

Johanna 27 years

with her son Harry 6 months



- Diagnosed at 6 months of age (-87)
- F508del/F508del
- PI
- Chronic *Pseudomonas aeruginosa* – 91
- Severe scoliosis
- Asthma
- Gluten intolerance

- FEV1 2002 50% (15year)
- FEV1 2003 60 – 70%
- FEV1 2010 37 – 71% (23 year)
- FEV1 2013 59% highest value in 2 year (26 year)

Pregnant – Childbirth by december 2013 baby's weight
3.6 kg

FEV1 2014 05 59%, inhale x 2 daily and regularly and
she notice a big difference

Poetry

Extensive treatment every two hours,
the rest of her life read the doctor's judgment when I was three years

When will she have time to play with other children, when will she have time
to go to the movies?

Wondered my parents

People with Cystic Fibrosis don't have time to stuff like that
Was the response

I can not even imagine the pain my parents felt

I can not imagine how my life would have been like, if the doctor's words
were true

There is in fact a person behind this disease
A person that have to cope with all of this treatment
Who will find time to live
At the same time

Because what is a life worth if you still do not have the
time to enjoy it?

At times it feels like I'm being chased
I run first and the disease closely by
I'm running for life
Literally

Sometimes the disease catches up
Keeps me caught
I'm stuck for a while, but eventually manages to free myself
It is most likely this race that eventually will take my life
The disease will catch up and I will not cope to tear myself away

I'm running and I'm in a hurry. I hurry to catch everything before the disease
catch up for the last time
The average age of Cystic fibrosis is over fifty now
Many are older than that
But you never know
There is always something breathing down my neck

one day I will die
all other days I will live

unknown author

