A welcome note from the Chairs

by Martha Grootenhuis, Claire Wakefield, and Lori Wiener

Welcome to 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: Brief biography about the Chairs
Page 2: Remembering Andrea Patenaude and Jimmie Holland
Page 3: PPO conference news
Page 5: PPO theses from around the world
Page 5: Recent PPO publications from PBC & Psycho-Oncology
Page 6: Highlighted article and upcoming book publication
Page 7: Personal memories of Andrea Patenaude
Dr. Martha Grootenhuis is a Professor at the Emma Children’s Hospital/Academic Medical Center in Amsterdam, the Netherlands and has worked there since 1992. She built a research group on pediatric psychology with a special focus on psychosocial oncology.

Dr. Grootenhuis works on studies in order to identify problems at an early age and stage, and on interventions to improve psychosocial functioning and quality of life. Her research relies increasingly on web-based applications for patients and their families.

Dr. Grootenhuis is founder and chairwoman of the Pediatric Psycho-Oncology Committee (SIOP-PPO) of the International Society of Pediatric Oncology (SIOP) and has organized the SIOP-PPO meetings during the annual SIOP conference since 2008.

She contributed to the development of standards for the Psychosocial Care of Children With Cancer and Their Families, published in a special issue of Pediatric Blood and Cancer. In 2015, she transferred partly to the Princess Máxima Center for Pediatric Oncology in Utrecht, the Netherlands. She was recruited to build a national program for pediatric psychosocial oncology research and healthcare innovation.

Dr. Claire Wakefield is a Professor at UNSW Sydney. She leads the Behavioural Sciences Unit, which is based at the Kids Cancer Centre at Sydney Children’s Hospital, Australia.

Dr. Wakefield’s research aims to address the needs to meet the needs of children and young adults affected by cancer, and their families. She currently coordinates several randomized controlled trials and psychological/behavioral interventions. Her focus is on developing strategies to prevent poor mental health in those most at risk through the use of evidence-based interventions and novel technologies.

Dr. Wakefield has a particular interest in the impact of genetics, genomics and precision medicine on children. She is committed to translating her research into clinical practice and has played a key role in the development of resources and changes in policy to improve the lives of families affected by cancer.

Dr. Wakefield holds several key leadership roles, including being Chair of the Pediatrics Special Interest Group for the International Psycho-Oncology Society. She is a Diamond Jubilee International Visiting Fellow at the University of Southampton, UK.

Dr. Lori Wiener is co-director of the Behavioral Health Core and Head of the Psychosocial Support and Research Program at the pediatric oncology branch of the National Cancer Institute (NCI/NIH).

As both a clinician and behavioral scientist, Lori has developed a robust clinical and research program that has focused on clinical issues such as distress screening, lone parenting, transnational parenting, preparation for amputation, sibling donation, graph-versus-host disease, and adolescent end-of-life planning.

Dr. Wiener has also dedicated a substantial part of her career to applying knowledge from her clinical experience and psychosocial studies to create innovative resources such as workbooks, therapeutic games and an advance care planning guide for adolescents and young adults.

Dr. Wiener has co-edited the Pediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management, 2015 and Pediatric Psychosocial Oncology: Textbook for Multi-disciplinary Care, 2015. She has been part of the leadership team that has developed the first evidence-based psychosocial standards of care for children with cancer and their family members.

In Memoriam: Jimmie Holland, MD

By Lori Wiener

Dr. Jimmie C. Holland, a renowned psychiatrist and tireless advocate for supporting the emotional and psychosocial needs of people with cancer was considered a founder of the field of psycho-oncology.

Dr. Holland created the nation’s largest training and research program in psycho-oncology at Memorial Sloan Kettering Cancer. In 1984, she produced the 1st syllabus on psycho-oncology and co-founded the International Psycho-Oncology Society (IPOS). In 1986, she founded the American Psychosocial Oncology Society (APOS), edited the 1st (1989) and each subsequent edition of the authoritative textbook Psycho-Oncology and was a founder and co-editor-in-chief of the leading journal for our field, Psycho-Oncology until her death.

In 2000, Dr. Holland published the landmark book, “The Human Side of Cancer,” written with Sheldon Lewis. You might remember seeing Dr. Holland featured on the 2015 PBS documentary “Cancer: The Emperor of All Maladies,” based on the Pulitzer Prize-winning book by Siddhartha Mukherjee. While Dr. Holland’s attention in her later years was with geriatric cancer, she held a tender heart and true commitment to the psychosocial care of children living with cancer worldwide.

She herself had lost a grandchild to cancer.

