



Children's Brain Tumor Foundation

Hope and help every day

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Children's Brain Tumor Foundation's Tissue Bank Consortium May Solve Dire Problem in Pediatric Cancer Research

Leading Institutions in Philadelphia, Pittsburgh and Chicago To Launch Collaborative Initiative

NEW YORK, July 1, 2008—In a major effort to speed treatment and cures for pediatric brain tumors and cancer, the Children's Brain Tumor Foundation (CBTF) today launched the initial phase of a tissue bank consortium designed to jump-start meaningful analyses that could lead to treatment and cures for these types of cancer, where survival rates are unacceptably low and neurocognitive and other damage is posed by today's treatment options.

"The need for this approach is nearly palpable among pediatric oncologists who specialize in brain and spinal cord tumors," said Robert Budlow, CBTF President. "As the advocate and voice for children and families fighting what can seem like insurmountable odds, the Children's Brain Tumor Foundation is committed to growing the tissue bank consortium to open the doors to speeding scientific progress on this horrible disease."

Susan L. Weiner, PhD., Chair of CBTF's Grant Committee, explained why this initiative is so urgently needed. "Tissue banks are repositories of tissue samples that can be characterized, analyzed and used to evaluate treatments. Breast cancer, prostate cancer and melanoma, for example, have all seen dramatic treatment improvements recently because of tissue banks and their ability to analyze large volumes of tissue samples. But for pediatric brain and spinal cord tumors, tumor tissue banking is like a small pie cut into too many pieces. Many hospitals have tissue banks, but few if any have sufficient volume of different kinds of tumors to conduct comprehensive research. Without the new tissue bank consortium, meaningful analysis that might lead to treatment and cures is virtually impossible," she said.

Under a planning grant from the Licensing Industry Merchandisers' Association, CBTF is conducting a feasibility study with participation by leading pediatric institutions. Through the multi-

institution research program, participating hospitals will agree to collect and analyze tissue samples and share data publicly. A standardized database will be used to collect and centrally record clinical data. Children's Hospital of Philadelphia, Children's Hospital of Pittsburgh and Children's Memorial Hospital in Chicago are participating in the planning study, which will be led by Tom Curran, PhD, Deputy Scientific Director, and Children's Hospital of Philadelphia.

According to Dr. Curran, although pediatric brain tumors can be devastating, their low incidence has created a roadblock for researchers who need a large enough data set to conduct statistically significant analyses. "Everyone in this field believes that research is the key to better treatments, but this is very much a numbers game," explained Dr. Curran. "We need the power of statistics with a large sample set to make a difference."

The consortium will provide the foundation for building that volume. In the project's initial phase, Dr. Curran is planning the procedures to establish consistent tissue collection and analysis from participating hospitals. The second phase will establish the network to collect and analyze the samples, creating a significant volume of uniformly processed tumor material. "Once we have this avenue for collecting and characterizing a large enough sample set, then we can apply very sophisticated genomic research tools to understanding the origin and genetic mutations responsible for pediatric brain tumors, with the hope of uncovering new therapeutic avenues," Dr. Curran said. "Collecting and characterizing the samples is just a beginning. We also would try to collect tumor materials to promulgate in model systems that we can make them available to any investigator who needs them for study."

While overall cancer death rates have been dropping since the early 1990s, children's brain and spinal cord tumors are still the deadliest childhood cancer. Nearly one in three of the 3,400 children diagnosed each year with such a tumor will not survive five years, and treatments can cause damaging late effects on survivors. Effects range from cognitive impairment to physical challenges to social isolation. The vast variety of brain and spinal cord tumors has stymied research, as investigators face the challenges of collecting and analyzing tissue and the ethical issues posed in treating children.

The Licensing Industry Merchandisers' Association (LIMA), CBTF's principal organizational contributor, has committed to help fund the effort. "LIMA members' products bring joy to countless children's lives, so we are excited by the opportunity to be part of a scientific venture that can extend that joy to kids suffering from brain and spinal cord tumors," says Cheryl Stoebenau, Co-Chair of

LIMA's Charity Committee. "We believe our commitment will make a real difference to the success of this undertaking and are proud to support the efforts of the Children's Brain Tumor Foundation."

CBTF is seeking co-funding support from foundations and organizations interested in a national, cooperative research effort to eradicate this disease that destroys children's lives.

About the Children's Brain Tumor Foundation

The Children's Brain Tumor Foundation (CBTF) was founded in 1988 by a group of parents, physicians and friends to improve the treatment, quality of life, and the long term outlook for children with brain and spinal cord tumors through research support, education, and advocacy to families and survivors. Our goal is to ensure parents and children know they are not alone in their struggle. Now in its 20th year, CBTF serves children and families nationwide with expert information, toll-free hotline staffed by pediatric oncology social workers, survivor program, and parent networking,

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