

Joy Rosen

I am proud and excited to be a 2012 elected IRSF Family Board member. I am the grandmother (lovingly called Nunna) to Caroline King, Atlanta, Ga.

We came into this unknown family of Rett Syndrome when Caroline was diagnosed in March, 2011 at 4 ½ years old. After several years of searching for answers, we finally knew what the cause behind her developmental delays was. As a former elementary teacher, I knew something was not right but never suspected the severity. When we received the formal genetic results I knew my daughter and son-in-law were on a journey no one is prepared for and realized I had to step in and get everyone involved with a support organization. How lucky we were to immediately find IRSF.

Caroline has 5 BOY cousins so she is the Princess that doesn't talk back but she sure lets them know what's on her mind and what she wants – and of course they jump to her beckon call.

I knew that we all needed an education on what we were experiencing and what was a head living with Rett Syndrome and the place to do that was the Family Conference in Boston. It was there that I knew I was hooked and part of a warm, loving group that would support us throughout the coming years.

I became an active participant on RettNet and took the opportunity to respond to new families. I felt I could be a “grandma” to all that needed a shoulder during those horrific first months. I pursued and got a State Proclamation for Rett Awareness in GA and assisted with a very successful Strollathon.

In my working years I spent several years at Apple and then with educational publishing companies so I found another niche within IRSF....offering my expertise and help to families about integrating technology into the lives of our special needs angels. I am committed to working with educational experts to develop a literacy program for non-verbal children and bringing it to life for our children. I hope to continue these passions as I serve on the board and beyond!