The May 2018 issue of Psycho-Oncology will be dedicated to Jimmie Holland.
In Memoriam: Andrea Farkas Patenaude, PhD
By Lori Wiener & Claire Wakefield

This is an excerpt from: Wiener L. In Memoriam: Andrea Farkas Patenaude, PhD. Psycho-Oncology. 2018;27(4):1357-1358.

Dr. Andrea Farkas Patenaude, a visionary and internationally renowned clinician and thoughtful clinical researcher had a significant impact on the field of psycho-oncology. Dr. Patenaude’s early career focused on children with cancer undergoing bone marrow transplantation (BMT).

Her excellent clinical skills and leadership abilities were well known and she was the Director of the Jimmie Fund Clinic of the DFCl Pediatric Psychology Program from 2000-2011, providing psychosocial services to children with cancer, their parents, siblings and survivors of pediatric cancer.

From 2011 until her retirement, Dr. Patenaude was the Director of Psychology Research and Clinical Service, in the Center for Cancer Genetics and Prevention where she developed a unique hereditary cancer psychosocial clinic to support and treat members of these high-risk families.


Amongst many other leadership roles, Dr. Patenaude co-chaired the Pediatrics Special Interest Group for the International Psychosocial Oncology Society (IPOS) and was a member of the Scientific Committee of the International Society for Pediatric Oncology (SIOP). She coordinated collaborative efforts between IPOS and SIOP to shine a light on human rights abuses involving the treatment of cancer in children globally, and particularly in Africa.

While promoting psychosocial research, Dr. Patenaude was a clinician at heart. She supported PROs but emphasized the importance of the clinical interview.

Her leadership and original contributions to the field of psychosocial oncology was complemented by her tremendous warmth, quiet manner, and ability to address pertinent questions, that went right to the heart of the issue, and that others found uncomfortable to explore.

It is no surprise that Dr. Patenaude was the recipient of many awards including the Noemi Fisman Award for Lifetime Clinical Excellence from the International Psycho-Oncology Society in 2013, a Presidential Citation from the American Psychological Association (1999), the Rosalee G. Weiss Award from the American Psychological Foundation (1999) and the 50th Anniversary Scholars in Medicine Award from Harvard Medical School (2000). Andrea Farkas Patenaude retired from the Dana-Farber Cancer Institute on August 31, 2017 after more than 40 years of service to the cancer care community.

She died peacefully on January 29th, 2018 surrounded by her family. We will miss her warm presence, colorful clothes, generous spirit, and contagious smile. Her contributions to the field of Psycho-Oncology will live on for generations to come.

Andrea’s family have named National Ovarian Cancer Coalition as a place to support if anyone would like to donate in Andrea’s memory. They are located in 3800 Maple Ave, Suite 435, Texas Dallas 75219.

To help us remember Andrea, some of her friends and colleagues have contributed a personal memory of Andrea which can be found at the end of the newsletter.

PPO conference news

Overview of upcoming PPO conferences

- **SPPAC**: April 5-7, 2018, Orlando, Florida, USA
- **APOSW**: April 11-13, 2018, Austin, Texas, USA
- **MASSC**: June 28-30, 2018, Vienna, Austria
- **ISPNO**: June 29 - July 3, 2018, Denver, Colorado, USA
- **EPPE**: September 20-21, 2018, Ghent, Belgium
- **IPOS**: October 31- November 2, Hong Kong
- **ISOqi**: 24-27 October 2018, Dublin, Ireland.
  - **PHO meeting**: 28-29 October
- **SIOP**: November 16-19, 2018, Kyoto, Japan
50th SIOP Congress 2018
The Congress of the International Society of Pediatric Oncology (SIOP) will take place in Kyoto, Japan 16-19 November 2018. This is a particularly special Congress, as SIOP celebrates their 50th anniversary. Abstracts are due 10th April 2018.

SIOP PPO educational day
The SIOP PPO educational day will be held on November 16, 2018. Abstracts will be managed through SIOP and should be submitted in the main system under the category “psychosocial PPO”.

Top abstracts may be chosen for presentation on the educational day or in the main SIOP program.

News from the DIV54 hematology/oncology/BMT SIG chair
By Amanda Thompson
The Hem/Onc/BMT SIG will be holding its annual meeting and student symposium at the Society of Pediatric Psychology Annual Conference in Orlando Florida on Friday April 6th from 6:15-7:15pm. Poster awards will be presented to outstanding student submissions. We’re excited to announce incoming leadership members for the 2018-2020 term, including Oncology Co-Chair, Jordan Gilleland Marchak, PhD, ABPP; Member-at-Large for Advocacy, Claire Russell, PhD; and Members-at-Large for Education and Training, Kristin Long, PhD and Molly Gardner, PhD.

