

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

## FAMILY/SCIENTIST CONNECTIONS AID RESEARCH GOALS

The children—kids with hydrocephalus and their siblings—peered through microscopes in a small lab. They opened their eyes wide at computer screens with squiggly lines and tubes with bubbling liquid. And they asked lots of questions—questions that were answered in kid-friendly fashion by a small group of dedicated neuroscientists in the Center for Integrative Brain Research at Seattle Children's Research Institute.

The children's parents—Hydrocephalus Research Guild (HRG) members—looked and questioned, too, during two tours hosted earlier this year by Center Director Dr. Jan-Marino "Nino" Ramirez and his staff. Afterwards, parents and scientists alike expressed the hope that connecting hydrocephalus researchers with affected families will hasten the day when so many kids will not suffer debilitating headaches, require frequent surgeries, or live with physical and cognitive impairments.



Back row (left to right): Dr. Sebastien Zanella, Dr. Henner Koch, Center Director Dr. Jan-Marino Ramirez, Dr. Atsushi Doi, and researcher Seoan Marler who is holding Morgan. Front row: Allison, Svend, \*Skylar, \*Claire, and William (\*siblings of kids with hydrocephalus).

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### FAMILIES SEE SCIENCE AT WORK

To kick off the January 9 tour, attended by about two dozen HRG members and their children, Dr. Ramirez presented a brief

slide show in which he reviewed nervous system and cerebrospinal fluid (CSF) details and outlined the lab's research goals. Following his presentation, the HRG

## MARK YOUR CALENDARS FOR THE HRG VENETIAN CARNIVAL ON OCTOBER 24!

You won't want to miss our carnival-themed gala and auction emceed by Seattle King 5 News anchor Dennis Bounds and featuring Dr. Jan-Marino Ramirez, director of the Center for Integrative Brain Research at the Seattle Children's Research Institute. For more information, see [www.hydroresearch.org](http://www.hydroresearch.org) or call Lori Poliski at 425-482-0479.

Where: **Hyatt Regency in Bellevue**  
When: **October 24, 2009, 5:30 p.m.**



*A magnified slice of mouse brain fascinates Svend.*

visitors asked questions and then toured the lab. The March 5 visit was a follow-up lab tour for 14 parents and children.

In the lab, parents peppered researchers with questions about the experiments and processes that might some day benefit their kids. Lori Lynn Phillips liked learning about the complicated process for making artificial CSF, while Cory Peffer was fascinated by “the small slice of mouse brain that could actually stay ‘alive’ during a testing phase.”

But actually connecting with the research team made the greatest impression on Cory and Lori Lynn. Cory commented, “You quickly understand that [the researchers’] work is their passion. And you realize that there’s no magic involved in what they are doing—it’s money and man-hours that will lead to a cure.”

The team’s rapport with the children impressed Lori Lynn. “It was great to see the scientists showing the kids the work they are doing,” she said. “And I hope it was helpful for the researchers to see the families who hope to benefit.”

#### KIDS INSPIRE SCIENTISTS

It was. Shortly after the first tour, Dr. Ramirez shared his reactions in an article in the February 2009 *Interaction* (see [www.research.seattlechildrens.org/about/mt/interaction](http://www.research.seattlechildrens.org/about/mt/interaction)), Seattle Children’s monthly magazine for researchers. He noted how one young boy kept returning to a microscope that revealed a magnified slice of brain tissue swimming in artificial CSF. “He kept looking into the lens, saying, ‘I never want to forget this for the rest of my life!’” recalled Dr. Ramirez.

That young boy was Svend Phillips, eight-year-old son of HRG members David Lundsgaard and Lori Lynn Phillips.

Svend suffered a Grade III intraventricular hemorrhage (brain bleed) shortly after his premature birth; his first shunt was placed when he was about a month old. A veteran of five brain surgeries, Svend is now a gregarious, curious second-grader who visited the lab twice, bubbling with enthusiasm, eager to see and touch everything, and asking a lot of questions.

So did the other kids, leading Dr. Ramirez to comment, “Talking with these highly intelligent kids, feeling their energy about our research, and hearing about their struggles was something you simply can’t learn about by reading a paper.”

#### CONNECTIONS INFLUENCE FUTURE RESEARCH

Dr. Ramirez noted that the HRG tours have helped influence the direction of some of his lab’s future research. “[HRG members and their children] have opened our eyes to the extreme need that exists. I see incredible potential in expanding the platform for research in this area,” he said.

That prospect encouraged Cory, who said, “It would be great to be able to fund a

team of scientists dedicated exclusively to hydrocephalus.” And it pleased Lori Lynn, who recalled sitting with baby Svend years ago in a neurosurgeon’s office and talking with a mother whose daughter had had 11 surgeries. “I could not imagine having to hand my son off for surgery so frequently,” she said. Now she can imagine it only too well, so her greatest hope is for a scientific breakthrough that leads to a cure or at least a way to avoid the need for repeat surgeries.

And Svend’s reaction to the lab visits? “It was so cool!” he said with typical enthusiasm. In fact, he confided, he might want to be a scientist when he grows up. “Or maybe a race car driver,” he added.

Whether Svend grows up to be a scientist,

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*Dr. Nino Ramirez, Director  
Center for Integrative Brain Research*

a race car driver, or something he’s not even thought of yet, his parents’ hopes for him are the same as the hopes of all parents—that their children will grow up happy and healthy and have productive lives. The power of family/researcher connections surely plays a part in turning those hopes into reality for kids with hydrocephalus.



