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Dear Editor:

Over the last couple of weeks, the news of an 18 month-old girl in India, Baby Roona Begum, has spread rapidly through online news media. As you have reported, Baby Roona has untreated hydrocephalus, a condition where cerebrospinal fluid (CSF) accumulates in the brain, thereby causing it to swell. In untreated infants, before the skull sutures have closed, the cranium expands creating an excessively enlarged head, as is the case with Baby Roona. Untreated hydrocephalus is fatal. There is currently no cure for hydrocephalus and the treatment options require brain surgery, typically the implantation of a shunt.

In your recent series of articles about Baby Roona, you state that "Hydrocephalus is an extremely rare condition that affects only about one in 500 children the world over." This, however, is untrue. In fact, while not common, hydrocephalus is much more prevalent. One to two of every 1,000 babies are born with hydrocephalus. That would make approximately 200,000 cases each year of congenital hydrocephalus in infants around the world and approximately 12,000 cases of congenital hydrocephalus each year in India. In the United States, this makes it as common as Down's syndrome and more common than spina bifida or brain tumors. Additionally, babies can acquire hydrocephalus after birth due to brain hemorrhage, infection, tumors, trauma, or parasites, to name a few causes. In fact, people of any age can acquire hydrocephalus at any stage of life for the reasons listed above or for unknown reasons through the aging process. Normal Pressure Hydrocephalus (NPH), which primarily affects the senior population, is often undiagnosed or misdiagnosed as Alzheimer's or Parkinson's disease. It is estimated that up to 5 % of all dementia cases are actually undiagnosed cases of NPH, making it recently referred to in the U.S. press as the only "curable" form of dementia. All totaled, there are currently over 1 million individuals living with hydrocephalus in the United States alone .

Early diagnosis and treatment of hydrocephalus allows the majority of individuals to live healthy and full lives. However, there are only two treatment options currently available, both of which require brain surgery. The first entails the placement of a shunt to drain fluid from the brain. The second, called an endoscopic third ventriculostomy (ETV), creates an opening in the floor of the brain to allow for the fluid to flow . In many countries around the world, the cost for treatment as well as the access to the proper healthcare facilities presents an insurmountable barrier, leaving children in similar situations as Baby Roona.

The need for new treatment options, and better access to the treatments that currently exist, was long ago identified by our organization as a critical public health issue. As the largest and most widely respected organization devoted to serving those affected by hydrocephalus, the Hydrocephalus

Association (HA) is a charitable organization dedicated to eliminating the challenges of hydrocephalus by stimulating research and supporting people who are affected by this condition. For the past 30 years, HA has been successful in creating a community of individuals, families and health care professionals addressing the complexities of hydrocephalus in all age groups, and funding research to find better treatments – and hopefully a cure – for patients suffering with this condition worldwide.

We were very pleased to learn that Baby Roona has been able to receive the care she needs due to a global outpouring of support and funds for her care. All of us here at the Hydrocephalus Association will keep Baby Roona and her family in our thoughts as she continues through her treatment of hydrocephalus, and we gladly offer support and educational resources to her family, and all others living with this condition.

Sincerely,

Dawn M. Mancuso  
Chief Executive Officer