



HCRN update



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The Power of a Registry

Our four-center pediatric hydrocephalus surgery registry is now live and collecting data! This is a powerful step in our fight to better understand this condition, its treatments, and outcomes.

Why is a registry so powerful? Because hydrocephalus is diagnosed in a small percentage of live births (about 1 in 1000), no single hospital institution can generate enough data from its own patient population to draw meaningful conclusions about the best standards for diagnosis, treatment and expected outcomes.

The HCRN registry will collect de-identified information on all patients seeing surgeons in our network. Network-wide data collection will accelerate accrual of data. This is a detailed digital registry that will hold a rich trove of data against which to test hypotheses about how best to treat the condition. Because we are tracking outcomes over time, we can also correlate patient characteristics, etiology, and treatments to validated measures of success. Thanks to all our researchers and data coordinators for developing this important tool for discovery.

HCRN Researcher Finds \$1.4 – 2.0 Billion Spent on Inpatient Pediatric Care for Hydrocephalus

Dr. Tamara Simon, in conjunction with the HCRN, recently published a paper titled “Hospital care for children with hydrocephalus in the United States: utilization, charges, comorbidities, and deaths” in the *Journal of Neurosurgery: Pediatrics* in February, 2008. She found that “For each year of the study, there were 38,200–39,900 admissions, 391,000–433,000 hospital days, and total hospital charges of \$1.4–2.0 billion (in 2003 adjusted dollars) for pediatric hydrocephalus.” These figures represent the largest estimated costs of hydrocephalus in the United States for patients of any age. These costs do not include adult care costs, outpatient costs or economic costs associated with ongoing hydrocephalus care so the actual costs are likely much higher.

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“Hydrocephalus research efforts received \$5.2, \$4.1, and \$3.8 million from the NIH in fiscal years 2003–2005 despite inpatient charges of nearly 2 billion dollars in 2003. The incidence of cystic fibrosis (1:2000–1:3000 Caucasian births) is comparable to hydrocephalus, and inpatient charges totaled \$0.59 billion in 2003. Cystic fibrosis researchers have obtained \$117, \$128, and \$89 million in funding in fiscal years 2003, 2004, and 2005, respectively.” Simon, T, et. al. Journal of Neurosurgery: Pediatrics 1:131–137, 2008

HCRN Vision: *Our vision is that, in 5-10 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. Over that same timeframe, we envision greater attention and financial resources directed toward hydrocephalus research and treatment.*

It’s All About Collaboration

Imagine how long it would have taken if just one person, or one small team in one location, tried mapping the whole human genome. We’d be waiting around for 100’s of years. The power of collaboration in science is speed and quality. More people working on the same problem, together, can unlock the code quickly.

But collaboration is hard work. Building trust, a common vision, mission, and culture are important foundations for good collaboration.

We are happy to support excellent collaborative practices by bringing together our research team at periodic conferences. At our HCRN conferences we discuss protocols and policies to ensure the best data qualities and studies possible. The photo below was taken at our annual meeting in Salt Lake City In addition to conferences, HCRN participants are linked by the latest technologies for group collaboration, hosted by our data center in Salt Lake City in March, 2008.



From left to right: (back row), Dr. Thomas Luerssen, Dr. James Drake, Dr. Jay Riva-Cambrin, Dr. Marion L. Walker, Dr. W. Jerry Oakes, Dr. John “Jay” C. Wellons, III, Dr. William Whitehead, Dr. John Kestle, Chevis Shannon (front row) Dr. Abhaya Kulkarni, Lindsay O’Connor, Rich Holubkov, Sheila Nguyen, Tracey Bach, Brittan Browning

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To make a contribution to the HCRN

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