A welcome note from the Chairs
by Martha Grootenhuis, Claire Wakefield, and Lori Wiener

Happy new year and welcome to the third Issue of the POPPI Newsletter: Pediatric Psycho-Oncology Professionals/Providers International!

The goals of POPPI are to stimulate international communication among professionals with a diversity of clinical and research backgrounds in order to foster collaboration in clinical care, research and education that relate to pediatric psycho-oncology, and to share resources, training opportunities, ongoing research, and upcoming events in the field of pediatric psycho-oncology.

Our hope is that this newsletter will provide information which will bring our field closer together and help each of us to deliver the highest quality of care to youth with cancer and their families.

In this issue:
Page 1: Welcome from the Chairs
Page 2: Research “in the spotlight”
Page 3: Bright IDEAS problem solving skills training
Page 3: World Health Organisation initiative
Page 4: Psychosocial standards of care update
Page 4: Upcoming PPO international conferences
Page 5: PPO theses from around the world
Page 6: Recent PPO publications from PBC & Psycho-Oncology + highlighted article
Research “in the spotlight”
Researcher in the spotlight: Dr Benedict Akimana

By Dr Benedict Akimana

Dr Akimana is a psychiatrist at National referral mental hospital in Uganda, he shares with us his role in establishing the first psycho-oncology service in Uganda/East Africa.

Hi! My name is Benedict Akimana, I am a psychiatrist from Uganda passionate about the mental health of persons with cancer especially the children.

My journey into psycho-oncology was sparked off by an event in December 2014. As I passed by the Paediatric oncology unit of the Uganda Cancer Institute, I saw a 13-year-old girl that looked very sad.

The attendants and staff were so distressed about her poor compliance to medication. I was allowed to talk to her and I found that she was severely depressed, and had lost the desire to live. I took her into care and immediately started her on treatment. This got me thinking about how many more patients with cancer are like her and what was being done for them. I therefore set out to study the prevalence of, and factors associated with, depression in child and adolescent cancer patients. Findings from the study showed that 26% of 352 young cancer patients assessed met criteria for clinical depression.

My study findings enabled me to start a drive to integrate mental health into the routine care of cancer patients in Uganda, and I am proud to say that we have gotten the administration of the Uganda Cancer Institute on board to support the establishment of a psycho-oncology unit. Currently they have provided funding to enable myself and a colleague to obtain further training in psycho-oncology and starting January 2019 we have been provided with space and staff to start the psycho-oncology service.

I am thrilled to be championing the psycho-oncology service in Uganda/East Africa and I look forward to promoting the mental health of persons with cancer especially the children.

Research project in the spotlight: family adaptation and cancer

By Lynn Fainsilber Katz

Having a child with cancer affects individuals and relationships within the family unit. However, which family members and relationships are most affected? When is distress highest during the treatment process? And how does the cancer experience contribute to these difficulties?

With funding from the National Cancer Institute, my research has focused on understanding family adaptation when a child has been diagnosed with cancer. In a short-term longitudinal study with monthly assessments over the first year of pediatric cancer treatment, we have investigated trajectories of marital, parent-child and sibling conflict, trajectories of caregiver and child psychological adjustment, and how various stressors are associated with these outcomes.

What have we learned?
Across the first year of treatment, caregivers experienced high levels of psychological distress while most children did not. For married caregivers, 25-36% of couples scored in the distressed range at each month over the first year of treatment, with more marital distress occurring at earlier months.

For parent-child and sibling dyads, overall conflict was low but the most difficult time periods were during later months.

To better understand how the cancer experience affects family relationships, we examined whether and how various stressors were associated with marital adjustment and sibling conflict over time. We found that when families experienced more frequent negative life events, treatment-related stressors and financial strain relative to others, they tended to have higher levels of sibling conflict and lower marital adjustment over time.

Taken together, these findings suggest that some family relationships are strained during the first year of cancer treatment, and that these difficulties may in part be explained by stress. While many stressors cannot be prevented, interventions targeting coping skills and stress management may lessen negative downstream effects on family relationships and reduce associated psychological distress in caregivers.

Bright IDEAS
Problem solving skills training in pediatric psycho-oncology: NCI Funded Workshops

By Robert Noll

Over the course of the past 25 years an interdisciplinary group of pediatric psycho-oncology professionals have been developing an evidence based intervention to teach coping skills and alleviate distress in caregivers of children recently diagnosed with cancer. With 1400+ caregivers we have demonstrated Bright IDEAS is acceptable and effective. Teaching coping skills leads to less distress, and parents can be better advocates for their children. This approach empowers caregivers.

