

Rehabilitation in CF Care



Female patient

- born in 1993
- diagnosed at birth
 - meconium ileus
 - homozygous Delta F 508 genotype

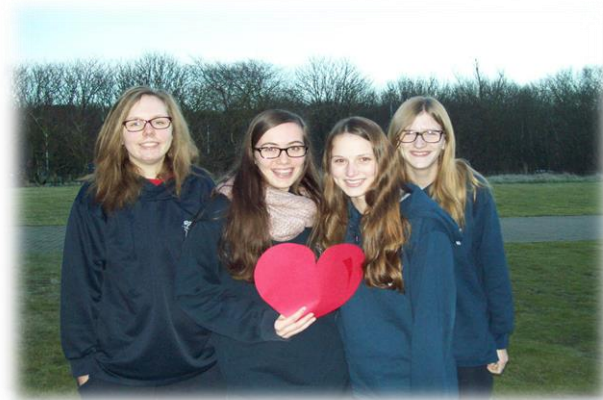
Summer rehabilitation program

- first contact with our Centre in 2004
 - 3 to 4 weeks rehabilitation program
 - stable health
 - pseudomonas aeruginosa since 2006
 - for the next 3 summers



Summer rehabilitation program

- sports – therapy- fun in a domestic environment
- physiotherapy (2 to 3 times a day)



- contact with other CF patients and chronic ill children

Summer rehabilitation program

- living together in group
 - under supervision of nurses and educators
- our goal:
 - provide tools to improve/stabilize health and self-care
 - trough out:
 - physiotherapy
 - dietary advice
 - sports
 - education
 - ...



this on an individual basis

Summer rehabilitation program

- 1x /week psychologist
 - most difficult part for her:
 - to let her illness come first
 - the confrontation with the physical decline and mortality
 - picture perfect view was broken
 - hard for her
 - especially hard for her parents

Summer rehabilitation program

- 4 years have past since her last admission:
 - age of 17
 - general decline:
 - several admissions to a general pediatric ward for IV therapy
 - PAC
 - heavy winter period
 - *Achromobacter Xylosoxidans* since 2012

Summer rehabilitation program

- increased energy needs
 - weight loss
- OGTT was not good
- more and more difficult to experience life as her peers
 - mentally and fysically

Pre-transplant admission

- march 2013
 - active on the lung transplant donorlist
 - over 3 years the FEV1 declined from 79 % to 33 % her last admission
 - almost in constant need:
 - IV therapy with AB and Medrol[®]

Pre-transplant admission

- TPN before her admission in our centre
 - problems keeping her weight stable
- anxious and trouble sleeping
- at the same time RELIEF
 - chance for a new and positive future



Pre-transplant admission

- trying to promote self-care on an individual basis:
 - taking care out of her hands in this confusing time:
 - she tried to be perfect for her family
 - desperate need of quality time:
 - away from home
 - without taking on a role for her family

Pre-transplant admission

- oxygen therapy was started
 - emotionally very difficult
 - visible for others
- impact of living with CF
 - extremely hard on different levels:
 - fysical
 - social
 - relationship
- end off life questions

Pre- transplant admission

- awaiting their new lungs:
 - optimisation of the condition by:
 - hard work of the patient and her physiotherapist
 - partly because of their social interaction with other chronic ill patients



Day of the transplant

- 2 months after her admission
 - sense of relief but also anxiety
 - preparing for transport to the transplant hospital
- making contact with her companion of choice
 - in her case our social worker Thijs

