



association luxembourgeoise de lutte
contre la mucoviscidose a.s.b.l.

Cystic Fibrosis (Mucoviscidose)





ALLM

- Established in 1991
- Run by volunteers
- Recognised as 'utilité publique' since 10-07-1998





ALLM activities

Fundraising, ... in order to be able to:

- Inform and support patients and their families
- Represent patients at the UCM, the Government and various other national and international organisations
- Inform the general public and the media
- Support research
- Etc.





Cystic Fibrosis (Mucoviscidose)

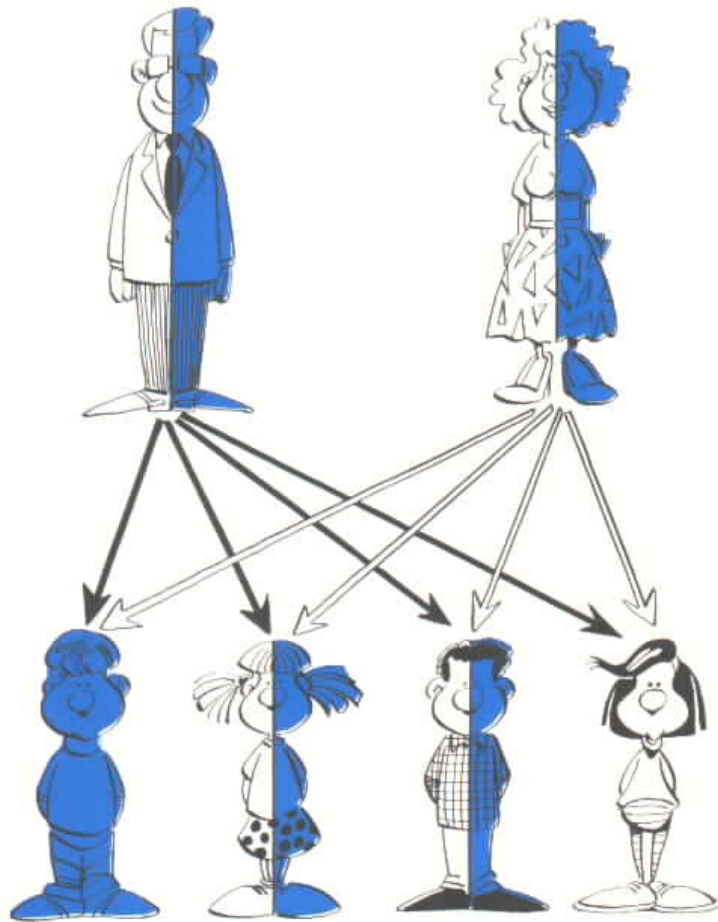


- Genetic disease (mutation on the CFTR-gene)
- Affects the Cl transport from and to the cells
- Lungs: Mucus + Viscosité = Mucoviscidose
- Digestive tract: pancreas: Cystic Fibrosis





