



HCRN *update*



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Our Newest Investigators



Dr. David Limbrick



Dr. Mandeep Tamber

The HCRN Keeps Moving Onward and Upward

This past year the HCRN has seen continued growth and productivity in its ongoing research efforts. In this issue we are excited to inform everyone about our recent network expansion, activities, and research progress. The picture below was taken during our Fall 2010 Bi-Annual HCRN meeting, which was held in Park City, Utah, and includes members from our now 7 Clinical Centers and the Data Coordinating Center. This group is an energetic and cohesive team which continues to be dedicated to contributing research that will improve the lives of those suffering with hydrocephalus.



The HCRN Adds Two New Centers!

Last summer the HCRN sent out a request for applications to expand the Network. Six high quality pediatric neurosurgery centers responded with competitive applications. Although it was felt that any one of the centers would have made a significant contribution to the ongoing hydrocephalus research effort, after all the scoring and discussion was finished offers were extended to Dr. David Limbrick (St. Louis Children's Hospital, Washington University in St. Louis) and Dr. Mandeep Tamber (Children's Hospital of Pittsburgh, University of Pittsburgh). Both of the Network's newest young investigators are well prepared researchers who are already bringing new ideas to the table as they have been getting their centers up and running with the currently active HCRN studies. We welcome them as well as their highly qualified Clinical Site Coordinators, Deanna Mercer (St. Louis) and Arlene Luther, RN (Pittsburgh) to the Network.



Preemie IVH Study Officially Launched!

What is the best way to treat hydrocephalus and hopefully prevent the need for a permanent shunt in premature babies who experience an intraventricular hemorrhage? This is the question that Dr. Jay Wellons of our Clinical Center at Children's Hospital of Alabama at Birmingham hopes to answer in a study titled, "Shunting Outcomes of Post-Hemorrhagic Hydrocephalus (SOPHH)." This new and ambitious study, which hopes to both determine the best course of treatment and develop standardized procedures for that treatment, has been launched and data collection is currently underway at the Centers which have received their IRB approval. The study of intraventricular hemorrhage has been a top priority of the HCRN since its inception and the current study is the latest phase to be rolled out in this ongoing branch of HCRN work. The data for this study will be collected over a two year period and we are excited to see the contributions it will provide to both knowledge and practice and ultimately improved patient clinical outcomes.



Jay Wellons MD, Chevis Shannon DrPH, and Amita Bey MPH

Congratulations to the HCRN team at Children's Hospital of Alabama, Birmingham, our SOPHH Study lead site.

Two New Studies Accepted at HCRN Meeting

The fall HCRN semi-annual meeting was held in Park City, Utah, September 29 – 30, 2010 where there was record attendance with 26 participants. During this meeting six proposals for new HCRN studies were presented and reviewed. Two were chosen to be incorporated into our body of work. Dr. Riva-Cambrin's and Dr. Limbrick's studies, which were selected, will each be further described in the next two sections below. The other projects which were presented are still in development. Some modifications and pilot studies were suggested so that these can come on line in the future.

Neuropsychological Outcomes Make the Grade

One of the two studies selected at the HCRN semi-annual meeting was subsequently selected for funding by the Hydrocephalus Association. The lead investigator, Dr. Jay Riva-Cambrin of our Clinical Center at Primary Children's Medical Center in Salt Lake City, Utah, received the HA Mentored Young Investigator Award. This two year award will provide funding for the new HCRN study entitled, "Ventricular Size Involvement in Neuropsychological Outcomes in Pediatric Hydrocephalus (VINOH)". The study will focus on school aged children (5-17 years) with a new diagnosis of hydrocephalus. They will have neuropsychological testing before their hydrocephalus is surgically treated and again six months afterward. The protocol for this study has been finalized and the Clinical Centers are in the process of obtaining IRB approval making this the next study to be launched by the HCRN.

