



# HCRN update



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## Recent Publications Support HCRN Efforts

HCRN Investigators Jay Riva-Cambrin and Jay Wellons have both published HCRN articles on premature children with intraventricular hemorrhage. The article by Dr. Riva-Cambrin demonstrates the variability across Clinical Centers in making decisions concerning the treatment of this patient population. The article by Dr. Wellons provides a look at agreement among surgeons when assessing patient symptoms that are involved in these treatment decisions. We thank the Journal of Neurosurgery: Pediatrics for providing links to the full articles:

RivaCambrin: <http://thejns.org/doi/full/10.3171/2012.1.PEDS11292>

Wellons: <http://thejns.org/doi/full/10.3171/2012.10.PEDS12329>

## HCRN Surgeons in Africa

Endoscopic Third Ventriculostomy with Choroid Plexus Coagulation (ETV/CPC) is a procedure that was pioneered by Dr. Ben Warf (Boston Children's Hospital) during his time in Uganda. Out of HCRN interest in this procedure, Dr. Warf was invited to attend the last HCRN meeting during which he reviewed the technique and the data he has collected through his own research. As a first step toward the possibility of doing a study on this procedure within the HCRN, Dr. Warf invited HCRN surgeons to accompany him to Uganda where he makes periodic trips to treat children with hydrocephalus at the Cure Children's Hospital of Uganda. In February the first group of surgeons, Dr. Riva-Cambrin (Salt Lake City), Dr. Whitehead (Houston), and Dr. Rozzelle (Birmingham), all went to Uganda where they were able to learn the fine details of the procedure under the direction of Dr. Warf and local surgeons, Dr. John Mugamba and Dr. Peter Ssenyonga. While there the HCRN team was highly pleased to discover that the surgeons at the Cure Children's Hospital had implemented the use of the HCRN Shunt Infection Protocol at their institution. The HCRN has made the Shunt Infection Protocol available to any non-HCRN surgeons and centers who have requested it. Later this spring other HCRN investigators will also be traveling to Uganda. We hope this experience will allow us to study this innovative procedure, aimed at eliminating the need for a shunt in the treatment of hydrocephalus, in the near future.



## New Study on CSF Biomarkers Up and Going

Across the network sites are beginning to obtain consent and collect samples of cerebrospinal fluid for a new HCRN study aimed at improving outcomes for the preemie IVH population of hydrocephalus patients. The study, called Cerebrospinal Fluid Markers of Post-Hemorrhagic Hydrocephalus, is being led by Dr. David Limbrick, the Site Investigator at St. Louis Children's Medical Center in St. Louis, Missouri. The proteins found in the CSF will be evaluated to determine their possible roles in indicating the presence of post-hemorrhagic hydrocephalus and informing the clinical decisions being made for treatment. In addition, this study will explore the relationship between the CSF proteins and later neurodevelopmental outcomes. Our St. Louis site coordinator, Deanna Mercer, did a great job demonstrating the collection, storage and shipping process of the samples as the sites prepared to get started. We are all excited to begin this new and innovative study which hopes to improve the care and outcomes for this vulnerable patient population.



David Limbrick, MD, PhD and Deanna Mercer  
Our CSF Biomarkers leaders from St. Louis, MO

## HCRN Fall 2012 Meeting in Salt Lake City

HCRN investigators, coordinators, board members and invited guests all met in Salt Lake City, Utah for the fall HCRN meeting where there was much to discuss. During the first day of the meeting each investigator currently leading an active study presented an update and provided opportunities for questions and issues to be raised and resolved. Included in this session was a thorough review of the CSF Biomarkers Study which was set to begin at each of the HCRN Clinical Centers. Another exciting topic of this meeting was the HCRN Registry, which had just undergone its first analyses. Dr. Tamara Simon shared results from the Infection portion of the Registry and Dr. Riva-Cambrin discussed analyses being done pertaining to Shunt Revisions. These first analyses along with outcomes from remote monitoring efforts have prompted some modifications to the Registry data collection forms. These changes were discussed with both the entire group and in more detail at the coordinator break-out session. The morning of the second day was devoted to Dr. Ben Warf's presentation on the ETV/CPC procedure. The HCRN surgeons asked many questions and the possibility of doing a future HCRN study of this innovative procedure was discussed at length. This was yet another highly energetic and successful meeting for the HCRN.