They will be joining existing SIG leaders, Hematology Co-Chair, Soumitri Sil, PhD; Member-At-Large for Research, Cynthia Karlson, PhD; and Communications Webmaster, Jeffrey Karst, PhD.

IPOS 2018 Symposium in memory of Andrea Patenaude, PhD
A symposium will be held this year at the International Psycho-Oncology Society (IPOS) World Congress as a tribute to the loss of our dear friend, colleague, and mentor, Dr Andrea Patenaude.

The symposium will feature invited international speakers in the field. The Congress will be held in Aberdeen, Hong Kong on 31 October - 2 November 2018. Abstracts are due 6th April 2018.

APOS Conference update
By Lori Wiener
APOS had a very successful meeting on February 22-24th. The pediatric SIG is working together on a study, “The End-of-Life and Bereavement Care Support Practices of Medical Institutions” expected to be completed in April-June 2018.

At APOS, the 1st Mattie Miracle Cancer Foundation grant was announced. This is being offered to graduate students and young investigators for research that aims to help implement any of the 15 published pediatric psychosocial standards of care. An LOI is due on April 10th, 2018. To find out more, please visit this information page.

APOS Poster Awards
Congratulations to this year’s APOS SPP Poster Award winners!
Kathy Ruble, Lisa Jacobson and Juliana Pare-Blagoev - Thinking Outside the Clinic: Returning to School After Diagnosis with Childhood Cancer
Sima Zadeh & Rachel Tunick - The Reality of Supportive Care in a Virtual World

SPARCCC Summit
By Kristin Long
In March 2018, the Sibling Partnership for Advocacy, Research and Care in Childhood Cancer (SPARCCC) hosted a two-day International Sibling Summit in Chicago, USA.

This Summit, their second funded by Alex’s Lemonade Stand Foundation, built upon a November 2016 Summit in which attendees discussed current gaps in the literature and identified four main areas necessary for moving sibling support efforts forward: 1) screening siblings for psychosocial risk; 2) calculating costs of sibling adjustment difficulties; 3) developing and evaluating interventions for siblings; and, 4) advancing education, awareness, and policy related to sibling issues.

The 2018 International Sibling Summit focused more narrowly on systematic screening of siblings for distress and unmet needs. Thirty psychosocial researchers, clinicians, advocates, policy makers, community providers, and parents and siblings of children with cancer from around the world participated.

The summit focused first on reviewing existing research, clinical initiatives, and screening tools relevant to sibling screening, and the application of this background knowledge to articulate a pathway a path forward to ensure systematic screening of siblings in clinical care.

Summit participants plan to continue their collaboration to address these initiatives over the next year, with the overarching goal of improving siblings’ access to empirically-based care and improve their trajectories of psychosocial adjustment to cancer.

SPARCCC group photo of participants from this year’s Summit
Contact: sparcccpartnership@gmail.com
PPO theses from around the globe

International PhD Candidates and recent graduates in the field share their theses

2017
Leigh Anne Donovan, Australia
Bridging the chasm between hospital and home: Exploring the experience and needs of parents following the death of a child from cancer

Alistair Lum, Australia
Comparing school-based needs and receipt of school support among children and adolescents with and without serious chronic illness: A multiperspective study with students, parents, and teachers

Sasja Schepers, the Netherlands
Changing pediatric cancer care: development and implementation of electronic patient and parent reported outcomes

Janine Vetsch, Switzerland
Long-term childhood cancer survivors and their parents - information needs, follow-up care practices and preferences

Your recent/future PhD thesis in the next issue of the POPPI newsletter? Contact us!

Recent PPO publications

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


Have you recently published a relevant paper in PBC or Psycho-Oncology that should be displayed in the next issue? Contact us!
By Michelle Scialla

The evidence-based Standards for Psychosocial Care for Children with Cancer and Their Families cover a broad range of psychosocial care from diagnosis through survivorship or end of life, and are endorsed and/or supported by key professional groups.

Preparing to Implement Psychosocial Standards: Current Services and Staffing (PIPS-CSS) is a national study conducted from June to December 2016 assessing the readiness of pediatric oncology programs to implement psychosocial care consistent with the Standards.

Participants include pediatric oncologists, psychosocial leaders and administrators from oncology programs in the United States (n = 144). Participants completed an online survey covering topics including when psychosocial care is delivered, to whom it is provided, and how psychosocial staff practice as members of the oncology team.

