Greetings from the President,

As I sit down to write this I am reflecting on the month of March trying to enjoy the last few days of Social Work Month secretly wishing it wouldn’t end. It is nice to have a month to honor our profession. I hope you felt encouraged this month and feel proud of the work you do each day. It feels good to be appreciated and recognized for the value we bring to our setting, particularly when there are increased demands on our limited time. It had me wondering about how we can feel more of that positivity on a regular basis: How can we maintain the “post-Social Work Month Zen?”

One of the greatest challenges we face in our work is there is not enough time in the day to do all that needs to be done to meet the needs of our families, satisfy our medical teams, and fulfill the requirements of our departments. I have yet to meet a Social Worker in Pediatric Oncology who on a daily basis is able to cross everything off their “to do” list by 5:00pm. I think I can count on 1 hand the times I have actually accomplished that great feat. However, that feeling of always having more to do than we can possibly accomplish weighs on us and can steal the enjoyment from the work we are doing. Perhaps we need to reframe our own thinking… instead of focusing on all that needs to be done, we should focus on what we did accomplish today and consider the positive outcome of it. In our work with patients and families we: ask the questions that allow them to share their hearts, listen with compassion, help them to problem solve, equip them with knowledge so they can navigate their new world, and empower them so they can advocate for themselves and their children. We get to walk alongside people on this journey and help them cope with what is for many parents their greatest fear. On a daily basis most everything we do is an intervention that is in some way helping to make their journey smoother. What a great privilege.

If I begin to train myself to take the time to reflect on those positive accomplishments each day I suspect it would increase my productivity to manage all that needs to be done the next. So while I go home tonight later than I “should be” leaving, looking at my “to do” list which is coming off the page, I am going to choose to focus on the difference I made in the life of a young mother and her family today and maybe this is how I can hang on to the “good feelings” of this month.

I hope to see many of you in Montana.

Regards,

Anne Kosem, MSW, LCSW

Send newsletter submissions to:
Rachel Rogovin
rrogin@lifespan.org

Anne Kosem, MSW, LCSW
Membership Matters...it really does!
Wendy Shama, MSW, RSW, Membership Chair
The Hospital for Sick Children

I’m so thrilled that we have SO MANY NEW MEMBERS to APOSW since our last newsletter:

Beth Hurst
Lindsay Daehlin
Chelsea Kaye
Sarah Mendoza
Shannon Brown
Jennifer Greunke
Jackie Lake
Diane McGinnis
Amanda Guerra
Melanee McClary
Carol Highland-Fritz
Lindsay Nolan
Julia Garcia
Leigh Ann Schultejans
Erin Lauinger
Jennifer Lorencovtiz
Nicole Faye
Elizabeth Hardesty
Lorann Pierzchala
Adam Fortune
Anna Marshall
Rachel O’Farrell
Tricia Coleman-Waterbury
Christina McCarthy
Laurel Stanley Glynn
Nancy Morreale

Welcome to a Bassam Kamal, new member from Jordan, and welcome back to two renewing members from outside North America, Mary O’Rourke from Dublin, Ireland and Alta Bence from South Africa.

It’s very exciting to see so many people registering for the conference in Montana! It is sure to be incredible - with fabulous speakers and an incredible opportunity to connect with one another while enjoying the most amazing scenery! You will likely see deer walk right past our hotel!

Membership Matters…it really does! And that’s why I’d love to hear from all of you! Do you have any thoughts or ideas about your membership? Are you interested in being part of a group to brainstorm ideas about how to best engage our members? Please contact me directly wendy.shama@sickkids.ca

Member Happenings

Leah Forster Gauvin, LCSW from Primary Children’s Hospital in Salt Lake City, Utah has obtained her Oncology Social Work Certification (OSW-C). This month Leah will also obtain her graduate certificate in End of Life Care from the Smith College School of Social Work.

JOIN US FOR THE 39TH ANNUAL APOSW CONFERENCE:
SOCIAL WORKERS AS LEADERS IN ADVANCING PEDIATRIC PSYCHOSOCIAL CARE
MAY 13 - 15
WHITEFISH, MONTANA
REGISTER ONLINE.
In 2009, the world’s economic climate changed and the social work department at St. Jude Children’s Research Hospital was faced with increased quantity and urgency of requests for financial assistance. Often, the requests could not be met due to limited community/charitable resources, as these resources were also affected by the recession. Our practice of first come, first served was not working well. Some families were more “resource savvy” than others, asking for referrals to all available resources, without understanding or appreciating that this would deplete already scarce resources and leave other families without help. Staff also had philosophical differences on the fairness of limiting families’ referrals: if they were asking for assistance and were eligible, should we always submit? Also, St. Jude had never used formal means-testing to determine eligibility for resources.

