

## **Psychosocial Support and Research Program**

As part of the care provided at the Pediatric Oncology Branch of the National Cancer Institute, we provide a wide range of support services to patients and their families. Education and research are also essential components of this program. Each part of the program focuses on addressing the social, psychological, emotional, and practical facets of pediatric cancer and supporting patients and families while they are enrolled in clinical research protocols.

### Psychosocial Support Program

The treatment of a childhood cancer presents extraordinary psychological, emotional and social challenges to the entire family. The Pediatric Oncology Branch offers a variety of services to help families adapt and mobilize resources during treatment for these diseases. At the heart of these services is the personal commitment of every multidisciplinary team member to understand each young patient as a unique individual with specific needs. Team members also collaborate with parents at each step in the process to be attentive to the quality of life of all family members, including siblings.

To address the informational and support needs of our families, the Psychosocial Support Program has “chat” sessions available several times each week that are designed for patient and family participation. Educational sessions focus on areas such as parenting skills, pain management, palliative care interventions, coping, adjusting, understanding financial resources, siblings, academic and vocational issues, adherence, learning styles, fertility concerns, nutrition, discipline, relaxation, cultural issues, complementary medicine, and treatment of sleep disturbances.

Families need different types of support at various times of their child’s illness. To meet the needs of our patients and families, we have a multidisciplinary team that is available to provide the following services while at NIH. The multidisciplinary team includes social workers, psychologists, recreation therapists, art and music therapists, and psychiatrists.

- \* Close collaboration with the NIH social work department
- \* Individuals, couple, and family counseling
- \* Play therapy
- \* Behavioral techniques to manage anxiety related to procedures, pill swallowing, illness.
- \* Support groups and workshops for patients and families
- \* Sarcoma chats between patients and staff
- \* Sibshops held at The Children’s Inn at NIH
- \* Bereavement program
- \* Psychology and psychiatry consultation service
- \* Neuropsychological testing
- \* Pain and palliative care service
- \* Camp programs
- \* Recreational therapy

- Medical play groups
- Art therapy
- Music therapy
- Massage Therapy
- \* School (K-12) Program
- \* Vocational Testing
- \* Spiritual Ministry
- \* Collaboration with the Spiritual Wellness Program at The Children's Inn at NIH
- \* BioEthics Consultations
- \* Interpreters
- \* Referrals to community resources

### **Psychosocial Research Program**

Description/Scope: The Pediatric Oncology Branch specializes in research aimed to improve the experience of living with or beyond cancer. Examples of some current research initiatives are listed below.

#### *Pilot Study of Educational Interventions in Pediatric Hematopoietic Stem Cell Donors to Increase Donation and Transplantation Procedure Knowledge*

Hematopoietic Stem Cell Transplant (HSCT) represents the second most frequent major organ transplant in the United States. The importance of preparation for children undergoing medical procedures has long been recognized in the field of pediatric psychology. In previous research, siblings who felt they were not adequately prepared for possible complications following HSCT donation and transplant often described negative emotions. Some siblings have reported feeling pressured and coerced to become a donor, while others describe a lack of attention to their physical fears associated with donation and their psychological concerns. No prospective studies examining educational tools and transplant knowledge in sibling stem cell donors are currently available.

The objectives of this study are to 1) assess pediatric sibling stem cell donor comprehension of transplant procedures and compare knowledge prior to educational interventions (pre and post-consent informational session) to knowledge following educational interventions; 2) assess the effectiveness of a workbook intervention as a learning tool for conveying information on stem cell donation and transplantation to pediatric donors; 3) assess the effectiveness of a board game intervention (ShopTalk) as a learning tool for conveying information on stem cell donation and transplantation to pediatric donors, and 4) identify donors who may require additional preparation prior to stem cell collection.

Eligible participants are between the ages of 10 and 26 and they or their parents must consent to participation in active stem cell transplant protocols at the NIH. Baseline knowledge will be assessed following consent. Knowledge will be reassessed following the information session for the transplant protocol. Donors will be stratified into 2 groups by age. Sibling donors ages 10 to 15 will be scheduled the following day to play a game

called ShopTalk. Sibling donors ages 16 to 26 will be given a workbook on HSCT specifically designed for sibling stem cell donors. Knowledge will be reassessed following the administration of these interventions. A follow-up assessment will be administered to all participants 1 month after baseline assessment was administered.

