

Contact: Kristen Kurtz  
Kellen Company on Behalf of  
The Hydrocephalus Association  
Phone: 917.561.2406  
Email: [kkurtz@kellencompany.com](mailto:kkurtz@kellencompany.com)

4340 East West Highway  
Suite 905  
Bethesda, MD 20814  
Phone 888 598 3789  
Fax 301.202.3813  
[www.hydroassoc.org](http://www.hydroassoc.org)



For Immediate Release

**Medical Practitioners Unite with Patient Community to  
Expose Neglected Brain Condition**

***More than 1 Million Americans Affected,  
700,000 Have Undiagnosed or Misdiagnosed Condition***

*New York, NY (September 17, 2014):* Fifty years after neurosurgeon Dr. Salomón Hakim first identified a treatable form of dementia he called Normal Pressure Hydrocephalus (NPH), an estimated 80% of the 700,000 Americans with NPH still suffer through this devastating but treatable condition because they have been unable to get an accurate diagnosis and proper treatment.

On October 16, members of the medical and research communities will join those whose lives have been affected by NPH, as well as other forms of hydrocephalus, at the 2014 Vision Dinner in New York City. The Vision Dinner will honor Dr. Hakim and other doctors who are leading the efforts to detect, treat and eventually find a cure for all forms of hydrocephalus.

Hydrocephalus is a chronic life-threatening condition that causes an abnormal accumulation of cerebrospinal fluid within the brain. There is no cure for hydrocephalus, which currently affects over one million Americans, from infants to the elderly, including two members of the family of Craig and Vicki Brown, the founders and hosts of the Vision Dinner.

The Browns created the Vision Dinner to shine a light on hydrocephalus which is as common as Down syndrome, but receives only 1/30th the public research funding. Similarly, both hydrocephalus and Parkinson's afflicts a comparable number of Americans, yet Parkinson's receives \$135 million in funding, and hydrocephalus receives \$6 million according to the National Institute of Health.

"It is critical for individuals and those within the medical community to know more about hydrocephalus. Awareness and funding for research for better treatments and a cure is paramount,"

said Craig Brown, Senior Vice Chair, Hydrocephalus Association. “It is a healthcare crisis—in addition to the widespread misdiagnosis, the cost of treating hydrocephalus exceeds over 2 billion dollars per year in hospital charges alone.”

At the Vision Dinner, Carlos Hakim, PhD, a neuroscientist and biomedical engineer, will accept the Inspiration Award from the Hydrocephalus Association on behalf of his late father, Salomón Hakim, MD, PhD, in recognition of his father’s research that led to the discovery of NPH as a distinct, treatable condition. Even today, NPH is often misdiagnosed because the symptoms are similar to those associated with Alzheimer’s disease or Parkinson’s disease. With proper diagnosis and treatment, NPH sufferers can be rescued from oblivion and regain more than their memories and mobility; they can literally get their lives back.

A Leadership Award will be presented to John R. Kestle, M.D., FRCSC, FACS, Professor and Vice Chair, Clinical Research Department of Neurosurgery, University of Utah. Dr. Kestle is a pediatric neurosurgeon who led the creation of the Hydrocephalus Clinical Research Network (HCRN). The HCRN has run the longest standing clinical research network for children born with hydrocephalus and seeks to dramatically improve their lives by conducting important and field-changing, multi-center research.

The Vision Dinner keynote speaker will be Michael A. Williams, M.D., Medical Director, Department of Neurology, The Sandra and Malcolm Berman Brain & Spine Institute, Sinai Hospital of Baltimore. Dr. Williams, a neurologist who specializes in NPH, is working with the Hydrocephalus Association to create an adult research network to increase research in all forms of adult hydrocephalus and to attract more physicians and researchers to the field.

### **More About Hydrocephalus**

Hydrocephalus is a chronic, life-threatening condition that can only be treated with brain surgery. It is typically treated by inserting a small tube, called a shunt, into the brain to drain excess cerebral fluid. Shunts save lives but frequently malfunction, become infected or blocked. It is not uncommon for a person with hydrocephalus to have ten or more shunt-related brain surgeries during the course of their lifetime and some individuals have more than 100 surgical procedures. Each surgical procedure within the brain brings the risk of unknown long-term cognitive and health effects.

The Hydrocephalus Association, the largest advocacy group dedicated to hydrocephalus, is fighting on all fronts to improve the quality of life for people living with the condition. The Vision Dinner is meant to encourage more research, increase public awareness, inspire physicians to specialize in hydrocephalus, and continue to guide and support people living with the condition.

**About the Hydrocephalus Association**

Founded in 1983 by the parents of children with hydrocephalus, the Hydrocephalus Association is the nation's largest and most widely respected organization dedicated to hydrocephalus. More than 60 percent of HA's funding comes from individual donations, and approximately 35 percent comes from foundation and corporate grants. The Hydrocephalus Association's mission is to promote a cure for hydrocephalus and improve the lives of those affected by the condition. For more information, visit the Hydrocephalus Association website at [www.hydroassoc.org](http://www.hydroassoc.org) or call (888) 598-3789.

###