The social work staff became significantly stressed due to some families’ perceptions that staff were withholding or unfairly distributing resources or requesting transfer to a different social worker. In this article, we will share the process that our department used to address these issues in a fair and equitable manner.

In an effort to meet the families’ needs, relieve staff distress, sustain harmony, and prevent burnout, we established a subgroup of our Social Work Practice Committee to examine the fair distribution of limited resources. Due to the lack of evidence in the literature, we surveyed eight similarly-sized pediatric oncology centers looking for standards in resource distribution. The results indicated that half of these centers were having similar issues. Hospitals dealt with the issue in several different ways: counseling with families, explaining resource limits, and using local options such as hospital or community-based funding. None of the hospitals surveyed used means-testing as criteria for referral.

The literature review did not provide solutions, but did offer some ethical guidelines. An ethicist was consulted to guide us as we formulated our departmental policies. He identified our stress as “ethical distress” and stated that it would be impossible for social workers to guarantee equality in distributing charitable community resources. Individual charities have their own eligibility criteria that automatically excludes some families, over which social workers have no influence or control. Also, the amount of assistance offered varies greatly among charities. As such, there is no way to give equal shares of resources, as they are inherently limited and unequal. However, we did determine that our social work staff could standardize the practice of informing families about resources and making referrals to charities.

The Practice Committee subgroup developed a financial resource handout to ensure uniform education for all families, providing a range of information, including cutting costs, accessing government benefits, and referrals to fundraising resources. Parents were educated about the scarcity of resources and frequent changes in eligibility criteria and were invited to discuss their concerns openly with their social worker. A script was developed to guide these talks with families. In addition, we developed a spreadsheet to track the use of resources in order to improve equal access. We educated organizations about the volume of need in our hospital. Some charities limited the number of applications accepted from our hospital to ensure resources remained available to other hospitals.

We recently surveyed the staff to look at their current perceptions. The results were mixed, however, most social workers seem to have a heightened awareness of these sensitive issues.
Serving Siblings of Children with Cancer
Super Sibs! Powered by Alex’s Lemonade Stand Foundation
Lisa Towry, Director of Programs and Services, ALSF

While the story of Alexandra “Alex” Scott, creator of Alex’s Lemonade Stand Foundation, may be well known, some may not know that beyond the lemonade stands that Alex held to find cures for childhood cancer, she has three brothers. It is not a stretch to say that Alex's battle against childhood cancer was, and remains, an integral part of their lives, which is why Alex’s Lemonade Stand Foundation, when approached, partnered with SuperSibs!, to take over this important program for siblings of childhood cancer fighters.

SuperSibs!, powered by Alex’s Lemonade Stand Foundation (ALSF), was first created in 2002 by Melanie Goldish, after seeing firsthand the unique journey siblings experience when a child is diagnosed with cancer. The program reached siblings far and wide, making a positive impact in their lives. In 2014, SuperSibs! transitioned to become part of ALSF, complementing the existing family resource program.

The SuperSibs! program is dedicated to comforting, encouraging and empowering siblings during their family's battle against childhood cancer. The program includes Comfort and Care Services, which are age appropriate mailings that provide tools to help siblings during and after the patient’s battle; Sib Spot, an online resource which includes activities and words of support for siblings; and the Sibling Ambassador Program, offering siblings the opportunity to share their stories and experiences with other kids, families and supporters. Parents can also share their SuperSibs!’ story on the Stories Section of SuperSibs.org.

Increased activity noticed on APOSW List Serve

The APOSW list serve has been very active this winter, featuring discussion on a variety of topics. Discussion of clinical practice has focused on distress screening, transition to adult care, collaboration with palliative care teams, and ethics surrounding parental decision-making. Other topics have included school resources, discharge planning, insurance issues, and advocacy news.