*An Exploratory Study of the Use of Five Wishes as a Tool for Advanced Care Planning in Young Adults with High Risk Cancer*

Discussing end of life (EoL) care with adolescents and young adults can be one of the most difficult aspects of cancer treatment. Few established resources exist to aid this population in accepting and understanding their changing physical, emotional and social needs when treatment is no longer effective. Standards in palliative care suggest that discussion of end of life issues be routine and commence soon after diagnosis. While many helpful documents exist to facilitate such conversations with adults, few address the particular concerns and needs of adolescents and young adults. One advance directive (AD) document, *Five Wishes*, has had particular success with the adult population because of the consideration of “personal, emotional and spiritual needs” in addition to medical and legal concerns.

This study is designed to determine if adolescents and young adults with advanced cancer feel that an AD document, such as *Five Wishes*, is useful in addressing end of life issues. The second objective is to develop and perform a pilot evaluation of a modified age-appropriate advance care planning tool for young adults and adolescents based on *Five Wishes* that reflects the participants’ opinions on which questions they feel are most useful and additional items that might be helpful.

Eligible participants are between the ages of 16 and 30, have a high-risk cancer and enrolled in an active NCI/NIH treatment protocol.

**Meet the Staff:**

Lori Wiener

Dr. Lori Wiener is the coordinator of the pediatric psychosocial support and research program in the Pediatric Oncology Branch of the National Cancer Institute. She has dedicated her career to the field of oncology and pediatric HIV/AIDS. Originally from New York, Dr. Wiener completed a PhD program in Social Work at New York University and held a private practice while working at Memorial Sloan Kettering Cancer Center. Dr. Wiener joined the Pediatric Oncology Branch of the National Institutes of Health in 1986 to help the Chief of the Pediatric Branch (Dr. Philip Pizzo) incorporate pediatric HIV disease into the existing pediatric oncology program.

Dr. Wiener has published numerous research studies and book chapters examining parental needs and coping, children's coping, sibling issues, mental health challenges, diagnosis disclosure, adolescent and young adult issues, and interventions designed to meet the needs of critically ill children and their families. She also brings with her a wealth of information about the inner worlds of medically challenged children, some of which have been published in a book entitled Be A Friend (Albert Whitman and Company, 1994), An Alphabet about Families Living with HIV/AIDS, a workbook for

children living with life threatening diseases called This is My World, and a workbook for siblings of ill children called Brothers and Sister Together. Dr. Wiener uses many forms of creative writing and artwork as part of her therapeutic interventions with children, adolescents and young adults.

#### Maryland Pao

Dr. Pao is Deputy Director in the Office of the Clinical Director in the Intramural Research Program at the National Institute of Mental Health. She is an Attending Physician on the Psychiatry Consultation Liaison Service and Director of Pediatric Psychiatry Consultations in the Clinical Center. A native of Bethesda, she attended Wellesley College before completing a BA/MD program at Johns Hopkins University School of Medicine. She completed Pediatric and Psychiatric Residency training as well as a Child and Adolescent Psychiatry Fellowship at Johns Hopkins Hospital. Dr. Pao was the Director of the Pediatric Consultation Liaison Service in the Children's Center of Johns Hopkins Hospital as well as the Director of Pediatric Consultation Liaison and Emergency Psychiatric Services at Children's National Medical Center in Washington, DC. She is board certified in Pediatrics, General Psychiatry and Child and Adolescent Psychiatry.

Dr. Pao's clinical and research interests are in the complex interactions between somatic and psychiatric symptoms in chronic diseases of childhood such as pediatric cancer, HIV chronic granulomatous disease, and in pediatric pain management. She writes on psychopharmacologic management of medically ill children and adolescents as well as on the importance of multidisciplinary management of coping and adaptation in youth and families facing chronic illness.

#### Tara Brennan

Tara Brennan received her doctorate in clinical psychology in 2006, with focused graduate training, work, and research experience addressing the close interplay between children's physical health and their psychological well-being. While working in pediatric inpatient and partial hospitalization programs, neurodevelopmental clinics, early intervention programs, and behavioral centers, Dr. Brennan has helped children and adolescents with acute and chronic diseases and their families with the maintenance of health, the promotion of positive health behaviors, and the behavioral and developmental aspects of serious medical conditions. Dr. Brennan has particular research and clinical interests in the areas of pain assessment, adjustment and coping of parents and siblings of children with complex medical challenges, and treatment adherence and compliance. As a postdoctoral fellow at the NCI, Dr. Brennan continues the research and practice of addressing the relationship between children's physical, cognitive, social, and emotional functioning and their physical well-being through both research and clinical services.