*Dr. Doi boosts William for a better view.*

## RESEARCH UPDATE: WHERE THE MONEY GOES

The Hydrocephalus Research Guild was founded in 2006 and with your help, we have raised over \$450,000 to date including direct and indirect efforts. This money goes directly to Seattle Children's Hospital's new research division—the Seattle Children's Research Institute (SCRI)—for hydrocephalus research.

Scientific research includes *basic* research—what happens in the laboratory and at the bench—and *clinical* research—work that includes patients. The Hydrocephalus Research Guild is funding both types to help children with hydrocephalus and other neurological diseases.

Your contributions provide the critical seed funding scientists need to develop a hypothesis, conduct experiments, and collect data over a short term of 3-5 years; this enables them to apply to the National Institutes of Health (NIH) for long-term funding. Thank you!

HRG is pleased with the recent hire of Dr. Nino Ramirez, the director of the new Center for Integrative Brain Research at SCRI. He comes to Seattle Children's from the University of Chicago, where he was the chair of the Department of Organismal Biology and Anatomy in the Pritzker School of Medicine.

Dr. Ramirez hopes to increase the focus on hydrocephalus research and is conducting a search for a hydrocephalus section chief. In addition, HRG is funding \$10,000 for Dr. Ramirez's team of dedicated researchers to conduct basic research investigating the generation and consequences of hydrocephalus.

To date, \$25,000 has been used by Dr. Eugene Kolker (chief data officer and principal investigator, Center for

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Developmental Therapeutics, Seattle Children's Research Institute) to analyze the proteomics research (study of protein composition of cerebrospinal fluid) that was previously conducted by Dr. Anthony Avellino and Dr. Richard Morrison.

Up to \$80,000 will be used to fund a clinical researcher position for one year for Seattle Children's Neurosurgery involvement with the Hydrocephalus Clinical Research Network (HCRN).

HCRN is a national network of parents, brain surgeons, philanthropists, and



*In a borrowed lab coat, Allison shares a moment with Dr. Ramirez.*

business and nonprofit experts who have joined forces to investigate ways to improve treatment for hydrocephalus patients. The hope is that a multi-site collaboration will overcome obstacles that have stymied previous research efforts: too few patients to study in any one hospital, uncoordinated research, and under-staffed studies. To learn more about HCRN, which Seattle Children's recently joined, go to [www.hcrn.org](http://www.hcrn.org).

## Whether you give cash or in-kind, we are deeply grateful for your contributions. Our kids are, too!

**HRG's fall non-event** raised over \$25,000 for hydrocephalus research at Seattle Children's. The fundraiser began when HRG members sent mailers to possible donors asking them to "Please don't save the date! Don't get all dressed up!" for a big night, but to give from the comfort of their homes. Thank you to all who donated so generously.

**Kathy Emery**, grandmother of seven-

year-old Max Graber, raised almost \$2,000 for the Guild when she sponsored a September 19 Jean's Day at her place of employment, Russell Investments, in Tacoma. During a Jeans Day, employees who contribute at least \$5 to a designated charity may wear jeans to work. Thank you, Kathy.

The pictures in this newsletter and other HRG print and electronic pieces are

the loving work of photographer **Nikki Gale** ([www.nikkigalephotography.com](http://www.nikkigalephotography.com)). Thanks, Nikki, for donating your time and talents to capture the spirit and courage of our beautiful kids.

**Lisa Herter**, aunt of 10-year-old Christian Norquist-Skeets, donates the design and layout through her firm, Ubiquity ([www.ubiquitygroup.com](http://www.ubiquitygroup.com)) for HRG's print pieces. Thank you, Ubiquity.

## HRG MEMBER NEWS

**Paul Gross, father of four-year-old William, has been elected Board Chair of the Hydrocephalus Association (HA).** HA is the nation's largest and most widely respected organization dedicated to hydrocephalus, providing support, education, advocacy, and research for people affected by hydrocephalus and the professionals who work with them.

We are proud that one of our members is leading this association. For more information, see [www.hydroassoc.org](http://www.hydroassoc.org). Congratulations, Paul!

**On April 1, Seattle's King 5 TV News featured HRG member Kelli Marble and her 14-year-old daughter Brianna in a lead story about the effects of proposed state budget cuts on Seattle Children's.**

Kelli movingly described Brianna's 30 plus hydrocephalus-related surgeries and Seattle Children's critical role in providing medical care for children, no matter their families' financial situation.



*Brianna went on camera for King 5 TV News.*

## WHAT IS HYDROCEPHALUS?



*Researcher Seon Marler bonds with young Morgan.*

Hydrocephalus is a life-long neurological condition that has no known preventative treatment or cure. Once referred to as "water on the brain," hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF)—a clear fluid surrounding the brain and spinal cord—within cavities called ventricles inside the brain.

Hydrocephalus may be acquired or congenital (present at birth). It occurs in one child per 1,000 live births and can cause minor to severe physical and cognitive disabilities.

Survival for someone with hydrocephalus largely depends on surgical placement of a shunt—a flexible tube placed into the brain

that diverts the flow of CSF. Developed in 1952, shunts have high failure rates (about 50 percent after just two years), leading to multiple invasive surgeries and the possibility of other complications, including infection and brain damage.

Hydrocephalus is the number one reason for brain surgeries for children in the United States and adds more than \$1 billion a year to health care costs in our country. To learn more or to make a donation to the Hydrocephalus Research Guild, visit [www.hydroresearch.org](http://www.hydroresearch.org).



*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.

Hydrocephalus Research Guild  
PO Box 141  
Woodinville, WA 98072  
p. 425-482-0479  
e. [info@hydroresearch.org](mailto:info@hydroresearch.org)  
[www.hydroresearch.org](http://www.hydroresearch.org)