** of a Mattie Miracle/APOS Early Investigator Research Grant:

- Christina Amaro, Ph.D. (Rutgers Cancer Institute, NJ) is awarded \$10,000 to conduct a research study entitled, Community Engagement in Developing a Web-Based Single-Session Psychosocial Intervention for Adolescent Siblings of Youth with Cancer. Mentors: Melissa Alderfer, Ph.D. and Katie Devine, Ph.D., MPH
- Lydia Chevalier, Ph.D. (Dana-Farber Cancer Institute, MA) is awarded \$10,000 to conduct a research study entitled, Developing Sexual Health Questionnaire for Young Adult Childhood Cancer Survivors: A Modified Delphi Project. Mentors: Sharon Bober, Ph.D. and Christopher Recklitis, Ph.D., MPH

Based on the caliber of proposals submitted, Mattie Miracle selected two additional research studies to fund at a lower level. We congratulate the **Mattie Miracle Implementation Grant recipients:**

- Sherilynn Chan, Ph.D. (Seattle Children's Hospital, WA) is awarded \$7,500 to conduct a research study entitled, Telehealth Group Intervention for Adolescents and Young Adults with Cancer: A Feasibility Pilot Study. Mentors: Nancy Lau, Ph.D., Joanna Patten, Psy.D., and Abby Rosenberg, M.D.
- 2. **Kristen Uhl**, Ph.D. (Dana-Farber Cancer Institute, MA) is awarded \$7,500 to conduct a research study entitled, *CAP CANCER: A Cognitive Behavioral Intervention for Pediatric Cancer-Related Pain.* Mentors: Rachael Coakley, Ph.D. and Anna Muriel, M.D., MPH

Reflections from The American Psychosocial Oncology Society (APOS):

We are excited to announce that two 2023 APOS/Mattie Miracle Implementation Grants were selected for funding by an APOS scientific review committee. These two grants were chosen to move the field of pediatric psycho-oncology forward on the Implementation of the Pediatric Psychosocial Standards of Care.

In addition, two Mattie Miracle Implementation Grants were selected by the Foundation based upon the caliber of the proposals and the ability to provide additional deliverable outcomes. Such tangible research is vital in the support of The Mattie Miracle Cancer Foundation's mission to implement the Psychosocial Standards of Care.

It is our pleasure to continue to partner with The Mattie Miracle Cancer Foundation in our shared missions.



Child Life Corner with Adina Levitan, CCLS



We welcome Child Life Corner to our newsletters. Each month you will hear from Mattie Miracle's Child Life Specialist, Adina Levitan. Adina will highlight topics, issues, and share stories from a child life professional's lens. Given the vital role child life plays in a child's medical and psychosocial journey, we are proud to feature this standing column.

Celebrating Child Life

March is Child Life Month! For this installment of Child Life Corner, I am excited to share some of the guiding principles and values that child life specialists uphold in our day-to-day support of pediatric patients and families.

First, and perhaps the most important to note, is that Child Life Specialists provide services to all pediatric patients regardless of age, gender, socioeconomic status, religion, race and other individual factors. Why is this important to note? As opposed to other hospital services, Child Life will not appear as a line item on a patient's bill. This means we are not bound by insurance protocols and are free to see all children as needed. Child life programs are often funded by grants (like the generous support of the Mattie Miracle Cancer Foundation), hospital funds, community organizations and generous donors. This is why Child Life programs are so grateful for community support which allows us access to the resources and funds needed to create a program that helps hospitals feel less clinical and more like places where children can heal through play, support, and connection.

Second is the mind-body connection that Child Life Specialists recognize and support as essential to healing. While our focus is the psychosocial needs of children, which is defined as "relating to the interrelation of social factors and individual thought and behavior" (Oxford Languages), we also understand that in order for children to heal their physical needs related to their healing and treatment must also be met. This is why Child Life Specialists advocate for the three P's of pain management: Physical, Pharmacological, and Psychological. We advocate for comfort holds and positions during procedures because we understand that when children are held down or forced to lie down, they feel vulnerable and restricted which inhibits their coping. We advocate for medications that may help a child feel more relaxed prior to a procedure. We use our assessment skills and connection with the patient and parent to make recommendations to doctors and nurses that will help a child cope better during a difficult intervention. We also incorporate mindfulness interventions such as guided imagery or meditation to help our patients relax and return to baseline when they are overwhelmed.

