

# Survivorship Research Update 2013

## National Leadership

The Cincinnati Children's Survivorship Center is one of the oldest and largest clinical care and research programs in the U.S. The Center currently follows approximately 1,500 patients, providing evaluation and care by a closely integrated team of specialists from diagnosis through adulthood.

In addition to direct patient care, our center conducts research into new and better ways to ensure optimal health of cancer survivors.

### *Survivor Center Research Focuses on:*

- The development of molecular markers to identify which patients are at high risk for late complications or secondary cancers
- Ways to improve quality of life and function in patients who have survived cancer
- The causes of early heart and lung disease in cancer survivors
- New approaches to ensuring reproductive health and improving fertility outcomes
- The evaluation and treatment of neurological and psychological side effects
- New ways to prevent secondary cancers and other complications associated with cancer treatment
- Early identification of late complications associated with cancer treatment

## Research Update

Karen C. Burns, MD, MS, directs the Cincinnati Children's Survivorship Center, a unique program that follows "children" some of whom are now well into adulthood. Dr. Burns studies long-term heart and lung health of cancer survivors. Her recent study of Hodgkin's lymphoma, which has an excellent cure rate in pediatric patients, showed that survivors are at increased risk for cardiopulmonary complications due to chemotherapy. This research has highlighted the importance of monitoring heart and lung health of



*Dr. Rajaram Nagarajan with patient*

survivors.

Dr. Burns also studies improvements in fertility preservation for patients who undergo chemotherapy and directs Cincinnati Children's fertility preservation program for children and adolescents undergoing chemotherapy.

Judy Correll, RN, CPNP, has participated in numerous research projects concerning survivors of pediatric cancer. Her primary areas of research are post-traumatic stress and social, emotional, and behavioral functioning in survivors of pediatric cancer.

Stella M. Davies, MBBS, PhD, MRCP, serves on the national steering committee for the National Institutes of Health-funded Childhood Cancer Survivor Study. This study uses data from more than 14,000 childhood cancer survivors to understand genetic influences on the risk of cardiac side effects from treatment, the risk of obesity in leukemia survivors and the risk of second cancers in children treated with radiation therapy, as well as other issues.

In her laboratory, Dr. Davies is looking at genetic markers in cancer survivors to determine which genes might predict susceptibility to long-term problems, such



as secondary leukemia. Her research will help improve treatments for aging survivors, as well as personalized cancer treatments based on a patient's genetic profile. Dennis D. Drotar, PhD, is identifying best methods to help families follow prescribed leukemia treatment regimens and manage treatment at home. He is also conducting studies to understand the factors that influence psychological outcomes of children and teens with chronic physical illness, including cancer.

Debra Kent RN, MSN, CPNP, has studied survivor health for more than eighteen years in collaboration with researchers across the U.S. and Canada. Her cancer survivor research includes studies of adverse cardiovascular events after treatment and physical activity interventions. Her main research interests are patient/family education strategies for optimizing health and transition issues for survivors. Debra was instrumental in the development of the Children's Oncology Group Long Term Follow-Up Guidelines for Children and Adolescents with Cancer. She devised and maintained the COG web-based Directory of Late Effect Services and recently published cancer survivorship practices for survivorship programs.

Rajaram Nagarajan, MD, MS, is the director of the Cancer Control and Outcomes Research Initiative. His research interests include limb function and quality of life of survivors of pediatric lower extremity bone tumors. Dr. Nagarajan also studies the effects of anthracycline and radiation therapies on cancer survivors. While most survivors do not experience significant heart abnormalities, this research has shown that all survivors who received these therapies should be monitored, as some do develop serious complications.

Ahna Pai, PhD has been conducting research with childhood cancer survivors for over eight years. She is examining factors that influence the degree to which childhood cancer survivors follow the Children's Oncology Group Long-Term Follow-up Guidelines for preventative screening and medical care. The goal is to identify factors that will directly inform novel models of health care delivery and best support the medical and psychosocial needs of survivors. Dr. Pai is also developing and testing a program to help adolescents and young adults with cancer follow prescribed medication regimens at home. Ultimately, this research will improve the supports provided to adolescents and young adults so they can more effectively follow their medication regimens.

Jonathan Tolentino, MD, is the 5+ Cancer Survivor's Scholar. His research focuses on the long term effects of chemotherapeutic drugs on the development of peripheral vascular disease and assessing risk factors that place adult survivors of pediatric cancers at increased risk for the development of peripheral vascular diseases.

Sara Knapke, MS is a Certified Genetic Counselor who provides cancer risk assessment and genetic counseling for childhood cancer survivors and at-risk family members if a genetic predisposition or familial risk for cancer is recognized. This type of partnership between genetics and oncology is unique to Cincinnati Children's. She recently led and published a study which revealed that up to 30% of childhood cancer survivors are eligible for genetic evaluation based on their personal and/ or family history. Identification of hereditary risk factors for cancer can lead to a personalized and effective approach to care. Mrs. Knapke is also the founder of the Pediatric Hereditary Cancer Predisposition Program at CCHMC.

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