



The World that Revolves Around Hydrocephalus: Hydrocephalus and Kacee

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Hydrocephalus is a medical condition that involves the buildup of cerebrospinal fluid in the brain. Dandy-Walker is a congenital syndrome that accounts for a small percentage of hydrocephalus cases, and relates specifically to the development of the fourth ventricle in the brain. When this ventricle does not form correctly, fluid cannot flow between the upper and lower areas of the brain and spinal cord. Signs and symptoms of Dandy-Walker syndrome are variable and can include slow motor development, enlargement of the skull, irritability, vomiting, convulsions, and headaches. Intellectual development in individuals with Dandy-Walker is also variable, ranging from severe developmental disability to normal cognitive function

The World that Revolves Around Hydrocephalus: Hydrocephalus and Kacee is the memoir of a young woman living with Dandy-Walker syndrome. In this brief account, Kacee Barnes tells about her diagnosis at the age of six months and the health problems that she has coped with ever since. The book is not just an account of Kacee's disease, however. It is the story of Kacee's life. She discusses her family, normal childhood experiences like attending dances and family reunions, as well as the challenges she has faced as a result of her illness. There are photographs from Kacee's childhood showing her at various stages of development both in and out of the hospital.

There are also poignant displays of love. For example, Kacee writes: "When the fluid would build up in my head, it would push my brain up, and that would cause pain in my head when I would smile. So in order to keep the pain away, I would look down, because it felt better for my head. So when I did smile, he [Kacee's father] said he knew that the fluid was being absorbed the way it was supposed to. My dad still smiles every time I laugh or smile."

The book is very simple and there is not a lot of information here to help the reader understand hydrocephalus. Those looking for clinical information will need to look elsewhere. The value in this book comes from the honesty of the author, and her willingness to expose her hopes and dreams. She states that her intentions in writing this book are to share her story in the belief that someone who reads it may feel less lonely as a result. She writes, "I was lonely for communication. I wanted to relate to someone like me. However, since I am unable to relate to anyone, maybe somehow, someone may in some way be able to relate to me, someday." Such noble intentions are certainly worthy of praise.

CATHERINE THURESON (September 27, 2010)

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