



MEDIA ADVISORY



hydrocephalus
clinical research network

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Hydrocephalus Association and Hydrocephalus Clinical Research Network Formalize Partnership *HA commits to sustaining HCRN's groundbreaking research*

Seattle, WA – The Hydrocephalus Association (HA) and the Hydrocephalus Clinical Research Network (HCRN) announced today that the two organizations have signed a partnership to ensure the continuation of HCRN's substantial research into treatments and outcomes in hydrocephalus that benefit HA's membership. HCRN Chairman Dr. John Kestle will join the board of directors of HA and the organizations will work together to promote HCRN's research.

"We are honored to be partnered with the first and only clinical research network for hydrocephalus," said Dawn Mancuso, CEO of the Hydrocephalus Association. "In just a few short years, this group of committed doctors has already improved the treatment of hydrocephalus by significantly reducing infection, which is one of the most difficult complications."

The partnership expands HA's Research Initiative beyond its young investigator and basic science awards with a burgeoning body of research intended to advance treatments for those who suffer from hydrocephalus. HCRN conducts multiple simultaneous studies, so it is able to advance research more quickly than traditional clinical studies. HA will promote HCRN's research and funding needs to its members. HA's funding commitment is substantial – more than \$1M over the next three years. These funds support the shared data coordinating center located at the University of Utah which pools patient populations and allows them to be studied more rapidly, as well as the research site coordinators at each center.

"HA provides an invaluable service to the patient population we study" said Dr. John Kestle, Chairman of HCRN. "We believe this partnership will greatly enhance our investigations into the most important problems for those affected by the condition."

HCRN receives support from a variety of organizations including private donors, participating hospitals, foundations and the National Institutes of Health. While HCRN will always seek public funding for its studies and scientists' careers, the partnership will allow HCRN to continue its promising work with more assurance of continued support.

About the Hydrocephalus Association

The Hydrocephalus Association (HA) is a 501(c)3 charitable organization dedicated to eliminating the challenges of hydrocephalus, a medical condition resulting from an abnormal accumulation of cerebrospinal fluid (CSF) within cavities of the brain called ventricles. Hydrocephalus affects people of all age groups across the globe. The Association works to meet its mission through the advancement of research, the promotion of advocacy, and the provision of support and education.

About the Hydrocephalus Clinical Research Network

The Hydrocephalus Clinical Research Network (HCRN) is a collaborative research effort of 14 doctors at seven institutions in North America with a Data Coordinating Center at the University of Utah, and seven Clinical sites at Primary Children's Medical Center in Salt Lake City, the Children's Hospital of Alabama in Birmingham, Pittsburgh Children's Hospital, St. Louis Children's Hospital, Seattle Children's Hospital, Texas Children's

Hospital in Houston and The Hospital for Sick Children in Toronto . HCRN's mission is to dramatically improve the lives of kids suffering from hydrocephalus by conducting important and field-changing, multi-center clinical research.

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