

Diet for Life Trudy's story

PKU

My name is Trudy Smith. I was born in August 1964 in Brisbane. At that time the only test available for PKU was the nappy test, but it came back negative. Everything came back normal. However, my mother felt there was something not quite right, so kept taking me back to the doctor. The doctor told her that she was worrying about nothing and being too fussy and that she should take me home and relax because there was nothing wrong.

When I was 10 ½ months old I started to have convulsions so my mother took me to a naturopath who told her that he didn't know what was wrong but was sure it was connected with my food. He made arrangements for me to see a paediatrician. After many tests it was discovered that I had phenylketonuria. The doctors realised that my diet had caused damage to the learning part of my brain and that my parents should consider putting me into an institution because they felt that I would never be able to walk or talk or be able to live a normal life. My parents were shocked and devastated but dug their heels in and said no way, and so my journey with the PKU diet and formula began.

Cynogram was the formula at that time which had the look and texture of grey wet cement. Each meal was a nightmare for all of us as I would try to fight off having it. It was foul. I would no sooner get some down, then vomit most of it back, and then mum would have to start all over again. It took about 18 months before I could take it without bringing it back up. Even now when I smell soy sauce it reminds me of the taste of cynogram. I also had a calcium tablet every day to help with bone growth. After a few years the formula was changed to aminogram which was a bit more pleasant.

Through the Lions club for a few years at Christmas time, my mother would take me to Melbourne for the PKU Christmas party arranged by the chief dietician Mrs Betty Lynch. It was good to see other kids eating the same sort of food as I was able to eat. In 1966 my brother Gavin was born but tests proved that he was PKU free. Gavin was my best friend and we are still very close today.

I went off the diet by the age of 12, as, at that time it was believed you didn't need the special diet anymore. I attended special school until I was 16, then worked in sheltered employment for some years. I enjoyed the physical work, especially working with timber. During this time I obtained my forklift licence which I was very proud of. Then there was a change and I worked as a cleaner in the Lutheran book shop and also enjoyed making and painting pottery.

As I was getting older I used to find I would quite often run out of energy especially during the afternoon. Around this time we heard about a young woman who had PKU and was still on the special diet. After many enquires I got an appointment with Dr Bowling at the Mater hospital in Brisbane. During this appointment it was discovered that all my records and files from the Royal Brisbane Children's hospital had disappeared.

It was as if I had never been there so I had never been contacted regarding the need for me to return to the PKU diet and formula. Dr Bowling was very thorough and it was recommended that I resume the PKU diet and formula. He also added Tyrosine to my medication. After a while I began to feel as if I had more energy and things became a little easier for me. The formula at that time was PKU Express. That was much more palatable and easier to take.

We were attending a church in Queensland and I became interested in the bass guitar. It was quite a challenge for me but with a lot of support and some lessons with a very patient and understanding teacher, I was able to take my place in the music team at church. This gave me a feeling of great achievement. I believe that my faith in God, and in Jesus Christ, has helped me to overcome the difficult situations in my life.

In 2006 we moved to Lakes Entrance in Victoria. My local doctor had never had anything to do with anyone with PKU so it was quite a learning curve for him at that time. I was referred to the team at the children's hospital in Melbourne where, during my first visit, some of my missing records were found. It was recommended that I have yearly visits to the hospital, which meant a four hour drive each way, and to continue with monthly finger prick blood tests to monitor my levels. Since that time with strict attention to my diet my levels are generally pretty good. After a time the clinic moved to the Monash medical centre at Clayton and then back to the Royal Melbourne Hospital where I am under the care of Dr Julie Panetta and her team. They have been and continue to be a great support to me.

I now work as a volunteer two half days a week at one of our local opportunity shops where my main task is sorting and steaming the never ending supply of donated clothing. I find my levels of concentration can go astray sometimes but on the whole I am able to manage with the help of family, especially my mum. I am interested in many areas of craft and enjoy things like cross stitch and tapestry in my spare time. I live with my mother and step father and we are all involved with our local Church. We have two small dogs who are great companions. During the last few years we have been able to take a few cruises to many different places including New Zealand, Tahiti, and Hawaii. These cruises have been awesome especially as, with my restricted diet, most of my meals are made to my special needs.

While it can sometimes be rather frustrating, especially when eating out, at the limited types of food that I am able to enjoy, I know that it is mainly due to the low protein foods that I can have that make it possible for me to enjoy the life that I now have. I agree with the title of the article by Con Giannas which said, "Diet For Life".

Trudy Smith's story as shared by John & Shirley Ray.

