

From: **Garmt**
Date: Sun, Sep 7, 2014 at 10:20 PM
Subject: Speech ALS
To: Menko

Hi Menko,

Morgen in de middag mag ik het woord richten tot een twaalfstal ALS stichtingen die bij elkaar zijn voor project MinE. Ik weet nog niet hoe mijn stem het gaat doen dus misschien vraag ik je namens mij deze woorden uit te spreken.

Thank you Marc and Gorrit Jan.

I love the City Swim. Last year I participated, you can see where I am now. The disease has not been kind to me, so I have not been kind to the disease. I spent the last year trying to kick it in the balls. I loved doing that and I saw some interesting things along the way that I would like to share with you. I hope it is of use to you.

- **There is hope ... share yours**

After my diagnosis I often heard "that's it, now you're going to die", even from doctors. Once I realized that ALS is just a problem that will be fixed I wanted to help fix it. All of you know that it will be fixed. Give that hope to patients.

- **I am not helpless ... I may need help but I can still put up a fight**

Some patient organizations treat patients like helpless victims. I met some resistance when I wanted to get involved: "what are you doing, you're supposed to be sick". I am really grateful that the ALS foundation and the ALS center embraced my wish to help. Your patients are your biggest resource; embrace them.

- **You are not helpless ... everyone loves a good fight**

When I told the news, so many people said "I wish there was something I could do!". Guess what, there is. In my experience, people can't wait to get involved, they just don't know how. Freud said "all men are heroes in dreams". You have the dream: you stand for a solution to an incurable disease. Who wouldn't want to join that dream?

- **Money is the easiest thing to ask ... but the hardest thing to get**

In the end, money makes the world go round and keeps researchers' salaries paid. I discovered that people donate much more value if you get them to donate their skill. Their skill may be to mobilize others or to connect you with a sponsor or to design the IT of project MinE, etcetera. It was easier for me to get my employer engaged in an ALS project than it was to find the first investor for the Qurit Alliance.

- **Try saying "no" ... to an ALS patient**

We went looking for budget within our company. We targeted twenty business leaders whom could give us a share of their profit. Two colleagues and myself divided the work and asked exactly the same question for money. My colleagues got zero and I always got "yes". Get your patients to ask the tough questions. You will be surprised.