Our efforts have been so successful that the National Cancer Institute (NCI) has awarded a grant to support the dissemination of Bright IDEAS. The NCI dissemination of Bright IDEAS has occurred over the past 3 years. Professionals who have received this training have been able to use Bright IDEAS for caregivers at any time during their child’s treatment, and with adolescents and young adults. It has also been used within palliative care and survivorship.

The grant supports up to $1000 in travel and lodging costs to attend a 1.5 day workshop training you to use Bright IDEAS and receive 4 follow-up phone consultation sessions with workshop leaders to support effective use of Bright IDEAS. The attached flyer, at the end of the newsletter, describes the opportunity at the Association of Pediatric Oncology Social Workers (April, 2019) and Children’s Oncology Group (September, 2019).

Availability is limited. These are the final workshops funded by this grant so we encourage early applications: https://redcap.ucdenver.edu/surveys/?s=9SwqcbJH6r

World Health Organisation initiative
Towards a global plan for psychosocial care for children with cancer & their families

By Claire Wakefield & Lori Weiner

We are excited to share that the World Health Organization (WHO) is focusing on children with cancer, through its Global Childhood Cancer Initiative. The WHO’s Global Childhood Cancer Initiative developed out of the United Nations’ 2030 Sustainable Development Goals, the 2017 World Health Assembly targets and the Post-2015 Millennium Development targets. While communicable and preventable non-communicable diseases remain the focus in each of these documents, children’s health priorities have increasingly moved to the forefront of humanitarian attention, allowing space for such an initiative. The inaugural meeting for the initiative was held in Geneva in August 2018, with a follow-up meeting in Kyoto in November.

The Initiative brings together experts in childhood cancer from around the globe, and importantly includes psychosocial representatives, including Claire Wakefield, Martha Grootenhuis and Lori Wiener, representing IPOS, SIOP and APOS. The disparity in outcomes for children with cancer across countries is stark. In fact, when researchers speak of paediatric cancer survival rates, more often than not they are referring to survival rates in countries with access to well-developed hospitals and comprehensive care. Professor Wakefield notes: “While we often celebrate that survival rates of children with cancer have increased to more than 80%, this does not recognize the much lower survival rates for children with cancer in low and middle income countries.”

Despite the focus of the inaugural meeting directed towards developing strategies to increase childhood cancer survival rates, the overall Global Initiative target now also includes the goal of the elimination of suffering of children with cancer worldwide. Our next goal will be to encourage the initiative to review (and adapt where necessary) the Psychosocial Standards of Care for children with cancer, particularly the Standards that recommend screening families for psychosocial and financial distress, ensuring access to continued schooling and facilitating access to effective pain management and palliative care.

We will keep the POPPI readers up-to-date with ongoing developments in the initiative and will continue to advocate for increased focus on, and treatment for, psychosocial challenges faced by children with cancer, and their families, worldwide.
Psychosocial Standards of Care Update

Evidence-based standards of care to be updated with implementation strategies

By Lori Wiener

The 15 published pediatric psychosocial oncology evidence-based standards of care continue to receive endorsements from professional and community-based organizations.

They also continue to be some of the most downloaded papers in Pediatric Blood & Cancer. Yet, we often hear that cancer centers are unsure how to implement the standards in their programs.

The standards were purposively written broadly in order to make them feasible for programs of different sizes and resources to implement. It seems what would be most helpful at this point, is for centers to be given suggested implementation strategies.

In response, and with the help of many devoted colleagues, and in collaboration with the Mattie Miracle Cancer Foundation, an institutional assessment tool (matrix) was developed for sites to use to determine/measure (on a 1-5 scale) how well they are implementing each of the standards.

Accompanying the matrix, individual guidelines are being developed for each standard. The matrix and guidelines will be reviewed by psychosocial experts in February and March and will undergo further review at the APOSW Conference in April.

The guidelines include strategies and resources/tools to help sites improve their score on the matrix and enhance their current practice. POPPI readers will be kept up-to-date with our progress in future newsletters.

The original guidelines can be accessed from: https://onlinelibrary.wiley.com/doi/full/10.1002/pbc.25675

PPO conference news

Upcoming PPO conferences

SAVE THE DATE!

- **APOS**: February 28 - March 2, 2019 in Atlanta, Georgia USA.
- **SPPAC**: April 4-6, 2019 in New Orleans, Louisiana, USA.
- **APOSW**: April 8-10, 2019 in Phoenix, Arizona USA.
- **IPOS**: September 23-26, 2019 in Banff, Canada.