## HCRN Well Represented at National Talks

The presentations given by HCRN members at national conferences have been generating much interest and discussion among attendees.

At the AANS/CNS Pediatric Section meeting in St. Louis, MO, Chevis Shannon, DrPH, gave the first talk of the conference, during which she discussed the identification of sources of infection at the Alabama Clinical Center. Dr. William E. Whitehead from the Texas HCRN Center gave a talk on the findings from his HCRN Ultrasound Study, generating considerable interest regarding catheter movement after placement. Dr. Riva-Cambrin and a resident from the Utah HCRN Center and Dr. Wellons and a resident from the Alabama HCRN Center also gave presentations, making the HCRN very well represented at this meeting.

At the American Society of Pediatric Neurosurgeons annual meeting held in Kauai, HI, in February Drs. Whitehead and Riva-Cambrin both gave well-received talks about their HCRN studies, which included results and discussion from the initial Registry analyses.

In May Dr. Tamara Simon from the Seattle HCRN Center will be traveling to D.C., where she will give a platform presentation at PAS on the results of her Registry studies investigating shunt infection.



## HCRN Helps Set the Standard

Each year the US News & World Report ranks children's hospitals. As part of the process a request is sent for data from the hospitals and surveys are sent to physicians around the country to gauge the reputation of each hospital. Many of the questions are the same from year to year but occasionally new ones are added. For the first time, this year the survey asks if the hospital's Pediatric Neurosurgery Program participates in the Hydrocephalus Clinical Research Network. We are happy to see this. It means that the editors of US News & World Report consider HCRN participation to be important enough to include it as a criterion to evaluate children's hospitals. Furthermore, this new criterion is also validation for the importance of hydrocephalus treatment in the specialties of pediatric hospitals. This is a major milestone for both the HCRN and hydrocephalus.



## HCRN Members Make Some Exciting Moves

### HCRN Chair John Kestle Moves to Vancouver

HCRN Chair, Dr. John Kestle, has recently moved from Salt Lake City, UT, to Vancouver, BC, Canada, where he has assumed the role of Professor and Head of the Department of Surgery for the University of British Columbia. In Vancouver, he will remain the Chair of HCRN and will do clinical work in pediatric neurosurgery. In addition to his care for children with hydrocephalus, Dr. Kestle will also treat some adult patients. Congratulations to Dr. Kestle for his new role! Dr. Jay Riva-Cambrin will continue in his role as the site investigator for the Utah Clinical Center.

### Jay Wellons and Chevis Shannon Move to Nashville

Dr. Jay Wellons, who has recently been conferred his MSPH degree by the University of Alabama, Birmingham, has since been recruited to Vanderbilt University in Nashville, Tennessee to lead their Division of Pediatric Neurosurgery. He is now Professor of Neurosurgery at Vanderbilt University Medical Center and the Chief of Pediatric Neurosurgery at the Monroe Carell Jr. Children's Hospital at Vanderbilt. This is a significant milestone in his neurosurgical career. Dr. Wellons will continue his Investigator role with HCRN and will continue to lead the studies on hydrocephalus due to intraventricular hemorrhage in premature babies. Congratulations to Dr. Wellons and best wishes in this new challenge!

Joining Dr. Wellons in Nashville is the HCRN's Chevis Shannon, DrPH. Dr. Shannon is now a Research Assistant Professor in the Department of Neurological Surgery at Vanderbilt University Medical Center and Director of the Vanderbilt Pediatric Neurosurgery Clinical Research Initiative at Monroe Carell Jr. Children's Hospital at Vanderbilt. Dr. Shannon will continue her role with the HCRN as the Follow-Up Principal Investigator of the SOPHH Study. Congratulations to Dr. Shannon on her career move as well!

### Dr. Curtis Rozzelle Joins HCRN

Dr. Curtis Rozzelle has stepped into the role of Site Investigator at our HCRN Clinical Center in Birmingham, Alabama. Dr. Rozzelle is an experienced pediatric neurosurgeon and has previously published randomized clinical trials in hydrocephalus. We are pleased to have him as part of the HCRN team.



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

<http://www.hcrn.org>

## 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.