Third, and this one may sound confusing, is that **we understand when our presence is helpful or when it is not.** Very often there are many staff members in the room at one time during a procedure, intervention, or conversation. We can recognize when children are

overwhelmed by too many people or if they are coping well, and we can also see when it maybe time to step out and check back later. My goal is to always ensure that my patients are coping well. In fact, I often give my patients the choice of having me stay in the room or step out. I have a designated area in my patients' rooms, and within that area, the child can choose whether I should stay or leave. On the flipside, if I notice there are too many people in the room and I am needed for the child's coping, I can advocate for others to leave. There may be nursing or medical students observing, however, their presence may be inhibiting a child from feeling successful during a stressful time.

In short, we are constantly using our assessment and observational skills to truly focus on the social and emotional needs of our patients in order to ensure optimal coping during hospitalization. We aim to provide our services to those who need them most while also striving to support positive coping.

Funding Child Life

On March 10, in honor of Child Life Month, Mattie Miracle donated \$48,000 to Children's Hospital at Sinai, in Baltimore, MD. These funds help to endow our Child Life Program Fund, which supports a full-time position at the Hospital.

We are honored to announce our **5th Child Life Specialist** is Lily Metzger. This Child Life position serves over **1,500 children** and families a year.

Mattie Miracle is committed to funding access to Child Life services for children with cancer. A Child Life Specialist has the necessary skills and abilities to make a very frightening and stressful medical experience more manageable. In fact, we believe Child Life services are just as important as the medical treatment.



Reflections from Lily Metzger:

I am The Mattie Miracle Child Life Specialist at the Pediatric Hematology/Oncology Clinic at Children's Hospital at Sinai (Baltimore, MD). I originally discovered the field of Child Life back in my home state of New Jersey. While in high school, I attended a career fair, where I met two child life specialists who explained the field to me. I was immediately struck with the importance of Child Life in the hospital environment and felt called to the profession. In the time between then and now, to expand upon my knowledge and love for the field, I attended Towson University, earning both a Bachelor's in Family Studies and a Master's in Child Life, Administration, and Family Collaboration.

When my time as a student came to a close and I started looking for work as a Child Life Specialist, I knew that the hematology/oncology population was close to my heart. I had previously been blessed with the opportunity to work with Children's Hospital at Sinai's outpatient clinic and experienced the magic of The Mattie Miracle Cancer Foundation.

As a new professional, I only hoped I would find a position with a similarly outstanding team and support services, like the ones offered through Mattie Miracle. When offered the opportunity to be a part of this organizational dream team, it was without question that I said yes to being a full-time Mattie Miracle Child Life Specialist. I am forever grateful to work with such a passionate

organization dedicated to serving children and families in the hospital and I admire their commitment to innovative research.

Our Upcoming Events

12th Annual Item Drive



In honor of Mattie's 21st birthday, we are hosting our 12th Annual Item Drive. All donated toiletries stock our Mattie Miracle Snack & Item Carts for pediatric families at MedStar Georgetown University Hospital (Washington, DC), Children's Hospital at Sinai (Baltimore, MD), and the Clinical Center at the National Institutes of Health (Bethesda, MD).

When living in a hospital 24 hours a day, seven days a week and caring for a child who is battling cancer or another life threatening illness, receiving these items can feel like a gift. Families often rush to the hospital when their children are ill and are unable to pack basic items that are needed for daily care.

The Carts fulfill basic psychosocial needs and provide items free of charge to families.

You can participate in our item drive from anywhere in the USA. Check out our Amazon wish list by clicking on the icon below. **Our Carts support over 2,500 families a year**. We ask that all items be received by <u>April 10, 2023</u>.

Walk with Us on May 21st



Our Virtual Awareness Walk will be held on **Sunday, May 21, from 10am to Noon** (in your time zone). You can participate wherever you are and help us turn your community **ORANGE!**

Our Annual Awareness Walk raises **90% of the funds** we need to directly support our psychosocial programs and initiatives which help children with cancer and their families.

Date: Sunday, May 21st

Time: 10am to 12pm (in your time zone)

Where: Mattie Miracle Facebook Page

GOAL: Awareness Event and to raise over \$100,000 (100% of funds support our psychosocial programs)

Great prizes for walkers with the greatest number of steps!

Click on the Mattie Miracle sun to register, purchase raffle tickets, and donate to our Awareness Walk.





Mattie Miracle Cancer Foundation www.mattiemiracle.com











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