

## International Hydranencephaly Support Group

Providing information, hope, and support for families of children with Hydranencephaly

---

Dear Dr.

I am writing you on behalf of the International Hydranencephaly Support Group. We are a group of parents, friends and families of children with Hydranencephaly. Our chief goal is to provide information and support to families as they care for their children.

It has come to my attention that you have recently acquired a patient with this condition and that you were very pessimistic in the information that you gave to the child's family. I agree that Hydranencephaly is a very serious condition and the children with it have many challenges. However, this diagnosis does not necessarily mean that the child will not have a full and happy life. Our group has been in contact with over 200 families of children with this condition over the past 7 years. We are not Doctors, however, as parents, we do know our children better than anyone else does.

I am enclosing our "fact" sheet and brochure for your information. These give the statistics we've gleaned from several informal surveys. The most recent one was done in the fall of 2002 and had 81 participants. Unless you have cared for a similar number of children with this condition, I don't feel that it is appropriate for you to make judgment calls on what is and isn't appropriate treatment for a child. When a parent is just beginning their journey in caring for their child, they, above all, need support and encouragement. Yes, they also need to know what might happen, but they don't need it all at once. No 2 children with Hydranencephaly are the same. Many of the children have relatively few health problems while others have many from a very early age. But, medical problems and physical challenges do not mean that they will not have a quality life. My daughter had Hydranencephaly and many challenges. Yet she was the happiest, most interactive child I have ever met. She loved life. She loved being out and about. She attended school and was fully included with typical children. She loved watching videos and knew what time each day her favorite TV show (Star Trek Deep Space Nine) was on. She had only her brain stem. Her successes are not unique among our children. Many can do more than she could. Some can talk, and move, and roll.

My daughter died at the age of 11 ½. Her body simply got tired and she slowly faded away. Throughout her life, though, Doctors who were constantly dwelling on the negative sides of her condition took a lot of joy from me. I had to fight with every illness to get her appropriate treatment. I kept being told that it was morally wrong to keep her alive. That is a judgment call, and Doctors have no right to make that call for a parent. It is a Doctor's job to present the options, and to care for the child and his/her family as needed. Ultimately it is the parents that live with the decisions. I hope that in the future when you care for a family who has a child with Hydranencephaly that you will be supportive and present the facts based on a large number of children who are living with this condition, rather than your own values.

---

Hydranencephaly website: <http://www.hydranencephaly.com>

Contacts: USA: Holly Fielder: [miraklekid@aol.com](mailto:miraklekid@aol.com)  
Canada: Barb Alemán: [angelbearmom@shaw.ca](mailto:angelbearmom@shaw.ca)  
Scotland/UK: Agnes Marshall: [arachelsmum@aol.com](mailto:arachelsmum@aol.com)  
Australia: Lisa King: [lisajking@hotmail.com](mailto:lisajking@hotmail.com)