CFTR-genes

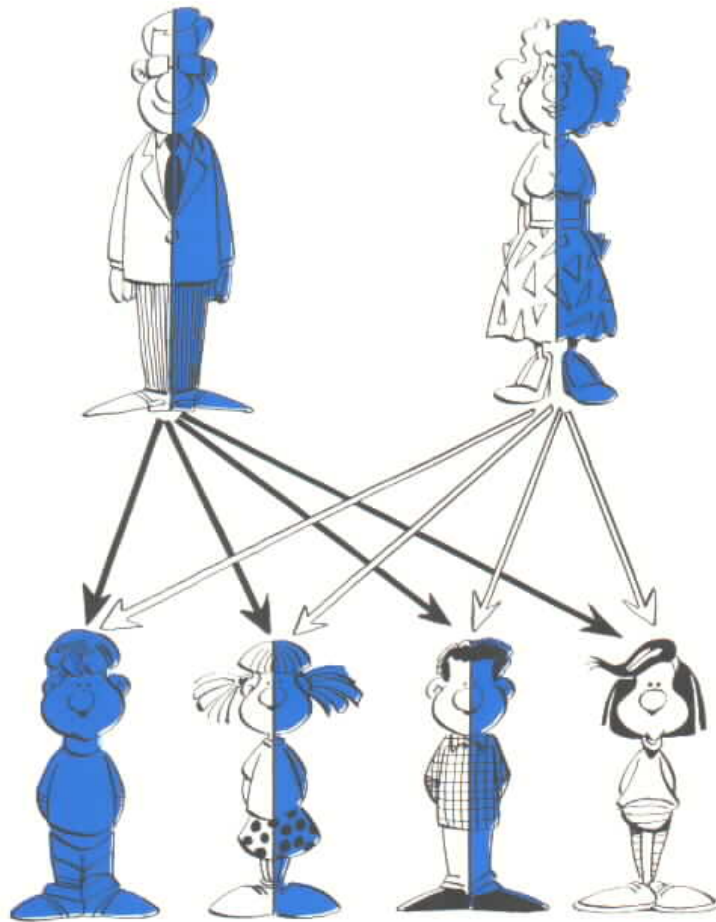


- We inherit two CFTR-genes: one from our mother and one from our father
- If we inherit one faulty gene, we are a carrier
- If we inherit two faulty genes, we have Cystic Fibrosis





CFTR-genes



- In our region,
1 in 25 people are carrier
- Chances of inheriting two faulty
genes is 1 in 4
- So around 1 in 2,500 babies are
born with Cystic Fibrosis





Symptoms

- Lungs
- Digestive tract (pancreas)
- Liver
- Reproductive organs
- Multi-system disease
- Not contagious





Treatment



- Lungs: nebulisation, physiotherapy, medication
- Digestive tract: enzymes, medication, insuline
- Liver: medication
- Diet: high energy
- Reproductive organs



- Complex multi-disciplinary treatment





Treatment





Other aspects

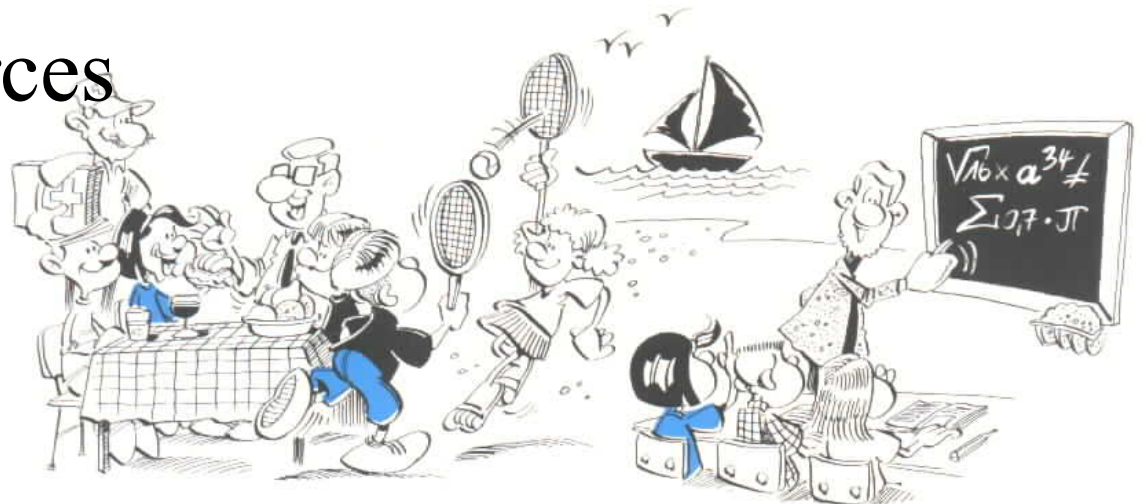
- Intellectual capabilities are not affected ...
- but, the time and energy spent on treatment is a big burden
- Physical exercise is a must
- So is an as normal routine as possible
- Hygiene is critical





Other aspects, ... for the others

- Neglected siblings
- The environment doesn't understand
- Breaks on careers
- Continuous stress and pressure
- High rate of divorces





Life expectancy

- 1938: 80% reached less than 1 year
- 1964: less than 5 years
- 1976: median survival 18 years
- 1990: median survival 29 years
- Today: median survival close to 40 years in some countries
- Today: almost 50% are over 18 years of age





