

## **A Sibling's Perspective**

**By Mary Kay Cowen, Chair, VOR Membership Committee**

My brother, Thomas Waldo (Tommy) has lived at the North Lake Supports and Services Center in Hammond, Louisiana for 45 years. He is profoundly mentally retarded, with an I.Q. of 8 months and motor skills of 18 months. He is very mobile and loves to be outside. North Lake provides the sanctuary he requires to allow all the freedom he seeks under the watchful and loving eyes of his “other family” – the direct care staff.



My father, Harry Waldo, was very much involved with the care and issues connected with Tommy. He stayed active in the Parents Association (now called Families and Friends) and got involved in the politics connected with the Developmental Centers from the time Tommy moved to North Lake at the age of 6 until the day he died – 47 years later.



During those years, Daddy allowed the rest of us (Tommy's siblings) to develop our own lives and families. He would send us information every year about Tommy's Annual Meeting, but did not keep us informed on other activities. My youngest brother, Bobby, was the first to realize we needed to get involved when he moved in with Dad during his college years. By the time he graduated, he had convinced me to begin attending the Parents meetings with them.

Daddy died April 9, 2005. By then, both Bobby and I were very involved with the Families and Friends Association and I had gotten involved with Daddy on a statewide level through the Alliance of the Families and Friends Associations of Louisiana (now called the Coalition). Since my children had “grown and gone” and Bobby's family had several issues that would take years to contend with, I became Tommy's guardian.

My siblings have thanked me for keeping them informed about what's going on with Tommy and also politically. Two live in Texas and one in Florida, but there are areas they have been able to get involved – even if it is in small ways.

I encourage them to visit Tommy at least once a year (preferably more), and highlight the months I will not be able to see him. I also make sure they are aware of special activities (Family Day, Christmas Party) occurring at Tommy's home. The goal is to make sure Tommy is visited by one of us each month.

Asking not just my siblings but other interested relatives to contact their legislators, I send information from the VOR, the Coalition, and the Families and Friends Association of North Lake concerning what is going on politically.

At first, they responded by visiting Tommy twice a year and responded to my requests for action. As time passes, they have adjusted to visiting Tommy once a year and respond to my requests for action after a little extra prodding. This was expected and has not discouraged me from keeping them informed.

I am thankful I began to participate in “Tommy’s stuff” while Daddy was alive and able to guide me through the emotions that one experiences when they first get involved. It enabled me to entwine the necessary activities into my life at a pace that prevented the total upheaval I have seen other siblings experience. Hopefully, by keeping my siblings and other family members informed, they will find a way to work “Tommy’s stuff” into their lives, too.