#### Pedro Martinez

Dr. Martinez is a psychiatrist with the Behavioral Endocrinology Branch at the National Institute of Mental Health. He completed training in Child and Adolescent

Psychiatry at Children's National Medical Center in Washington, D.C. He works with the Psychiatry Consultation Liaison Services with a special focus in Spanish speaking populations.

Dr. Martinez' research includes the study of long-term outcomes of offspring of parents with mood disorders, the medical consequences of depression and the effects of reproductive hormones on mood. He has a special interest in the physiological and psychological adaptation to chronic adverse conditions.

#### Emilie Steffen-Smith

Emilie Steffen-Smith is a post-baccalaureate clinical research fellow in the Neuro-Oncology Branch of the NCI. Emilie's current research includes assessment of cognitive functioning and neurotoxicity in pediatric patients with brain tumors and patients undergoing radiation and/or high dose chemotherapy. Other research interests include quality of life of pediatric patients and their family members, specifically psychosocial functioning in healthy siblings of pediatric cancer patients. She has worked with Dr. Lori Wiener to evaluate the experiences of sibling stem cell donors at the NIH and helped in the development of educational tools and interventions for donors.

#### Elizabeth Ballard

Elizabeth Ballard is a post-baccalaureate fellow (IRTA) at the NIMH working with Dr. Pao and collaborating with the Psychosocial Oncology Program at the NCI. Elizabeth is interested in pursuing graduate study in pediatric psychology with a particular interest in the impact of chronic illnesses on child development. She is also interested in research and clinical work in pain, somatization and cognitive therapy.

#### Recent Publications Relevant to Pediatric Oncology:

Wiener L., Hersh SP. and Kazak A. Psychiatric and Psychosocial Support for Child and Family. In Principles and Practice of Pediatric Oncology.(5<sup>th</sup> Edition) Pizzo, PA and Poplack, DG (Eds.). Lippincott, Philadelphia, 2006.

Wiener L, Battles H.B., Bernstein D., Long L, Mansky P & Mackall C. Persistent Psychological Distress in Long-Term Survivors of Pediatric Sarcoma, PsychoOncology, DOI: 10.1002/pon.1024

Mansky P, Arai A., Stratton P; Bernstein D; Long L; Reynolds J; Chen D; Steinberg S' Lavende N;Hoffman K; Nathan P; Parks R; Augustine E; Chaudhry U; Derdak J; Wiener L; Gerber L; Mackall C.. Treatment Late Effects in Long-Term Survivors of pediatric sarcoma, Pediatric Blood & Cancer, DOI 10.1002/pbc.

Rosenstein DR, Pao M, Cai J. Psychopharmacologic management in oncology in Bethesda Handbook of Clinical Oncology, 2<sup>nd</sup> edition, Abraham J, Allegra CJ, and Gulley J (eds.) Lippincott Williams and Wilkins, Philadelphia, PA, 2005, p521-528.

Pao M, Ballard E, Rosenstein D, Wiener L, Wayne A. Psychotropic Medication Use in Pediatric Oncology Patients. Archives of Pediatrics and Adolescent Medicine, 160, 818-122, 2006.

Pao M, Ballard ED, Raza H, Rosenstein DLR. Pediatric Psychosomatic Medicine: An Annotated Bibliography. (Psychosomatics, in press.)

Wiener, L, Steffen-Smith, E., Fry, T., Wayne, A. Hematopoietic Stem Cell Donation in Children: A Review of the Sibling Donor Experience. Journal of Psychosocial Oncology. in press.

Wiener, L., Zobel M; Battles H; Ryder C. Assessing Transition Readiness. Social Work and Health Care, in press.

Additional resources for families:

Wiener, L. This Is My World. A workbook for children with chronic and life-threatening illness. Child Welfare of America: Washington, DC, 1998.

Wiener, L. Brothers and Sisters Together. A workbook for siblings of siblings who are sick (pdf file)

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