Two papers have been published describing the results. Over 90% of programs have social workers and child life specialists who provide care to children with cancer and their families. Fewer programs have psychologists (60%), neuropsychologists (31%) or psychiatrists (19%).

While most participating pediatric oncology programs appear to have at least the basic level of staffing necessary to implement some of the Standards, programs that lack a comprehensive multidisciplinary team may struggle to implement the full set.

Many oncologists and psychosocial leaders perceive the psychosocial care provided at their program as consistent with the Standards. However, only half of the oncologists (55.6%) and psychosocial leaders (45.6%) agreed or strongly agreed that their psychosocial care was comprehensive and state of the art.

The perception of state of the art care was associated with practices indicative of integrated psychosocial care and the extent to which the Standards are implemented. These data can be used to advocate for expanded integrated psychosocial care in pediatrics which is necessary to implement comprehensive care consistent with the Standards.


If you would like your recently published article highlighted in our next issue, contact us!

Book and reference guide by Joanna Breyer “When your child is sick”

In ‘When Your Child is Sick’, psychosocial counselor Joanna Breyer describes decades of experience working with sick children and their families into a comprehensive guide for navigating the uncharted and frightening terrain.

She provides expert advice to guide them through the hospital setting, at-home care, and long-term outcomes. Her book is based on her experience with children with cancer and their families but she also makes some more general points about children sick from other causes.

‘When Your Child is Sick’ has three sections, the first about children on treatment, the second about survivorship and the third section about children who cannot be cured.


Register on the PPOP website

Visit the Pediatric Psycho-Oncology Professionals website from the National Cancer Institute and find information on collaboration, resources, and training opportunities!
Personal memories of Andrea Patenaude

Some memories from a few of the many people whose lives were touched by Andrea...

Andrea Patenaude, PhD

“Andrea was a strong yet gentle role model for me, way beyond the professional sphere. I met Andrea when I was still a very young psychologist from Senegal and she was a prestigious director at Harvard. Yet Andrea remained humble, supportive and oh so generous! I will never forget how Andrea was willing to pay out of her own pocket so I could participate in an IPOS meeting in Dublin; simply because of her strong belief in values such as equity, fairness, and knowledge transfer. She will be greatly missed by her international colleagues who shared her passion for the defence of human rights and paediatric oncology.”

Sokhna Ndiaye, Nouakchott, Mauritania.

“A first memory: one day, many years ago at the beginning of the AIDS epidemic, Andrea, the leader of our group of psychologists, corralled us along with several other psychosocial staff. She asked us to work on a deeply sensitive research project: To what extent did our own medical community fear, and avoid working with, AIDS patients? She knew of several concrete examples. She thought the study would help these most vulnerable patients by diminishing the likelihood that they would have to endure unnecessary rejection and isolation. It would tell those in high places that staff at all levels likely needed further education about AIDS for it would suggest that even prominent institutions like our own faced these challenges. She argued that professionals and others would not be so much shocked at the results as they would be grateful that the study brought the problem - the problem of irrational fear - to light. That idea - that day - helps us see who Andrea was and how she worked. She believed in the power of empirical study; she was imaginative in devising her studies; she was courageous in taking on what, for many, was intertwined with hers. As with all of her work, she made it real with brilliance, wisdom, compassion and inclusion. Most of all, I treasure our friendship - her thoughtfulness, warmth, honesty, and love. In addition to her professional work, she was also a gourmet chef. Every time I eat good bread (her criterion for a good restaurant), prepare a salad (making sure to dry the leaves sufficiently), fix berries (so they won’t be smashed) I remember her patience and humor in showing me things that any good cook should know. We shared our lives, happy and difficult times. There was no one like her.”

Mary Jo Kupst, Wisconsin, USA.

“Her wisdom inspired us all.”

“A second memory: this Christmas, when her cancer was already far advanced, Andrea arrived at my house with her annual basket of exquisite, home-baked goodies with the usual truffles, mint cookies, butter cookies, chocolate covered cookies, and mini macaroons, each carefully wrapped in its own transparent decorated holiday paper. She admitted it had, perhaps, been a little more challenging for her to make them this year. But that challenge had not deterred her for a second. No, not the indomitable Andrea. So I thank you, Andrea, for those wonderful cookies and for the innumerable other gifts, tangible and intangible, which you gave me in my professional and in my personal life. Now when a complex problem arises, I, and many other friends and colleagues from around the world, will continue to ask ourselves and each other “And what would Andrea do here?” Andrea, you were a marvel. We miss you very much indeed.”

Joanna Breyer, Boston, USA.

