



ASSOCIATION OF PEDIATRIC
ONCOLOGY SOCIAL WORKERS



October 2017

Fall Greetings from the President:

The Association of Pediatric Oncology Social Workers has a rich heritage thanks to a group of six (6) social workers, who were working with children with cancer, who met together to discuss common issues and provide support to one another in their practice.

Association is defined as a group of people organized for a common purpose. Synonyms to association include alliance, coalition and connection. Since 1976, the Association of Pediatric Oncology Social Workers has grown to three hundred plus members from North America and many other countries across the globe. Why is membership important to the strength of an organization? I have been asking myself that very question in recent months. Perhaps there have been times when you wondered about the benefits of being a member of APOSW.

Our mission as an association is clear; the Association of Pediatric Oncology Social Workers advances pediatric psychosocial oncology care for children, young adults, and their families through clinical social work practice, research, advocacy, education, and program development. Over the past several months APOSW has advocated for the children and families we serve regarding the future of healthcare by publishing a *Position Statement on Universal Health*

Coverage / Access to Affordable Care / Palliative Care / Psychosocial Care, which can be found on our [website](#). As a member organization of the Alliance for Childhood Cancer, we were able to sign on and support *H.R. 820/S. 292, The Childhood Cancer Survivorship Treatment, Access, and Research (STAR) Act of 2017*. Additionally, many of the children and families we serve participated in the Alliance's Childhood Cancer Action Days in Washington, D.C. advocating for all children and families touched by childhood cancer. APOSW is also actively involved with the Children's Oncology Group, an international cooperative group.

According to our Membership Chair, Wendy Shama, we are currently 338 members strong! Please consider joining forces with the Association of Pediatric Oncology Social Workers by renewing your membership. Encourage your colleagues to join or renew their memberships. Collectively our voices need to be heard in support of our children and families both in the United States and around the globe! **It's not about what APOSW can do for you, but what APOSW can do for those we serve.** We need everyone's support!

All the best,

Anita Graham, MSW, LCSW

Reflections on Oncology Camping

by Nancy Cincotta, LCSW, MSW, MPhil

Psychosocial Director, Camp Sunshine at Sebago Lake

A childhood cancer diagnosis challenges the homeostasis of the entire family in big and small ways. For each family member, that which is known and routine becomes new and unfamiliar, and even though individuals do acclimate, they never really return to their pre-diagnosis selves. In pediatric oncology social work, we understand that a “new normal” is formulated, but how do families live in that new place comfortably and find joy again?

Although the pediatric cancer journey is not one that any family would choose, many children, teens, or parents will tell you, “I would never have become the person I am, if not for this experience,” or “I would not have made the friends I have made, not had the experiences I have had, or not gained a perspective on life I now have.”

Many specialized programs in the oncology arena have emerged to provide families unique experiences during the illness journey, programs through which lasting family memories are made. In such environments, families can relax and be part of something that is illness-related, but that exists outside of chemotherapy, spinal taps, or scans. Such spaces afford moments to think, moments to “not” think, moments to re-energize, and moments to feel safe. Being away from the day-to-day medical regimen while being part of an understanding community can help families at every stage of their journey.

At Camp Sunshine at Sebago Lake, a family camp/respice program, we blend recreation, support and relaxation to foster the creation of that understanding community. Even if only for a week, everyone around you also lives in that illness world. You do not have to have your guard up, explain yourself, or pretend; you just have to be. After a week of exploring commonality and compassion, families are invigorated to once again entrench themselves in their day-to-day medical realities.

We hear from adults all the time that at Camp they are exposed to activities they have not participated in since before they had children, nonetheless before having a child diagnosed with cancer. By affording children, teens, and adults a unique camp experience with the rest of their family in arm’s reach, families are able to exist as individuals and group members, and share the day’s accomplishments with one another.

One day, when on route to the pool from the climbing wall, a quiet teen saw her parents involved in entertaining ice-breaker activities in the dining room. She stopped in the doorway and said, “My parents forgot to tell me that they know how to laugh.”

Programs that enable children and teens to find hope and joy amidst long or never-ending protocols give families something to look forward to through chemo days and hospital visits. At Camp, and I suspect in many other similar programs, there is a talent show, an evening of “unconditional support.” Everyone who performs, child or adult, is categorically accepted and applauded. The stage itself is transformative; children (siblings and children with cancer) may do things that their parents never expected. Parents may do things which embarrass their children. Pride, connection, laughter, and newfound talents become small (and large) pathways toward helping families feel “whole” again.



One of the ways that we, as pediatric oncology social workers, aid in the cancer journey is by helping families communicate, live, and connect by reminding them that they can have fun, and accept support. Within the context of that support, there is a sense of autonomy, competence, even freedom from the illness. At a program where everyone else is living with the same or a similar illness, families can be themselves, separated from their cancer selves, roles, and experiences.

This past week, I met a family in which child was diagnosed with a high-grade brain tumor (two months and one day before arriving). In the last discussion group, with other parents who were further down the road, the mother said, "I am looking at all of you, and I just want to know that I can get to the other side of this." The room embraced her, with an unequalled commitment of support, help, and hope.

Whether it is Camp Sunshine, or any of the many supportive programs around the country, when you refer

families, you are enabling fun and the creation of enduring memories, and you are increasing a family's network of support.

On the existential journey to find peace and experience joy again after diagnosis, we are pillars that help families find stability, helping them manage the arduous journey by enabling them to find the special moments that help them grow, help them cope, and help them find themselves. As we encourage families to reflect on the past, embrace the present, reframe their current experience, and rethink their future, we help them deal with cancer, one day at a time.

It is the combination of what we all do, in the hospital and outside of the doors of medical care, that really empowers families to endure as they navigate the childhood cancer experience, wherever the journey takes them. I applaud all of you as we each help, one family at a time, get to the other side. ■

Do you want to honor a colleague, mentor, or trainee?

Are you celebrating a milestone in your career?

Looking for a way to express your appreciation for APOSW?



Make a contribution to the HTR Scholarship Fund!

The Houston Tyler Rothschild Scholarship provides support for social workers, especially those new to the field of pediatric oncology social work, to attend the annual APOSW conference. Forty- five social workers have received the scholarship since 2005.

Donations can be made by credit card during online membership registration or by mailing a check to:

Jeanette Lavecchia, LCSW
St. Jude Children's Research Hospital
262 Danny Thomas Place
Mailstop 141, Social Work Dept.
Memphis, TN 38105

Checks should be made payable to APOSW with HTR Scholarship Fund in the memo line.