



HCRN update



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Courtesy: Nikki Gale Photography
(nikkigalephotography.com)

Funding Success: The Power of a Public/Private Partnership in Medical Research

The mission of the HCRN is to dramatically improve the lives of kids suffering from hydrocephalus by conducting important and field-changing multi-center clinical research. One of HCRN's funding goals is to leverage private donations to stimulate government funding to help fund studies of this under-researched condition. We are pleased to announce that Dr. Tamara Simon from Primary Children's Hospital, has received a National Institute of Health (NIH) K-Award! This is a five year award that supports her in conducting hydrocephalus research through the HCRN. This is an impressive accolade for Dr. Simon, as well as for the HCRN as it should raise our profile on the national level and enhance our future applications. NIH is the largest public funder of medical research in the US and partnering with the NIH is critical to our long term success. We are pleased to celebrate this major milestone.

HCRN is Growing: Welcome Seattle!

Our vision is that, in 5 years, doctors will use HCRN research-based evidence to improve the diagnosis, treatment and outcomes of hydrocephalus patients and that these patients will live longer, more trouble-free lives than at present. In order to answer the tough questions quickly about what *exactly is the* best practice care for hydrocephalus, it helps to have a network of centers which are already treating large volumes of pediatric hydrocephalus to "power" our studies with more patient data. We are pleased to announce that Seattle Children's Hospital has joined the HCRN. Dr. Sam Browd will lead the HCRN research efforts in Seattle and will be ably supported by Research Coordinator Amy Anderson, BSN RN. We are delighted to have them on board and, with their support, hope we can get answers to the vexing questions of hydrocephalus even faster.

New Study Launched!

What is the best way to put a shunt in a child's brain so that you don't need to do it again a few months or years later? Dr. Bill Whitehead of Texas Children's Hospital is the principal investigator on a new study analyzing shunt insertion with intra-operative ultrasound assistance. Since our last report, all centers have obtained Institutional Review Board (IRB) approval and have begun entering patients on the protocol. We anticipate having data to report within about a year on this potentially field changing study aimed at reducing incidences of shunt failure and subsequent revision surgeries for hydrocephalus patients undergoing shunt insertion.



Dr. Bill Whitehead of Texas Children's Hospital stands next to an ultrasound machine.

Patient Treatment and Outcome Registry – Helping to Build a Database to Get Answers

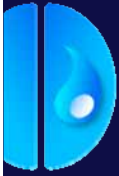
In the broadest sense the HCRN is tackling this question: which hydrocephalus treatment practices have the best outcomes? With so many different causes and treatments out there, this is a daunting question. Where does one begin? So, we've built a core database to track every patient (anonymously), procedure and associated outcomes at all our participating research centers. A large volume of very detailed information covering all aspects of the diagnosis, management and outcome of children with hydrocephalus is being diligently collected at each center. We call this our Core Data Project, or Registry, and it is being led by HCRN investigator Dr. Jay Riva-Cambrin from Primary Children's Hospital. With it, we can ask questions of the data and quickly see, for example, the difference in outcomes associated with practice variations across the participating research centers. The registry is already showing its promise for enabling future research projects! Dr. Abhaya Kulkarni of SickKids is using the registry to study a practice called third ventriculostomy and Dr. Simon uses the registry to collect information on the detailed management of shunt infection.

Registry Update

We are pleased to report that to date we have added more than 750 patients to the Registry database across our HCRN participating centers. A formal analysis of the first year's data is underway, a component of which will allow us to identify variation in practice patterns between surgeons and centers. This analysis is a key step in identifying new study questions and designing the research that will appropriately address them.

Other Government Funding Opportunities

Two NIH funding applications have been submitted by the HCRN. Dr. Jay Wellons, a principal investigator at HCRN's Alabama site, submitted an R01 grant to the NIH's National Institute of Neurologic Disorders and Stroke (NINDS) to study management of post-hemorrhagic hydrocephalus in premature babies. His application was based on privately-funded pilot research conducted in the HCRN. Dr. John Kestle also submitted a "challenge grant," a special grant program at NIH funded from the stimulus package that seeks to support multi-center research networks. This is an excellent opportunity to get support for our multi-center approach at the HCRN even if the odds of getting selected to this very popular grant program are very low (about 1%).



Thanks for Your Support

HCRN would like to express its appreciation to the individuals and organizations that generously provide support for our research.

*Since its inception the HCRN has made great progress in designing and producing quality research through the collaboration of its investigators and staff at the clinical centers all dedicated to the same mission: To **dramatically** improve the lives of children suffering from hydrocephalus.*

With all of us working together we are confident that the progress we continue to strive toward will be realized.



Flowers for sale at Seattle's Pike Place Market
(Photo courtesy of Melanie Kay Photography, UT
melaniekay.net)

Recent Medical Publications

Publishing our research findings is one of the main ways we hope to achieve our vision. Having papers accepted for publication in peer reviewed medical journals helps persuade doctors to use best-practice care by convincing them with evidence from our studies. Dr. Jay Wellons is the lead author on a publication in the Journal of Neurosurgery: Pediatrics, July 2009 issue. The paper is entitled "A Multicenter Retrospective Comparison of Conversions from Temporary to Permanent Cerebrospinal Fluid Diversion in Very Low Birth Weight Infants with Post-Hemorrhagic Hydrocephalus". Included at the end of the list of co-authors is the phrase "For the Hydrocephalus Clinical Research Network". This raises HCRN's visibility in the neurosurgical community. This study compared reservoirs and subgaleal shunts in premature babies with post-hemorrhagic hydrocephalus and suggested that the permanent shunting rate may be lower among the patients who received a reservoir. It was this research that helped Dr. Wellons gather the pilot data necessary to prepare his NIH R01 grant.

Also recently published in the Journal of Neurosurgery: Pediatrics, August 2009 issue, and acknowledging the HCRN in the list of co-authors, is a paper on which Dr. Simon is the lead author. The paper is entitled "Infection Rates Following Initial Cerebrospinal Fluid Shunt Placement across Pediatric Hospitals in the United States" and analyzes shunt infection data from the Pediatric Health Information System (PHIS) database. The results indicated a five fold difference in infection rates among the 41 children's hospitals included in the database. This retrospective study will be valuable in contributing to the design of future prospective multicenter research studies.

To Contact the Hydrocephalus Clinical Research Network

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To make a contribution to the HCRN

Please contact Douglas Nielsen at Primary Children's Medical Center Foundation at (801) 662-5970. All contributions are tax deductible as allowed by the IRS.

Visit us on the web at www.hcrn.org

