

Hydrocephalus is the #1 reason for brain surgery for children in the U.S.

Top Geneticists to Study Hydrocephalus at Seattle Children's

The Hydrocephalus Research Guild (HRG) is thrilled to announce that two world-class researchers are coming to Seattle Children's Research Institute to focus on hydrocephalus at the Institute's Center for Integrative Brain Research (CIBR). What an exciting payoff for three years of fundraising and hard work!

William B. Dobyns, MD, PhD, is among the top ten pediatric geneticists in the country and has published numerous articles on hydrocephalus. He will serve

as CIBR's hydrocephalus section chief. CIBR has also recruited Kathleen Millen, PhD., and her research team. She is an expert geneticist who has also published widely. Drs. Dobyns and Millen recently discovered the genes underlying Dandy-Walker malformation. Currently colleagues at the University of Chicago, they will arrive in Seattle this summer.

According to Dr. Nino Ramirez, director of CIBR, bringing these renowned researchers on board moves

CIBR into the ranks of top research institutes doing hydrocephalus research in North America. "Furthermore, our work will be unique nationally and internationally because

Dr. Dobyns will head a section whose team members will take a holistic view of hydrocephalus, integrating molecular biology, genetics, and other components of brain research," says Dr. Ramirez.

He adds, "As a pediatrician, neurologist and geneticist, Dr. Dobyns will bring both scientific and clinical expertise, which will be perfectly complemented by Dr. Millen's expertise in bench research. We believe they are the right people to help us unlock the mysteries of hydrocephalus and hopefully uncover new treatments or even a cure."

HRG eagerly welcomes Drs. Dobyns and Millen to Seattle Children's and looks forward to supporting their research. We thank all who have played a part in making their coming possible.

"Dr. Dobyns and Millen are the right people to help us unlock the mysteries of hydrocephalus."

Dr. Nino Ramirez, Director
Center for Integrative Brain Research

Watch For It!

Our major 2010 fundraising efforts won't require you to get dressed up or leave your home, but you *will* get the chance to help us continue funding the exciting hydrocephalus research you'll read about in this issue!

Watch our website and your mail for more information. Or, to help us save costs and trees, send an email to info@hydroresearch.org with the subject line: Please add me to your email list.

Our kids thank you for your generous support. You are making a difference.

HRG's 2009 Gala Raises \$183,000

In late October, the Hydrocephalus Research Guild (HRG) benefiting Seattle Children's welcomed more than 250 generous guests to our Venetian carnival-themed gala sponsored by Filament Advisors in the Hyatt Regency in Bellevue.

After a successful silent auction, guests gathered in the ballroom for an evening

emceed by our honorary chair and master of ceremonies, King 5 News co-anchor Dennis Bounds. Dr. Nino Ramirez, director of Seattle Children's Center for Integrative Brain Research was our special speaker. And high school sophomore Mary Conyard shared what it's like to live with hydrocephalus, concluding, "We need your help."



Gala notables (left to right): King 5 News co-anchor Dennis Bounds, honorary co-chair and master of ceremonies; director of Seattle Children's Center for Integrative Brain Research Dr. Nino Ramirez, speaker; sophomore Mary Conyard, speaker; HRG president Betsy Conyard, and Filament Advisors representative Conrad Gehrman.



And help her listeners did, after giving the teenager a prolonged standing ovation. They donated generously during the live auction, the “raise the paddle to hire a researcher” event, and the spirited dessert dash.

Gala proceeds, including donations sent in by people who could not attend, exceeded

\$183,000—bringing us recognition from Seattle Children’s Guild Association as one of five top fall fundraising auctions.

To Filament Advisors, all other sponsors, our presenters and speakers, generous donors, and other contributors and volunteers, we say a heartfelt “thank

you!” You are helping to make the hydrocephalus research taking place at Seattle Children’s a reality.

Go to www.hydroresearch.org to see more gala pictures or the gala video produced by ProMotion Arts, “Faces of Hydrocephalus.”

Clinical Studies Hold Promise of Improved Treatments and Outcomes

HRG is helping to fund, in collaboration with the Hydrocephalus Clinical Research Network (HCRN), a clinical research position in Seattle Children’s Neurosurgery Department.

Under the direction of principal investigator and pediatric neurosurgeon Dr. Samuel

Browd, clinical research coordinator Amy Anderson, BSN RN, is building a patient registry that includes a detailed record of kids who come in for surgery and of their treatment. According to Anderson, who also coordinates several other hydrocephalus-focused studies, comprehensive patient registries will allow researchers to track variations in practice and identify possible care improvements.

Through HCRN, other North American children’s hospitals are also working on these projects and sharing their data. The promise of HCRN is that this collaboration will lead to nation-wide adoption of standards of care that improve treatments and outcomes for kids suffering from

hydrocephalus (see www.hcrn.org).

While Anderson’s job requires data gathering and analysis, what she loves most is connecting with kids and their parents. “I get to see how happy the families are that hydrocephalus is finally receiving this kind of attention,” she says.

Dr. Browd is also pleased. He talks about the day when “hydrocephalus is relegated to the historical record of pediatric neurosurgery.” Collaboration with other premier children’s hospitals and with bench scientists will move us closer to that day, he believes.



Amy Anderson, clinical researcher; and Samuel Browd, pediatric neurosurgeon.

“Research provides the ultimate pathway for a cure.”

Dr. Samuel Browd
Seattle Children’s Neurosurgery Department

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Hydrocephalus Research Report is a publication of the Hydrocephalus Research Guild (HRG), a special interest guild of Seattle Children’s Hospital, Seattle, WA. HRG seeks to fund research at Seattle Children’s to find better treatment outcomes and someday find a cure for hydrocephalus.

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