“It has been a privilege working with Andrea. I am grateful for her dedication in fighting hospital detention practices. Her wisdom inspired us all. Andrea was not only the driving force in establishing our Global Taskforce, she also ensured that hospital detention was on the agenda at various SIOP Congresses and at a Human Rights Symposium in Dublin. Andrea contacted numerous organizations and initiated the IPOS Statement of Support. Andrea is and will be greatly missed and we will continue the fight against hospital detention in her spirit.”

Saskia Mostert, Amsterdam, the Netherlands.

“We shared our lives, happy and difficult times. There was no one like her.”

“Her wisdom inspired us all.”

“..above all, she kept as her first priority the well-being of the patient”

“Associate Andrea with gifts. She was a very generous, sympathetic and gifted person. Gifted in connecting - with people, with different ages, in different countries, on different topics. She was gifted in listening and giving support, even at a distance. She was very good in buying and giving gifts. Her gifts are everywhere in my house. I drink coffee from a cup with ‘I love Boston’. I have a shawl, in typical Andrea colors. I will never forget when we visited Marrakesh where she bought gifts on every corner because all looked so beautiful and was just the right thing for someone at home. On my fridge is a picture of us on the dancerfloor of the dinner at the SIOP Boston meeting taken in 2010. Two “buddies” based on a collaboration which started when I asked her to help our SIOP PPO committee as a local organizer. The friendship which followed was a gift for life. I will never forget her.”

Martha Grootenhuis, Amsterdam, the Netherlands.

“Andrea was a remarkable woman. She accomplished so much in her career and was very successful, but still made time to provide support and guidance to me. She always took the time out of her busy schedule to email me advice and provide feedback on my work. Andrea was a rare combination of professionalism, compassion and genius. She will remain a true inspiration and will be sadly missed.”

Eden Robertson, Sydney, Australia.
“Within the Children’s Oncology Group (COG), during the transformation of the Psychology Discipline committee to the Behavioral Science committee, Dr. Patenaude played key roles. Along with broader inclusion/mission, a new Behavioral Science steering committee was created where members of the steering committee within Behavioral Science conjointly served on additional COG steering committees. Dr. Patenaude volunteered to serve on the BSC steering committee and the COG Bioethics committee. While this required additional time, her participation ensured greater integration. Multiple behavioral projects that focused on bioethics unfolded over several years as a result of Dr. Patenaude’s joint participation.”

Robert Noll, Pittsburgh, USA.

“When I think of Andrea, I think about how colorful she was — warm, sincerely interested, and supportive. One of the earliest memories I have with Andrea is during my first SIOP PPO experience as a fresh PhD student in London (2012). I remember how approachable she was for a “VIP scientist”. In the years (and many PPO e-mails & activities) that followed, her warmth and approachableness were only confirmed more and more. It feels strange to plan next activities when she’s not around. Her loss is a great miss for all early-career PPO scientists.”

Sasja Schepers, Memphis, USA.

“Andrea was a wonderfully wise, warm and generous mentor for me as a new PhD student. In the last few months before she passed away she provided such thoughtful feedback on one of my manuscripts, peppered with smiley faces and words of encouragement. I felt her warmth radiate off the page and she really helped to make a process, that can sometimes be quite confronting or anxiety provoking for new students, so easy. I will always remember this feeling and I am forever grateful for her mentorship.”

Brittany McGill, Sydney, Australia.

“It is very hard to put into words how special Andrea was, and even more difficult to describe how special she was to me. Andrea was un-endingly kind, open-hearted, funny and so so clever. What a combination! I loved her hugs, her advice and her beautiful handwriting (which absolutely covered every draft of my papers). Her feedback was always thoughtful and brought the needs of real patients and their families to the fore. Her love of her family and generosity toward her friends were clear to everyone she met. Andrea was incredible in how she brought together special people from across the world, across cultures and across generations. She was truly a one-in-a-million woman. I will remember her always.”

Claire Wakefield, Sydney, Australia.

“The co-founders of the Mattie Miracle Cancer Foundation will deeply miss Andrea. The magnitude of her loss for us, the psychosocial community, and her family and friends are indescribable. Andrea played an instrumental role in the development of the evidence based Psychosocial Standards of Care for Children with Cancer and their Families. She was a gifted clinician, researcher, and leader in the psychosocial field and what made her stand out was her kind, approachable, humble, and incredibly compassionate nature. Andrea’s mark on the Psychosocial Standards of Care will leave an everlasting legacy that will forever impact children with cancer and their families.”

Victoria Sardi-Brown, Washington, DC, USA.

“She was truly a one-in-a-million woman.”

“What made her stand out was her kind, approachable, humble, and incredibly compassionate nature.”