



ARNOLD PALMER HOSPITAL
For Children
Supported by Arnold Palmer Medical Center Foundation

PEDIATRIC BRAIN TUMOR PROGRAM UPDATE

SUMMER 2013

Thanks in part to the generous support from Runway to Hope, the Pediatric Brain Tumor Program at Arnold Palmer Hospital for Children continues thrive.

Led by pediatric neuro-oncologist, Dr. Amy Smith, the Pediatric Brain Tumor Program is a comprehensive team dedicated to the care of children, teenagers and young adults diagnosed with brain and spinal cord tumors. Our mission is to provide children and young adults diagnosed with brain and spinal cord tumors the most effective treatment options available while aggressively protecting their quality of life.

Our goal is to become the pre-eminent facility in the Southeast serving patients dealing with cancerous brain and spinal tumor diagnoses.

Since its founding in 2011 as a division of The Center for Children's Cancer and Blood Disorders, the program has seen a marked increase in patient volume, an intensification of research activity, and a growth in staff.

Team

- Dr. Amy Smith, Director
- Hillary Bess, CPNP, Clinical Program Coordinator and Physician Extender
- Christi Reilly, RN, Outpatient Clinical Coordinator
- Emily Owens Pickle, CCRP, Research Coordination and Program Support
- Michelle Richey, MSW, Social Work Coordinator
- Rachel Baucom, Administrative Coordinator

New Patient Volumes (includes consult)

Our patient base has grown at a significant rate, as we serve more patients from Central Florida and beyond. We have recently received referrals from as far away as Miami, Jacksonville, and the Florida Panhandle.

- 2011: 10 new patients (August – December)
- 2012: 25 new patients
- 2013: 30-35 (Projection); 15 (Actual, January-June)
- 2015: 60 (Projection)

Research

Clinical Research

By supporting the move to Arnold Palmer Hospital, Runway to Hope has facilitated an increase in research activities and access to early phase clinical trials, a key component of a leading neuro-oncology program. In 2013, we are beginning a series of novel immunotherapy trials. These include studies for recurrent ependymoma and a vaccine trial for recurrent medulloblastoma, which is the most common type of pediatric brain tumor.

Bringing these studies to Orlando and into the State of Florida is not just convenient, it is crucial for the 35% of our patients and families who rely on Medicaid. Out of state experimental therapies – which are sometimes a patient’s last or best chance for help – cannot be covered under Medicaid.

Collaborations

We are collaborating with some of the most respected pediatric oncology research groups in the world:

- Invited to participate with St. Jude Children’s Research Hospital on a personalized therapy protocol for newly diagnosed medulloblastoma. This landmark study is based on recent discoveries about the molecular stratification of medulloblastoma and will accrue patients for approximately 10 years
- Recently completed collaboration with several sites on a long-term follow-up for infants diagnosed with medulloblastoma (LTFU-MB) to seek ways we can minimize long term effects of treatments on this vulnerable group of infant brain tumor patients.
- We continue our affiliation with POETIC, composed of 10 medical centers in North America with a major emphasis on comprehensive cancer care and research, and with Children’s Oncology Group (COG).

Technology

Funds from Runway to Hope have made it possible to execute a contract with REDCap (Research Electronic Data Capture). This system, used by 686 institutional partners in 58 countries, allows us to capture data for all patients enrolled in our biobank and research trials, and to track outcomes and genomic data for all patients seen in our program. These results can be used to compare or benchmark studies.

Recent Research Publications/Academic Productivity

- International Symposium on Pediatric Neuro-Oncology (ISPNO) June 2012: 3 posters and 1 oral presentation
- International Society of Paediatric Oncology (SIOP) September 2013: 2 posters
- American Society of Clinical Oncology (ASCO) September 2013: 2 posters
- Hillary Bess, ARNP co-author for the American Academy of Neurology Pediatric Neuro-Oncology Practice Guidelines (Publication date August 2013)
- Emily Owens Pickle, CCRP: leading an international study to find strategies for retaining pediatric oncology clinical research associates through the Children’s Oncology Group (Publication date Spring 2014)