**APOS 16th Annual Conference**

The conference will be held Feb 28th-Mar 2nd, 2019 in Atlanta, Georgia and the theme is: ‘We’re All In This Together: Bringing Together Diverse Perspectives, Professionals and Programs’.

Pediatric, adolescent and young adult oncology content will be presented throughout the conference. A sample of sessions that might be of interest to POPPI readers are listed at the end of the newsletter, and include financial toxicity, standards of care, quality of life, and end of life care. The Pediatric Psychosocial Standards of Care session will feature the first research funded by Mattie Miracle Cancer Foundation.

The research addresses 6 of the pediatric psychosocial standards including an intervention for parents (Dr. Kimberly Canter), siblings (Dr. Kristin Long), bereavement (Dr. Gillian Regan), palliative care (Dr. Marie Barnett), medication adherence (Dr. Alexandra Pishogios), and school re-entry (Dr. Kathryn Kirkpatrick).

The session will conclude with a panel discussion facilitated by Victoria Sardi-Brown and Peter Brown.

- **16th International Conference of Long-Term Complications of Treatment of Children and Adolescents for Cancer**: June 20-22, 2019 in Atlanta, USA.
- **SiOP**: October 23-26, 2019 in Lyon, France.
- **ISOQoL**: October 20 - 23, 2019 in San Diego, California, USA.

**APOSW 43rd Annual Conference**

The conference will be held April 8th-10th, 2019 in Phoenix, Arizona and the theme is ‘Embracing the Diverse Landscape of Pediatric Oncology Social Work’. Learn more about APOSW [here](#).

There will also be a half day preconference workshop, titled: “Addressing the Needs of the AYA Population Across the Treatment Trajectory” hosted by Lori Wiener, PhD and Stacy Flowers PsyD.

Content of the workshop will include an overview of issues unique to working with the AYA population across the treatment trajectory (initial diagnosis, survivorship, end of life). Clinical tools, interventions and resources to support patients and families will be reviewed.

Topics covered involve enhancement of coping and adjustment, communication, and legacy building.

Learn more about APOS [here](#).
The recent 20th International Psycho-Oncology Society (IPOS) World Congress of Psycho-Oncology was held 29 October - 2 November 2018 in Aberdeen, Hong Kong and was a great success! The theme for the conference was Optimizing psychosocial supportive services in cancer care. There was an exceptional turnout from delegates from all around the world, including low and middle income countries.

Pre-conference workshops and several noteworthy presenters provided updates on the psychosocial needs of diverse populations and disadvantaged groups globally.

Another key focus of the Congress was translational research, including strategies for designing and conducting implementation trials. The IPOS pediatric SIG has had a productive year, including celebrating the launch of Dr Joanna Breyer’s book, called “When Your Child Is Sick”.

The Congress also featured two heart-felt tributes to the loss of dear friends and colleagues, Dr Jimmie Holland and Dr Andrea Patenaude, which were very well attended. Both Andrea and Jimmie were passionate about the well-being of children with cancer and their families and will be missed.

50th SIOP Congress 2018
By Martha Grootenhuis & Sasja Schepers

Last year marked the 50th birthday of the International Society of Pediatric Oncology (SIOP). Lots of good things happened within the SIOP PPO community in 2018. First, the POPPI newsletter that was launched in 2018 reflects the memorandum of understanding that was signed by SIOP and IPOS to facilitate closer collaboration between these two groups with similar missions.

Second, next to the already sitting SIOP PPO committee members Martha Grootenhuis (the Netherlands), Maria McCarthy (Australia), and Stephen Sands (USA), three new members have joined the committee: Fiona Schulte (Canada), Christopher Recklitis (USA), and Sasja Schepers (the Netherlands). Finally, pediatric psycho-oncology topics were well represented on the SIOP conference held November 16-19 2018 in Kyoto, Japan. The SIOP PPO pre-conference educational day was well-attended and covered state-of-the-art sessions on ‘Genomics and Precision-Medicine’, ‘Survivorship’ ‘Parenting Issues’, ‘Neuropsychology’, ‘Adolescents and Young Adults’, ‘Interventions’, and ‘Sleep’. In addition to the PPO educational day, we also had two PPO free paper sessions, poster discussion sessions, a very successful symposium organized by our PPO committee on ‘Cultural Differences in Truth Telling to Children’, and a PPO keynote on ‘Sleep’.