Thank you to all of the members who have posted to the list serve, or responded to a colleague’s request for information, support, and feedback. Our list serve is a wonderful benefit of APOSW membership and provides members with an opportunity to collaborate and consult with pediatric oncology social workers from around the world, outside of the annual conference.
Research News

Jaehee Yi, MSW, PhD, Research Chair
Assistant Professor, University of Utah College of Social Work

APOSW’s research agenda was the focus of much discussion at the Fall 2014 board meeting. As a product of that discussion, I have designed a long-term research project on compassion fatigue among pediatric oncology social workers. APOSW has partnered with social work students at University of Utah, and Kristin Frazier, APOSW’s Education and Professional Development Chair and pediatric oncology social worker at Children’s Healthcare of Atlanta, to form a research task force. Our Internal Review Board application has been approved and the task force is ready to begin.

During the first phase of the project we will conduct focus group interviews with APOSW members at the upcoming APOSW conference in Whitefish, Montana. We will soon be recruiting study participants who are interested in contributing to our understanding of this important issue, via an announcement on the APOSW listserve. We are very excited and look forward to active participation from the APOSW membership. Please contact me at jaehee.yi@utah.edu with any questions.

Should Social Networking Sites Be Used to Support Families?

Wade Iwata, LMSW, OSW-C
Director of Family Support Services, Children's Brain Tumor Foundation

Online support comes in a variety of ways from email support to online support groups, and most recently, social networking sites. Families confronted with illness often seek out information online to share clinical information and receive support. Greene et al. (2011) indicate patients search the internet more frequently than they ask their doctors health care questions. With the rise in online social networking sites such as Facebook and Twitter, people are often turning to these mediums to meet their medical needs. As social networks have been shown to improve disease management and health outcomes outside of the internet, will this be translational to the online social networking sites? When looking at Children’s Brain Tumor Foundation’s (CBTF) online presence, Facebook is well ahead of our other online mediums. Is Facebook the future of online support?

To date, there is little research on using social networking sites in a professional capacity. Professionals in the helping field are concerned with boundary issues related to such involvement with families and the ethical issues that may arise. However, some of the research coming out shows a benefit in utilizing these new mediums of engagement. Facebook’s popularity, currently estimated at over 1.4 billion registered users, is an opportunity for professionals to reach out, support, and offer reliable information to patients and their families seeking support online.
With social media penetrating the US population independent of education, race/ethnicity, or health care access as reported by Chou et al. (2009), the ability to interact with families is far greater than traditional engagement opportunities. Social networking sites provide opportunities for users to gain interpersonal and community support, access specialized knowledge from peers, and articulate positive yet realistic self-images of someone going through illness. Greene et al. (2011) further explain there is a number of individuals who repeatedly and regularly use Facebook as a forum for collective identity-building, emotional support, and informal disease management information. As a whole, Facebook and other social networking sites appear to provide a unique platform for professionals to reach families in a forum that is comfortable and tends to be easily accessible for them.

As with any new intervention or medium for engagement, there are growing pains and areas that need further exploration and development. Social networking sites allow for the publication of false and misleading information, little control over harmful or abusive content, and inability to regulate times of discussions. Additionally, professionals have access to information that may not be shared with them and must decide how or if to integrate the information in the work with the client. To address these types of situations, clinicians should be extremely clear with their clients about their professional role and the limitations to your online networking relationship. Finally, when a professional is on a social networking site, clients have access to information that may impact your relationship with them. Learning to balance your professional online self and personal self can be tricky. Consider using a professional profile or hiding your personal profile to protect information you want to keep private.

Here are some thoughts to consider when utilizing social networking sites as a professional:

**Boundary Issues.** Social networking sites allow clients to interact with you “outside” of the office/hospital which can create boundary issues. Identify what you are comfortable sharing with clients and what you are not.

**Confidentiality.** Clinicians should be cognizant of confidentiality issues and inform “friends” of their professional role on social networking sites.

**To Friend or Follow?** It is hard to know if or when you should become online friends with a client. Allow clients to contact you first and depending on your clinical expertise, decide if becoming friends with them is appropriate to your work together. If you decide not to be “friends” with them, explain your decision.

**Informed Consent.** Providing informed consent immediately after accepting a friend request encourages a professional relationship and clearly defines your role.

As professional roles on social networking sites are still being defined and reviewed, it is important to recognize the changing ways our society is sharing and gathering information. As a profession, it is important to utilize additional avenues to support the families we see day to day and to support them in ways which are helpful to them.

