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August 3, 2011

Dr. Francis Collins, Director
National Institutes of Health
9000 Rockville Pike
Bethesda, Maryland 20892-0002

Dear Dr. Collins:

I am writing to express my support for expanded research into hydrocephalus, a serious neurological condition characterized by the abnormal buildup of cerebrospinal fluid in the brain. Leaders in the medical field, seniors, veterans and patient communities support additional resources for critical research into the causes and treatment of hydrocephalus,

For decades, hydrocephalus was thought to be a neurological condition affecting a small number of children who were successfully treated with implantation of a shunt. As we are learning more about traumatic brain injuries among our armed forces and neurological problems affecting the elderly, our understanding of hydrocephalus is changing rapidly, and medical research must keep pace both to assist those with this condition, and to reduce medical costs.

Congress recognized the importance for heightened research on hydrocephalus in 2006, when the need for better treatments was highlighted in the report accompanying the Labor Health and Human Services Appropriations bill. In 2007, Congress expanded the call for more research into hydrocephalus with language included in the fiscal year 2008 Labor Health and Human Services report. The following year, Congress passed a Joint Resolution expressing support for increased research into hydrocephalus.

Intensive support for expanded hydrocephalus research has recently taken on additional urgency given two important findings:

- a incidence of hydrocephalus among members of the military and veterans from Iraq and Afghanistan who have suffered traumatic brain injuries; and
- recognition of the prevalence of Normal Pressure Hydrocephalus (NPH), a form of the condition that affects older adults and often goes undetected or misdiagnosed for many years as dementia, Alzheimer's disease, or Parkinson's disease.

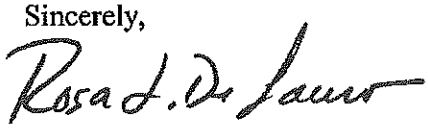
Many falsely believe the "cure" to hydrocephalus is the shunt that is generally implanted in patients. But shunt technology was invented over 50 years ago and is unreliable.
Shunts fail frequently and infection rates are unacceptably high, causing thousands of expensive

surgeries annually and prolonged medical care. In fact, the shunt has the highest failure rate of any medically implanted device, with nearly half of all shunts failing within two years. As a result, it is not unusual for teen-age children with hydrocephalus to have experienced a dozen brain surgeries.

In addition, hydrocephalus occurs in one out of every 500 babies born in the United States, a far greater frequency than many childhood conditions and diseases that receive a much higher research priority.

Given the growing numbers of seniors and military personnel who are undiagnosed yet living with hydrocephalus, in addition to the many thousands of children already living with this condition, I am writing in support of a significant expansion of the National Institute of Health's (NIH) current efforts to establish broader collaborative research efforts into the incidence, causes of and treatments for hydrocephalus. With a better understanding of who and how many people -- children, soldiers and other adults, and the elderly -- suffer from hydrocephalus and better, more coordinated research into new treatments, we can give new hope to the hundreds of thousands of people living with hydrocephalus today.

Sincerely,



ROSA L. DeLAURO
Member of Congress

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