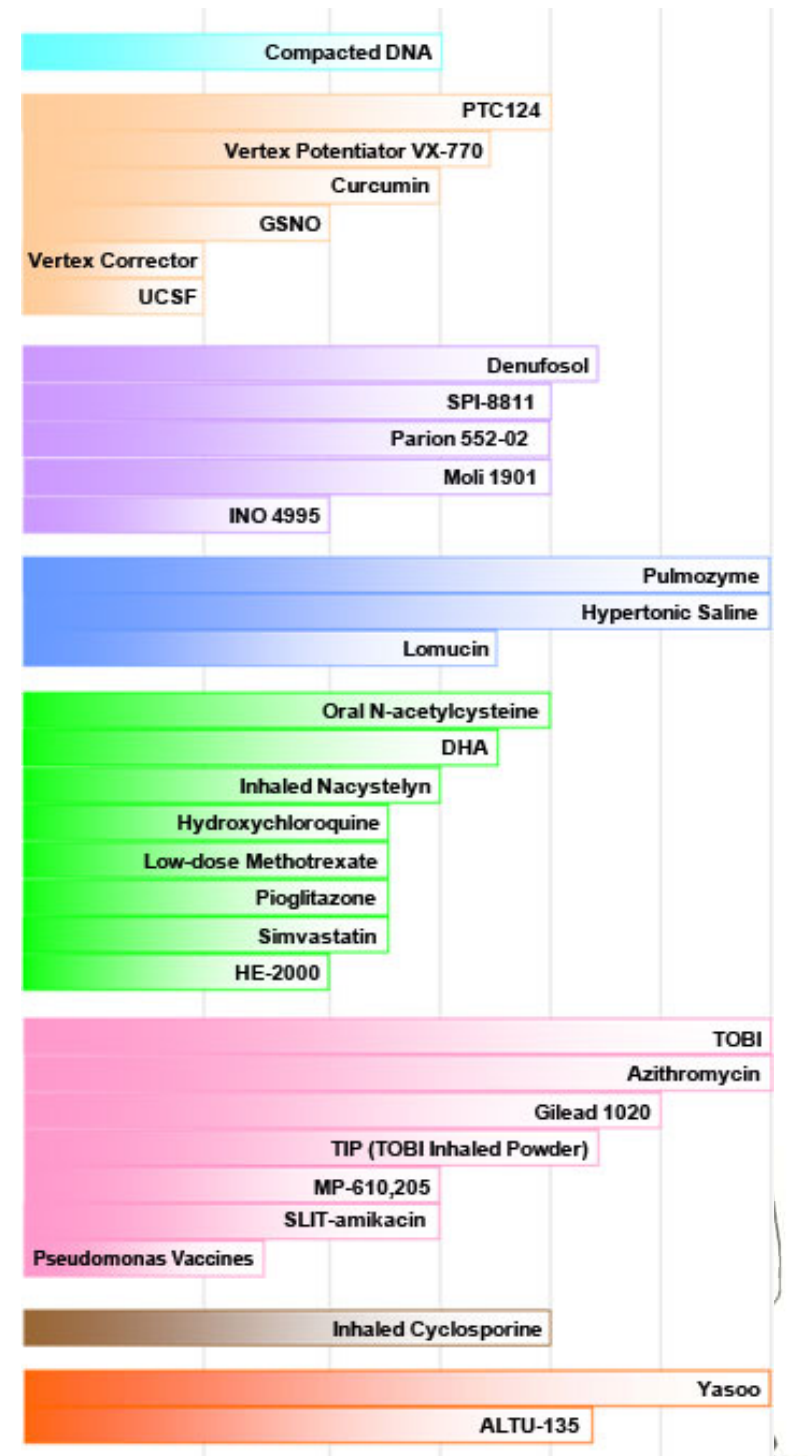
Progress

- New antibiotics
- Enzymes
- Physiotherapy
- CF-clinics (multidisciplinary treatment)
- Improved nebulisation
- Improved diagnostics
- Improved nutrition
- New 'support' medication





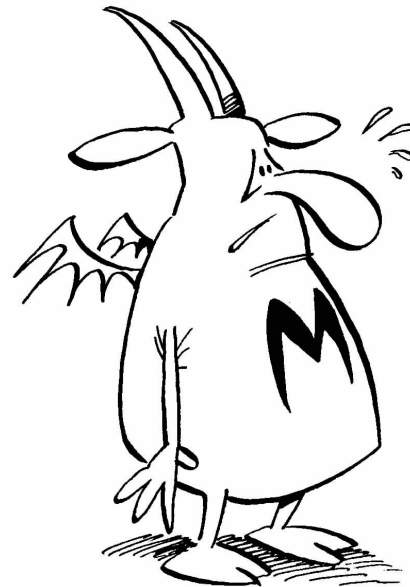
Progress





So it's OK now ??