Dr. Sean Phipps presenting on resilience and growth on the SIOP PPO educational day in Japan

PPO theses from around the globe
International PhD Candidates and recent graduates in the field share their theses

By Hanan Salem, Denmark


Parents of children with cancer face one of the most stressful life events: the threat of losing their child. Cross sectional studies have shown that many parents, survivors and siblings experience psychological distress, even years after ending treatment. The aim of my thesis was two-fold.

First, in a nationwide registry-based study we investigated the risk for prescription of psychotropic drugs as an indicator of psychological stress among parents whose child has been diagnosed with cancer compared to other parents. Second, we developed FAMOS (FAMily Oriented Support), a home-based psychosocial intervention for the whole family after ending medical treatment. The study was conducted as a national randomized controlled trial and included 109 families.

The intervention consisted of a six-session program for parents, siblings and children with cancer.

This home-based psychological intervention showed promising feasibility and parental satisfaction. Results of both studies will be published this year. Together, these two studies provide important knowledge for health professionals in order to include psychosocial support in follow-up guidelines in survivorship clinics, and prevent long term psychological consequences of childhood cancer on the parents.

We will share the link to results of Hanin’s thesis in a future POPPI newsletter.
**Recent PPO publications**

Recently published articles in *Psycho-Oncology* (official journal of APOS and IPOS) and *Pediatric Blood & Cancer* (official journal of SIOP):


**Contact us** if you would like to feature your PhD thesis in the next issue of the POPPI newsletter, or if you know any students who have recently submitted in the field.
Our most recent study was based on a sample of 2802 cancer survivors from the Childhood Cancer Survivor Study (CCSS) who completed two measurements of positive outlook, the Posttraumatic Growth Inventory and the Cantril Ladder of Life Scale for posttraumatic growth (PTG) and life satisfaction (LS), respectively. The sample consisted of survivors diagnosed before age 10 and following for almost 15 years through adolescence to adulthood.

We found that childhood cancer survivors report a generally positive impact from their cancer experience and are mostly satisfied with their life as young adults. Cancer survivors who reported high PTG were more likely to be older when diagnosed, be diagnosed with blood and solid cancers, have more severe health conditions, and have cancer recurrence. Interestingly, survivors with higher PTG perceived their health as worse with more emotional problems roughly five years later. However, survivors who were satisfied with their life as young adults reported less anxiety, depression, and pain, and perceived their health more positively five years later. They were also more likely to have higher social skills as adolescents. Our study identified that satisfaction with life is a worthy pursuit for survivors and can help the hundreds of thousands of survivors protect themselves from anxiety, depression, and somatization.

HIGHLIGHTED PPO ARTICLE:


By Aurélie Weinstein

Childhood cancer survivors can be challenged with diminished health and psychological distress, yet often still portray a positive perspective on their lives. Our goal has been to understand the origin of their positive outlook and determine if this positive outlook can help protect survivors from future health or mental challenges as they mature. If we can understand this link between positive psychology and improved outcomes, we might be able to design therapies at the time of cancer treatment to impact long-term quality of life.

Our most recent study was based on a sample of 2802 cancer survivors from the Childhood Cancer Survivor Study (CCSS) who completed two measurements of positive outlook, the Posttraumatic Growth Inventory and the Cantril Ladder of Life Scale for posttraumatic growth (PTG) and life satisfaction (LS), respectively. The sample consisted of survivors diagnosed before age 10 and following for almost 15 years through adolescence to adulthood.

We found that childhood cancer survivors report a generally positive impact from their cancer experience and are mostly satisfied with their life as young adults. Cancer survivors who reported high PTG were more likely to be older when diagnosed, be diagnosed with blood and solid cancers, have more severe health conditions, and have cancer recurrence. Interestingly, survivors with higher PTG perceived their health as worse with more emotional problems roughly five years later. However, survivors who were satisfied with their life as young adults reported less anxiety, depression, and pain, and perceived their health more positively five years later. They were also more likely to have higher social skills as adolescents. Our study identified that satisfaction with life is a worthy pursuit for survivors and can help the hundreds of thousands of survivors protect themselves from anxiety, depression, and somatization.
A sample of sessions that might be of interest to POPPI readers are listed below.

