



# *International Member Spotlight: Christine Mutena*

I first joined the Chromosome 18 society in late 2013 when I found out my daughter had Ring 18. I'm from Kenya and we did not have local genetic testing or counselling (we still do not have counselling, though we do have a number of laboratories that have opened up) and I did not have anywhere to get information from in regards to ring 18. I was devastated to say the least but I got all the help, love, and support from the Registry.

To say the Society has been of help is an understatement. They helped me with details and explanations on what Ring 18 is and even gave me an infopack that I could share with the medical fraternity on this end. They helped me in restructuring the demon that was the diagnosis into something palatable and understandable.

Now if we have to see a new specialist all we have to do is print the infopack and give it to the new doctor... there is no need of trying to cram the details that is the diagnosis and prognosis.

In July of this year, I was privileged to attend the Chromosome 18 Decoded Conference and that literally changed my life. I met other parents going through the same journey, self-advocates who are thriving in life, doctors who are well versed in these conditions but most of all I made friends. Friends that I cannot wait to introduce my children to when they get older, friends who understood me for who I am and why I would travel thousands of miles just to attend a 3-day conference.

I came back home (okay I had a two week holiday in the US post conference) glad to know that my daughter had hope in life... that with the right care (of which we already had embarked on) she would live a long and fulfilling life. I guess it is those small reassurances that made the trip worthwhile.

For future reference, I would love to see the Registry grow to include more families in Africa. It would be great to hold our little conference in the continent and invite those in the north to come and visit. That would be great. Till then, sadly it seems I'm the only Kenyan thus far.