

Samantha's Story



Samantha is our daughter. She has ML4. I am not going to tell you our story of how we found out that she has ML4. I think that you have heard it all before. In fact when we first discovered the ML4 Foundation and read through the newsletter, the story about Paul was like reading my own life!

Instead, I am going to write how Samantha, now 4, began her journey to being successfully integrated into a mainstream Jewish school in Melbourne, Australia.

We began early intervention with Samantha when she was about 18 months. We knew something was not quite right but we were still looking for answers. Samantha together with Mum started a playskills and communication group. This ran once a week and it was a very special 2-3 hours for us. There were neither phone calls nor dirty washing to disturb me. It was just time to play, to sing, to eat (very important in Samantha's life) and to interact generally. There was a speech therapist involved in the group and she suggested Samantha and I go along to her signing group after the playskills group.

Little did I know what effect that would have on our lives. It took Samantha 6 months to understand that she could use her hands to make herself understood but imagine my delight and her revelation when she finally did the sign for "more." Of course she was referring to food! Three years on and Samantha uses and understands about 70 different signs. This is how we communicate with her. Samantha does have a few words. She can say no; more; hi; bye and OK(kay). We are also at the beginning stages of using augmentative communication aides – Compic and an electronic communication device.

We also started physiotherapy at about that time and worked with a wonderful lady who was very flexible and open to alternative therapies and encouraged me to try different options. We went to a Chinese doctor who works with pressure points. This was quite stressful, as Samantha did not readily allow him and me to do the treatment. We did not pursue this avenue although I did and still do think that there is merit in it. Samantha was in a splinted lycra suit for about 6 months. She was in it for about 6 hours a day and this gave her more stability in her hips and trunk. At this time we were still with our physio and Samantha spent time in a stand-

ing frame and in a walking frame. We also had Samantha at hydrotherapy and horse riding for disabled. Quite a lot of physical activity for a petite little girl. Today Samantha uses a Kaye-Walker. She is not yet independent in it and still needs help to get in and out and to steer.

In amongst all this there was still her occupational therapy; her regular crèche and I still worked 3 days a week. Our days were full and became more full as we now started seeing different doctors and specialists and finally got our diagnosis when Samantha was about 2 and a half. At this point I stopped work – well the paid work anyway.



It was now time to think about kindergarten and school for Samantha. My husband and I decided on a mainstream Jewish school. We felt this important for our life style as we wished future children to attend the same school. We also wanted Samantha to be aware of traditions and familiar with regular religious routines as well as being