Thank you, Mr. Chairman and Members of the Subcommittee, for this opportunity to testify on a rare birth defect called Dandy-Walker Syndrome and a commonly associated condition called hydrocephalus. The causes for both are largely unknown.

My name is Eric Cole and my son, Ryan, is affected by both. I see it as my duty as a father and my social obligation to speak for millions of Americans presently without a national voice who are affected directly or indirectly by Dandy-Walker and hydrocephalus and can not advocate for themselves. I am not a doctor and am not here to present to you a bunch of medical terms or lengthy background information. I am here to share with you some of what is needed by people with Dandy-Walker and hydrocephalus and submit to you two ways in which you can help.

While Dandy-Walker is present from birth, hydrocephalus can be acquired for no known cause or secondary to many conditions, illnesses or injury. The treatment for individuals with Dandy-Walker generally consists of treating the associated problems versus the syndrome itself. Hydrocephalus is treated today the same way that was developed in 1952, by inserting a special tube called a shunt into the brain to drain off excess fluid.

I do not see my life as being determined by circumstances. Instead, I believe that we create our own future and can work to define how things will turn out for ourselves and those we love. This belief extends to our nation’s most fragile members of society. That is why I am here to ask that you please introduce language into the fiscal year 2008 House appropriations bill for the National Institutes of Health to form a coordinating committee for Dandy-Walker and hydrocephalus research. This coordinating committee would report its finding to the public on the progress in the epidemiology, pathophysiology, disease burden, treatment improvements, diagnoses and awareness for Dandy-Walker and hydrocephalus.

We also need open dialogue between researchers, clinicians, advocates and members of society who are themselves directly affected by Dandy-Walker and hydrocephalus. That is why I am also asking the Subcommittee to please introduce language into the fiscal year 2008 House appropriations bill for the National Institutes of Health to take the lead in sponsoring a workshop to increase awareness and set national research priorities for Dandy-Walker and hydrocephalus.

I understand that balancing the policy needs of our nation is a difficult job. I also believe that budget conscious initiatives like a coordinating committee and workshop will help to better disseminate the direct and indirect outcomes of translational research and move these results from the bench to the bedside in a safe and expeditious manner.

While I praise the current system of knowledge management, information dissemination and technology transfer at the NIH, coordinating committees and workshops like those previous described would also allow further opportunities for the research community to collaborate with medical practitioners, private industry representatives, advocates and people affected with Dandy-Walker and hydrocephalus.

With your leadership, guidance and support we have the opportunity to act on behalf of millions of disabled members in society who can not advocate for themselves. A coordinating committee that reports its findings to the public and a workshop as described will increase awareness and set national research priorities for Dandy-Walker and hydrocephalus. In addition, these forums will give a voice to a silent Dandy-Walker constituency and one million Americans who presently rely on 55 year old technology to treat their hydrocephalus.

Mr. Chairman, my goal in being before you and by submitting testimony is to seek your help in raising the national profile of Dandy-Walker and the condition hydrocephalus. I want to give my son Ryan and other individuals affected by this syndrome and condition the same full access, possibilities and experiences as any other person.

Ryan, who along with my wife is here today, is doing very well. He will be 2 years old this May. While his disabilities will always be something that will affect him, they do not define who he is. All I respectfully ask is that you partner with me in asking the NIH to help us raise awareness, report its progress and host a forum for open dialogue on Dandy-Walker and hydrocephalus. Thank you for the opportunity to participate in this hearing.

I will be happy to answer any questions you may have. Thank you.