

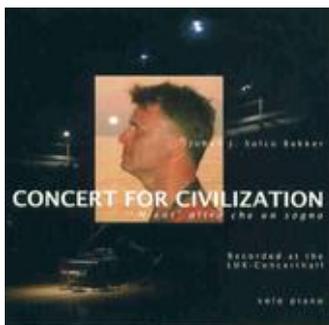
A Second Life

Johan Bakker, November 2011, The Netherlands

My name is Johan Bakker (1958). I live in the Netherlands. Until 1998 at the age of 30, I had just a normal life. Nobody noticed anything and I didn't know about my Pompe Disease. After that year I got more and more physical problems: climbing hills on the bike became difficult. I couldn't take a sprint anymore for the ball by tennis. Sometimes I had a fall. I walked uphill by bending the body forward. People thought it was strange, but no one wondered.

In 2002 I had a serious car accident. I lost consciousness while driving on the highway and crashed. Later they found out it had to do with blood gases, hypo-ventilation and my very bad respiration. In this year I became one of the directors of one of the largest water boards in the Netherlands. After 2002 a rapid deterioration started. More than 300 of my employees were my daily witnesses: 'the Boss and his Pompe disease'.

At the end of 2005 I was almost disabled. I was partially reported sick. Walking even with crutches was almost impossible. I was sleeping with a ventilator. I got an adapted car. I got a staircase elevator etc. I had to quit all kind of activities: biking, playing improvisational theatre, skiing, even walking a small distance. And worse of all: I could only play the piano for not more than 5 minutes because of pain and cramps. I realised it



The CD that I thought would be my last one.

was Myozyme or a placebo, but after a few months I felt it was Okay. I got more energy, less hours of sleeping. After 2,5 years I was able to walk without crutches and to climb a small stairs again.

In February 2006 I got my first infusion with what I hoped to be Myozyme in the clinical trial in Rotterdam. I didn't know if it



I needed to walk with crutches.



Playing the piano and giving concerts is again possible.

In April 2007 I gave my first piano concert after 7 years. I played the piano non-stop for 1,5 hours. I did it again in November 2007. It is just wonderful that I can play again without pain or cramps! On the 4th of July 2008 the U.S. Embassy of Berlin chose the music from Concert for Civilization for the opening of the new Embassy Building 'Pariser Platz 2'. Thank you for Myozyme. I am pleased and grateful that I could do something back with my music for society.

In May 2009 I played a piano concert in Italy (Palermo). I am reserve coach for the soccer-team of my son. Can you imagine: walking, standing and shouting for more than one hour on the field!?!?

In 2010 I resumed my work again fully. I am working as a director for all the 'big project files' of Water board Rivierenland for example all the dike improvements in the Mid-Netherlands (river delta). Sometimes I make 16 hrs working days. And I am just tired after such a day. I am living my second life!!



Enjoying a bike ride in Paris

In October 2010 my wife, son and I went for a short holiday to Paris. We explored Paris by bicycle!!!! After 20 years back there!!!! Okay, okay, my bicycle is an e-bike, but I could keep my balance and produce the cycling necessary to use the e-bike.

In 2011 I increased my physical training. I am still improving a little as I managed to decrease the acidification in my upper-legs. So it feels much more comfortable for my endurance. Only my diaphragm muscle is a bad boy. It is the only muscle working less.

Johan Bakker, The Netherlands