

## **Raymond's Story**

I was diagnosed with Pompe's disease (Acid Maltase Deficiency) in February 2001 after some time of increasing difficulties. I am 54 years old and I have a loving wife and 12 year old daughter who are my constant supporters. Pompe's is unfortunately not a new visitor to our family as my brother was also a sufferer and passed away of Pompe's some 10 years ago when he was only 52 years old.

The Pompe's disease and associated Skeletal Myopathy has severely damaged my back and leg muscles and the nerves in my legs. This makes walking any distance most difficult and like most Pompe's patients I have increasing respiratory difficulties particularly when sleeping.

I am no longer able to do simple things like visiting the super market or walking the dog or riding with my daughter. Due to my mobility difficulties I am also no longer able to travel as I once would both domestically and internationally. I am currently only able to work part time with the support of my employer who has been very understanding and provided me with a special office with no steps. My respiratory difficulties limit my ability to attend meetings or give presentations. If my condition continues to decline I believe that even my part time work will soon become impossible.

I now find it increasingly difficult to cough and just a simple head cold causes great distress and the potential of server complications.

My future is very uncertain and I fear for the burden both physical and financial that I will impose on my wife and daughter as the disease deepens and my independence is lost and I become dependant on my loved ones.

Raymond  
August 2005

