# Pompe Testimonial

## Raymond Saich, September 2011

I was diagnosed in 2002 at the age of 51, Pompe is not a new visitor to our family, as my brother passed away at 54 years old, due to Pompe. When I was first diagnosed Myozyme was not available in Australia and it was very difficult to accept the changes that would be needed.


Raymond with his wife and daughter

When you have a disease like Pompe your world just keeps getting smaller as the disease progresses, in my work I would often travel overseas but as the disease advanced, that became impossible and then soon interstate travel also became too difficult. Then I noted that I hadn't visited the local shopping centre for six months or more. The situation was made more challenging by the emotional barriers we as patients must overcome. Using a walking stick for the first time and then a wheelchair, what will people think. Now some ten years on, if someone offers help with my wheelchair or offers other help, I accept it gladly. I may not actually need help that day but I may do next week.

I started treatment with Myozyme in February 2007, a day full of emotion, my neurologist, to limit my expectations had said "if it stops the disease progression it's a success" and he was right. I believe that having Pompe Disease is about accommodating to the disease and finding a way to cope.  Once the progression stoped, it was so much easier to accommodate to the disease.

As the treatment continued, I started to feel better and regained some of my lost strength and wanted to do more. It is a challenge to find that level of doing enough but not doing too much, something I have yet to understand and conquer.

I have now been having Myozyme treatment for four and a half years and I just had my 120th infusion, my general muscle strength and lung capacity is still better than it was before I started treatment. I can still drive but I am limited as to how far I can walk, so I use a wheelchair outside the house. I am involved with a number of community projects and still keep in touch with my work colleagues, who I miss a lot.

Myozyme treatment has give me so much, I have a loving wife and a 19 year old daughter, it has given a very different outcome, to that we discussed, when I was first diagnosed. I have the greatest admiration for the team at Genzyme for seeing that they had an outstanding, life saving treatment and making Myozyme available to the patients in Australia, while regulatory approval and government funding where sought.

**Raymond Saich, Australia**