**References:**

**UPDATES FROM THE ALLIANCE FOR CHILDHOOD CANCER:**

As previously reported, I continue to serve as APOSW’s representative to the *Alliance for Childhood Cancer*, which has joined a policy roundtable with member organizations of CAC2 (Coalition Against Childhood Cancer) to work collaboratively on national legislative, administrative goals and actions.

After multiple meetings and conference calls we have concluded the first phase of our work and now have an action plan. As a member of the subgroup maximizing delivery: care, quality of life, survivorship, and caregiver support, I surveyed APOSW members via the list serve about barriers to obtaining services and procedures for survivors. Thanks to your input, our list was included as an action item in the final report, in order to seek payment solutions and to push for inclusion in COG’s standard of care for survivors.

The list includes, but is not limited to: neuropsych testing, fertility testing/treatment, dental coverage/implants, hearing aids, mental health services, post-treatment scans, access to needed referrals and survivorship internists, vitamin repleatement, nutrition counseling, hormone replacement, hair replacement, orthotics, and billable hours for survivorship programs.

Along with the *Alliance*, APOSW co-signed a letter to the members of the Childhood Cancer Caucus, led by Representatives Michael McCaul and Chris Van Hollen, to increase funding to NCI and NIH for childhood cancer. The letter lobbies to make funding for childhood cancer research a higher priority, in order to “continue the important work of the Children’s Oncology Group, the Pediatric Brain Tumor Consortium, the Pediatric Preclinical Testing Program, the pediatric “MATCH” trial and renewal of the Childhood Cancer Survivor Study,” among other things.

The *Alliance* will host the annual *Childhood Cancer Action Days* in Washington, DC on June 15 – 16th, which includes issues and advocacy training and pre-arranged visits to Congressional Representatives and their staff. The *Alliance’s* goal is to provide the childhood cancer community - parents, children, healthcare professionals and others - with the opportunity to visit their legislators and advocate for the important childhood cancer issues currently before Congress. 250 parent and professional “Advocates” participated last year from around the country.

APOSW members can encourage parents who want to take their advocacy to the next level, to make a difference by carrying their message directly to members of Congress. For more information or to make a reservation under "Alliance Childhood Cancer Action Days", please use this link.

**IMPORTANT: CHILDREN’S HEALTH COVERAGE**

More than 3.3 million children could lose their health care coverage if Congress does not renew the Children’s Health Insurance Program or if the Supreme Court strikes down subsidies in the federal marketplace and states scale back coverage. Read full article on potential impact in Roll Call of the *Congressional Quarterly*.
The Alliance for Quality Psychosocial Cancer Care, of which APOSW is a member, has released its 2015 update of the Resource Guide for Patient Centered Practices. The comprehensive guide delineates standards and provides a listing of national, state and local resources.

The Alliance for Quality Psychosocial Cancer Care’s mission, "to ensure psychosocial care is integrated into the medical standard of care for people with cancer," is based on recommendations of the IOM’s report, Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.

APOSW members can contribute to the 2016 guide by suggesting additional resources related to childhood cancer. Email Julie Taylor at jtaylor@cancersupportcommunity.org with information.

INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES

IOM’s National Cancer Policy Forum & American Cancer Society Hosted March Workshop: "Comprehensive Cancer Care for Children and Their Families"

Children’s Cause for Cancer Advocacy reports that “a recurring theme throughout the two-day event was the need for integrated, patient-centered cancer care and maximum cooperation among stakeholders. Family advocates in attendance shared powerful personal stories that revealed wide disparities among pediatric hospice programs, as part of a compelling panel on palliative care and quality of life issues. Other topics included patient-reported outcomes, funding needs, data collection, the impact of poverty, and more.” Full presentations from the event can be viewed online.

COMMITTEE MEMBERS WANTED:

COMMUNICATIONS AND SOCIAL MEDIA
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RESEARCH AND PUBLICATION
jaehee.yi@utah.edu

QUALITY OF LIFE
elevinrussman@partners.org

APOSW wants to hear your perspective. Join us at our annual committee meetings in Whitefish, Montana or email committee chairs to share your voice and become involved. We look forward to hearing from you!
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The Matthew Larson Foundation for Pediatric Brain Tumors