**SESSION TITLE: Financial Toxicity in Pediatric Cancer: Prevalence, Risk-Factors, and Consequences.**

**Speakers:**
- Kaitlyn Fladeboe (Chair), “Perceived Financial Strain Predicts Caregiver and Child Adjustment During the First Year of Pediatric Cancer Treatment”
- Melanie Zeppel, “The Financial and Quality of Life Costs of Childhood Cancer and Precision Medicine in Australia”
- Liana Galtieri, “Caregiver Perceptions of Financial Strain During Pediatric Cancer Treatment: Change Over Time and Predictors of Risk”
- Sheila Santacroce, “A Conceptual Model to Guide Interdisciplinary Collaboration in Evidence-Informed Practice and Research to Identify and Mitigate Financial Toxicity in Pediatric Oncology”.

**SESSION TITLE: Pediatric Psychosocial Standards of Care: A Review and Discussion of In-Progress Research Projects on Implementation of the Standards** (based on Mattie Miracle Cancer Foundation funding)

Lori Wiener (Chair)

**Speakers:**
- Kimberly Canter (Key Presenter), “Community Implementation of eSCCIP: A Psychosocial eHealth Intervention for Parents of Children with Cancer”
- Kristin Long, “On the Outside Looking In: A Nationwide Examination of Barriers to and Facilitators of Implementing the Standard of Psychosocial Care for Siblings of Children with Cancer”
Gillian Regan, “A Novel Online Support Group for Bereaved Pediatric Cancer Caregivers: An Update on Data Collection and Dissemination”

Marie Barnett, “Team-Based Integration of Palliative Care in Pediatric Oncology Practice: Implementing the Pediatric Psychosocial Standards of Care”

Alexandra Psihogios, “Real-Time Medication Adherence Assessments among Adolescents and Young Adults with Leukemia”

Kathryn Kirkpatrick, “Evaluation of a Tiered Service Model to Support Academic Continuity and School Re-Entry for Children with Cancer”

Victoria Sardi-Brown and Peter Brown (Discussants)

SESSION TITLE: Developing and Refining Conceptual Frameworks for Patient-Centered, Health-Related Quality of Life Domains among Adolescents and Young Adults with Cancer

John Salsman, (Chair)

Speakers:

Suzanne Danhauer, “Conceptualization of Financial Burden in Adolescent and Young Adult Cancer Patients”

Justin Moore, “Conceptualization of Body Image in Adolescent and Young Adult Cancer Survivors”

Mollie Canzona, “Understanding Fertility and Parenthood Concerns Among Adolescent and Young Adult Cancer Patients”

Brad Zebrack, Discussant

SESSION TITLE: Pediatric Special Interest Group Meeting, including a presentation by: Tammi Young-Saleme on ‘Bereaved Parent Perceptions of Care at the End of their Child’s Life’

POSTERS

Breaking Down Virtual and Physical Walls: Multi-Site Interdisciplinary Collaboration to Enhance the Care of Adolescents and Young Adults with Cancer. Julie Germann, Caitlin Murphy, Madhuri Vusirikala, Mona Robbins, Hsiao Li

Promoting Resilience in Stress Management (PRISM): A Prevention Model for Psychosocial Care - Nancy Lau, Miranda Bradford, Angela Steineck, Samantha Scott, Claire Wharton, Joyce Yi-Frazier, Abby Rosenberg

Engaging with Online Communities to Recruit Pediatric Cancer Caregivers to Research. Kelly Tan, Mary Killela, Shawn Kneipp, Jill Leckey, Sheila Santacroce

Integrative Review Examining the Development and Testing of Mobile Apps Targeting Adolescent and Young Adult Cancer Patients and Survivors. Casey Walsh, Abby Rosenberg, Karen Syrjala
The evidence supporting Bright IDEAS is clear:

- 25 years of research testing
- Successfully implemented with >1200 caregivers of children recently diagnosed with cancer
- Dramatic & sustained improvement in caregiver well-being
- Identified by the National Cancer Institute as one of a select group of Research-tested Therapies and Intervention Programs (RTIPS)

Our goal is to make Bright IDEAS available at every childhood cancer setting. The NCI is supporting a new national training program to make that happen.

Convenient
- 1½ day workshop
- 2019 workshops: April 6-7 in Phoenix, AZ at APOSW & September 9-10 in Atlanta, GA at COG
- These are our LAST workshops!

Economical
- Training fees have been waived
- Travel expenses reimbursed up to $1,000 for the first 20 participants per session
- CE’s available

Peer & Professional Support
- Training conducted in partnership with COG, APHON, APOSW, and SPP.
- Mentored case consultation during the first 6 months after training

For questions contact: Robert Noll at nollrb2@upmc.edu