A New Test for Hydrocephalus

The diagnosis of hydrocephalus and shunt malfunctions can be difficult and often requires more information than can be provided by MRI, CT, or ultrasound. Our St. Louis investigator, Dr. David Limbrick, has begun the search for biomarkers of hydrocephalus and shunt malfunction. He is testing CSF and blood from infants suffering from post-hemorrhagic hydrocephalus in order to identify proteins that can be used for early diagnosis. In addition, these proteins may provide real-time feedback on the effectiveness of treatment. Ultimately, we hope that these or similar biomarkers will provide a tool to compliment current imaging methods and facilitate the diagnosis and treatment of hydrocephalus.



HCRN Publications

The HCRN continues to be hard at work collecting data for its many ongoing studies. While many of the studies are not quite ready for analysis, the HCRN is pleased to report that results of another HCRN study have been published in the *Journal of Neurosurgery*. Drs. Simon, Kestle, and Riva-Cambrin recently studied factors associated with recurring shunt infections. The study utilized a database of 675 children who had experienced a shunt infection and examined several aspects of surgical intervention that may be related to re-infection. The data, which was extracted from hospital discharge diagnosis codes, did not provide sufficient detail to speak definitively about the factors that most contribute to the re-occurrence of a shunt infection. The data utilized in the study was not gathered into the database by the HCRN and speaks to the exciting possibilities that the carefully constructed data collection of the Core Data Project (or Registry) will offer in more effectively addressing the questions hydrocephalus researchers seek to answer. The HCRN Registry currently has over 1800 pediatric hydrocephalus patients and continues to grow. The Registry investigators have begun discussions around the first wave of analyses to be conducted with this rich source of information.

The *Journal of Neurosurgery* has kindly provided us with a complimentary link to the full article.
<http://thejns.org/doi/pdf/10.3171/2010.5.PEDS09457>

We are pleased to share the results of this study and look forward to sharing more results in the studies currently underway.

HCRN Momentum at AANS Pediatric Section Meeting

The HCRN made a big splash at the recent national meeting for Pediatric Neurosurgery in Cleveland, Ohio, November 30 - December 3, 2010. This meeting is the annual highlight for pediatric neurosurgery. Surgeons and researchers from across the country, as well as from Canada, submit abstracts for presentation and only the best are accepted. The first session of the meeting was on hydrocephalus and there were eight talks, three of them from the HCRN. Dr. Wellons presented a paper entitled, "Assessing premature infants for findings of increased intracranial pressure: an HCRN inter-rater reliability study." Dr. Whitehead presented the results of his ultrasound-guided shunt insertion study. Dr. Riva-Cambrin presented his paper entitled, "Variations in the neurosurgical care of premature infants with intraventricular hemorrhage: A multicenter study." In addition, although not an HCRN study, HCRN investigators Kulkarni, Riva-Cambrin and Browd collaborated on a paper presented by Dr. Kulkarni on endoscopic third ventriculostomy. There was plenty of discussion at coffee breaks about the large representation of HCRN in the national meeting.

HCRN Announcements and Kudos

- The HCRN started a blog last year to convey new findings, advancements and news about the state of clinical research in hydrocephalus. Visit the HCRN website, <http://www.hcrn.org> to sign up for blog updates via email.
- Dr. Tamara Simon, a hospitalist with the HCRN, moved from Salt Lake City, Utah to Seattle, Washington. Dr. Simon's hydrocephalus research is funded by an NIH K-Award and contributes significantly to the Network, specifically in the area of shunt infection. We are pleased she was able to stay within the HCRN network.
- Chevis Shannon, who has served as the Clinical Site Coordinator at The Children's Hospital of Alabama, Birmingham, completed her doctoral degree in public health, and we are glad to report that she remains involved in HCRN research activities. Her successor, Amita Bey, has a Master of Public Health degree and has brought a wealth of knowledge and experience with her in her role as the new Clinical Site Coordinator for our Birmingham, Alabama center.
- Sheila Ryan, Clinical Site Coordinator at our Baylor College of Medicine Clinical Site in Houston, Texas, was recently named the Society of Clinical Research Associates (SOCRA) Chairperson for the Greater Houston/Galveston Chapter.



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Please be sure to see them by visiting our website at:

<http://www.hcrn.org>

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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.