- Still no cure: only symptom fighting
- One in three patients who die are children
- Increasing age brings new complications
 - Medical
 - Social
 - Ethical





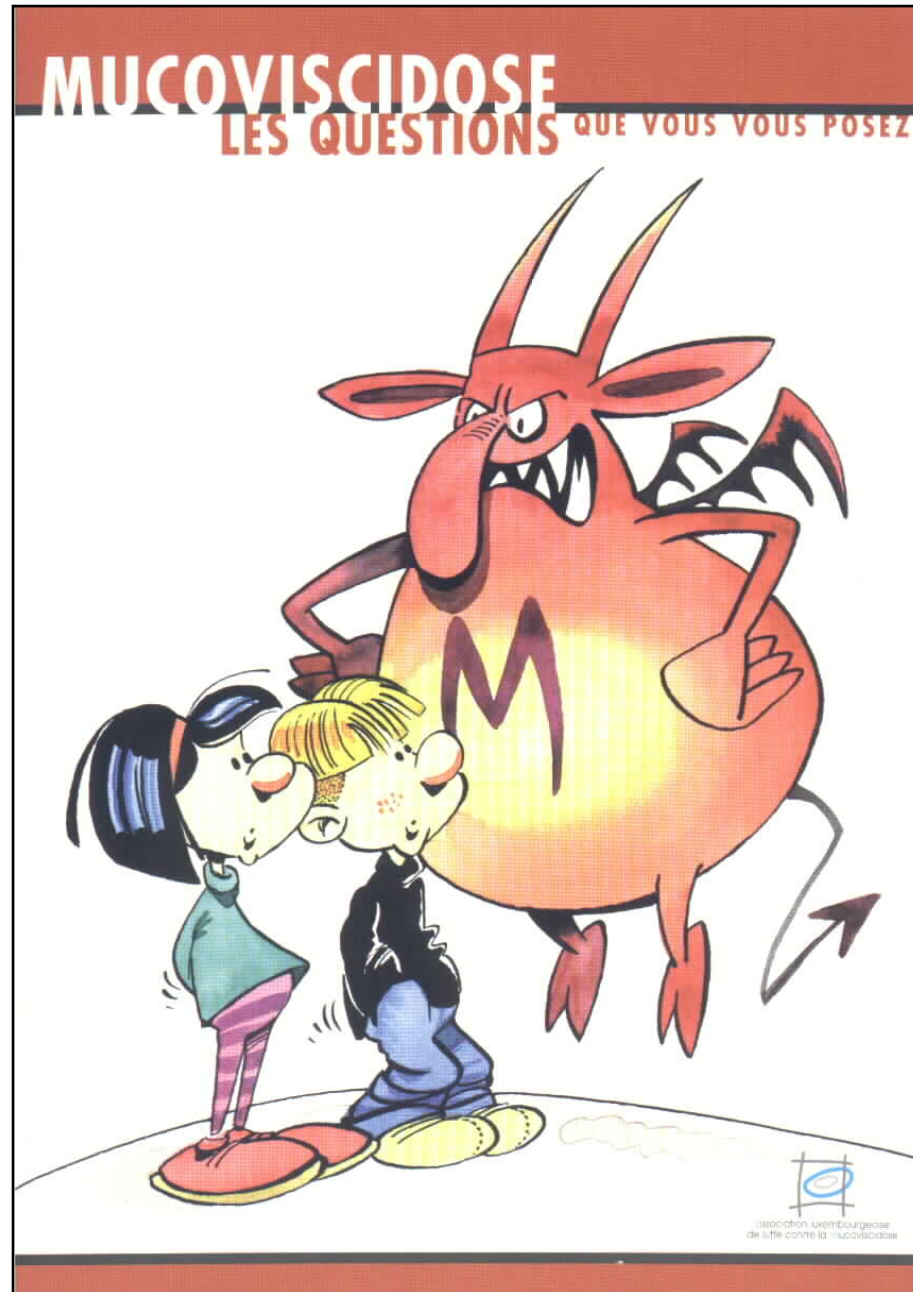
Further developments

- Further improve symptom fighting
- Gene therapy
- Pharmaceutical cure





Thank you





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IBAN LU14 1111 0398 0030 0000

