

## Victoria Kiriara

My husband, Herb, and I live in Honolulu, Hawaii with our daughter Michelle and three special dogs. Michelle has three sisters, a brother, and two nephews, Noah (8) and Logan (6). Her one younger sister, Nicole, with husband, Travis, visit Michelle weekly for Sunday Dinner, helping her to eat or just sit to “talk story” or play with the dogs.

When Michelle was born, 1977, no one heard of Rett Syndrome. She was a beautiful doll-like baby. Then, at 9-months, after a few months of concern about her development, she was hospitalized for “failure-to-thrive”. This was only one of many subsequent diagnoses some of which included “mother’s psychological rejection of child”, Cerebral Palsy, and Infantile Autism. It was not until 1988 at a school re-evaluation meeting that Rett Syndrome was discussed. The teacher had a video from a conference of a child with Rett Syndrome that could have been Michelle’s twin. Later that year Michelle’s neurologist confirmed a diagnosis of Rett Syndrome. At the time there were no tests, no markers, just observations of behaviors. My science background helped me with the needed objective observations.

Presently, I am a retired education administrator. As an elementary vice principal, I led many of the most challenging IEP meetings. Then as a district level administrator responsible for a complex of ten schools, K-12, I assisted each principal with needs in the area of school improvement, renewal, and adherence to legal requirements including those for the special needs population.

Finding another girl with this same rare syndrome on a small island is almost impossible. Our service agencies typically serve a wide variety of disabilities. I like that. As an example Michelle attends the monthly beach event put on by AccesSurf. It is heartwarming when, with the help of six volunteers, they are able to customize a surfboard for Michelle to lie on and ride the wave with the surfer behind her. Her tight hand clenching is a great asset to this activity.

Over the years I have volunteered to a variety of charities. Some examples of boards I have served on include: Past President Hawaii Society for Autistic Citizen (During my stay, the society proudly received a national award for our adult vocational program.), Therapeutic Horsemanship for the Handicap (Michelle rode in many Aloha Day Parades), HI Dept. of Health DD Division, Human Rights Committee, and Assistive Technology Resource Centers of HI. I am a puppy raiser for Hawaii FIDO, the only organization that trains and certifies service dogs in Hawaii. Michelle loves the dogs; they get her to smile. Michelle’s agitation makes it difficult to fall asleep. The dog will get in bed, tap her legs and then snuggle with her. With that Michelle lets out a giant sigh of release, smiles, then closes her eyes and calmly goes to sleep.

Given all my service to local charities I think it is time that I give to such a worthwhile organization as IRSF. I hope that my experiences will be helpful in moving this advisory board to productive endeavors and supportive to individual families.

Email: vkiriara@gmail.com