# **WELCOME IN BELGIUM**

DELACOLLETTE F - CF NURSE-LIEGE 10th June 2015



## Situation of Belgium



BORDERS : France, Luxemburg, Germany and The Netherlands LANGUAGES : Dutch, German and French



### Belgium map



POPULATION : 11 millions 3 regions : Flanders , Wallonie and Brussels-capital



### What does Belgium mean for you

















# CF CENTERS IN BELGIUM



Since 1999 7 CF Centers 2 transplant centers 2 rehabilitation centers

#### **CENTERS AIMS**



To provide a medical, psychological and social help for the patient and his/her family

To increase patient life expectancy with good quality of life





#### ■ $\geq$ 50 patients

#### <u>A multidisciplinary team</u>

-Physicians (pulmonologist, gastroenterologist, ENT ...)

- -Nurses
- -Physiotherapist
- -Psychologist
- -Dietician
- -Social worker
- -Secretary



### THE BELGIAN CYSTIC FIBROSIS REGISTRY

#### **Depends on the Scientific Institute of Public** Health

#### Important tool for monitoring the patient's quality of care and trends





#### 1) For the new diagnosis

- Age
- Gender
- Clinical symptoms and/or family history
- Screening test (NBS not required)
- -Sweat testing and mutations

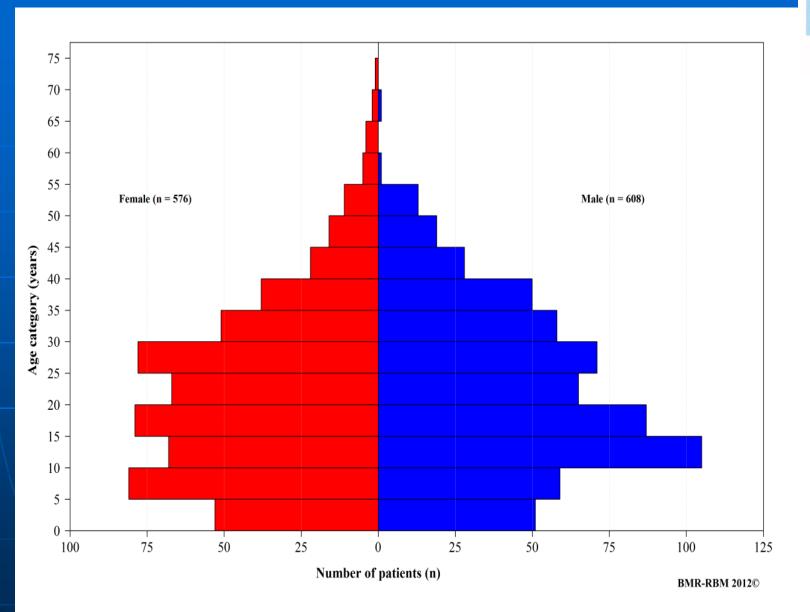


- 2) For patients who were registered  $(\leq 3)$  consultations per year in the center)
  - clinical data (height, weight...)
  - lung function (FEV1, FVC...)
  - complications
  - microbiology results
  - treatments
  - social data
  - Transplant or not



# Data collected in 2013

| Number of patients | Adults ><br>18 Y (%)                | Males<br>(%) | Median age<br>(years)     | New<br>diagnosis | Number of<br>transplant | Deaths<br>reported |
|--------------------|-------------------------------------|--------------|---------------------------|------------------|-------------------------|--------------------|
| 1186               | 57                                  | 52           | 20.7                      | 28               | 6                       | 5                  |
|                    |                                     |              |                           |                  |                         |                    |
|                    | Neonatal screening<br>Diagnosis (%) |              | Homozygous<br>F508del (%) |                  | erozygous<br>8del (%)   |                    |
|                    | 16.9                                | 6.9          |                           | 40.              | 4                       |                    |
|                    |                                     |              |                           |                  |                         |                    |
|                    |                                     |              |                           |                  |                         |                    |



Muco Liège

#### THANK YOU FOR YOUR ATTENTION