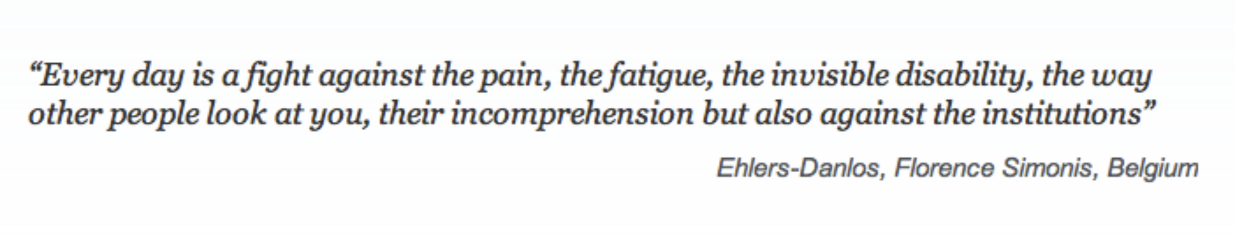
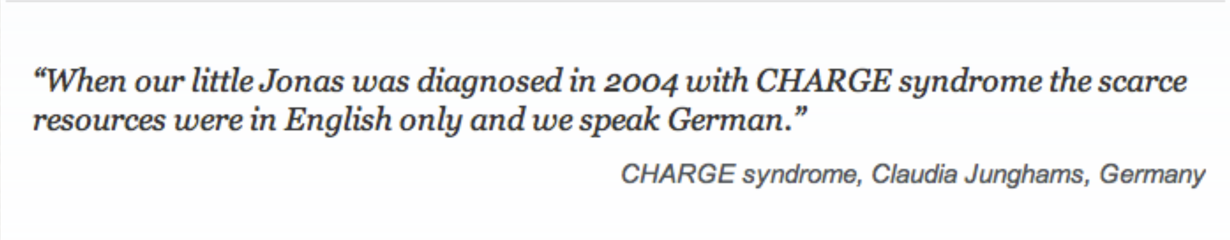
The unheard voices of the unknown millions



"Every day is a fight against the pain, the fatigue, the invisible disability, the way other people look at you, their incomprehension but also against the institutions"

Ehlers-Danlos, Florence Simonis, Belgium



"When our little Jonas was diagnosed in 2004 with CHARGE syndrome the scarce resources were in English only and we speak German."

CHARGE syndrome, Claudia Junghams, Germany

"12 years and counting. Cant sit at all, can't walk much either. ....Last visit they said growth in stomach, enlarged liver and shadow they never have seen. But when they biopsied nothing was there. .. Even went to drug rehab because doctors blamed the medications - rehab sent me home because I had a medical problem that needed to be fixed first, but they didn't know what, pain is so bad, can't do anything anymore ..... have been desperate for a long time. PLEASE help me and my family. Why can't I sit down?" dgeeg@aol.com

The unheard voices of the unknown millions

HELP me help them.

to feel IN CONTROL of their conditions
to COPE with a new lifestyle.

This is a personal project.
For a multi-lingual online community.
For rare disease patients.
I need help because I do not know if people I pay to develop the site is doing the right things or not.

- It is not profit oriented, but it is the intention that it can generate income to sustain itself in the future. I do not want to ask money/ donations from patients.
- I need someone to overlook my shoulders to:
  - check if the site is well programmed
  - to quickly check if the codes are well developed
  - advise me on IT things that I should look out for
  - if you can make more time, explain some IT stuffs to me
- It is build using Ruby on Rails.
- Design work is already completed. Programming work started on 1 July and expect to complete 27 August.
- Connect to me [Jeannie Ng] at jeannie.ng1@gmail.com or call at 0619-758 962