Cystic Fibrosis in Europe - Facts and Figures 2013

The European Cystic Fibrosis Society Patient Registry (ECFSPR) is happy to present this report with key information about how cystic fibrosis (CF) affects people with CF and their families throughout Europe.

The ECFSPR collects, measures and compares data of people with CF living in Europe and neighbouring countries who agree to be in the registry. The information is important to better understand CF, encourage new European standards of care and treatment, conduct research, and inform European public health-planning.

If you want to know more about the ECFSPR visit our website
For more in depth information see the full report here

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Map of countries that contributed 2013 data to the ECFSPR

- Countries that sent the data to the ECFSPR as a national registry
- Countries with individual centres that sent data
- Countries not in the ECFSPR

38,985 registered patients in 27 countries; number of patients on map.
Proportion children-adults

- The proportion children-adults varies between the countries.
- For some countries only a few individual centres sent data to the ECFSPR.

Genetics

F508del mutation in Europe

- F508 del is the most common CF-causing mutation in Europe.
- People with CF have two CF-causing mutations, one inherited from the mother and one from the father.
- Homozygous: both mutations are the same.
- Heterozygous: the two mutations are different.
Median FEV1% of predicted in adults

- FEV1 is a measure for lung function. It is the maximum amount of air that forcefully can be exhaled in the first second after taking a deep breath.
- FEV1% is a percentage of the average value for healthy people of the same age, gender and height, which is set at 100%.
- In patients aged 45 and older there is a higher incidence of mutations causing milder forms of CF. This influences the lung function value for the patients in this age group represented.

Median BMI Z-score in children

- A z-score of 0 means that the BMI is the same as the BMI of healthy peers of the same gender and age.
- From the age of 6, children with CF have a lower average BMI than their healthy peers.

Median BMI in adults

- Healthy peers have values for BMI between 18 and 25.
- As patients get older the BMI values increase.
- In patients aged 38 and older there is a higher incidence of mutations causing milder forms of CF. This influences the BMI for the patients in this age group represented.
Pancreatic enzymes

Enzymes released from the pancreas are vital for the digestion and absorption of fat and vitamins from food. In many people with CF the release of these enzymes is blocked and they must take supplements.

% of patients who use pancreatic enzyme supplements

- Of the people with CF are using pancreatic enzyme supplementation.

At-A-Glance report 2013

33% of the people with CF are chronically infected with the Pseudomonas aeruginosa bacteria in their lungs.
Infection

% chronic Pseudomonas aeruginosa in children*

% chronic Pseudomonas aeruginosa in adults*

* In this graph the missing values are not included nor are data from countries with a high % of missing values.
Inhalation Treatment

% of patients on hypertonic saline*

Hypertonic saline is prescribed to help to clear thick mucus from the lungs.

* In this graph the missing values are not included nor are data from countries with a high % of missing values.

% of patients on inhaled antibiotics*

Inhaled antibiotics are prescribed to treat CF specific bacteria, such as chronic Pseudomonas aeruginosa.

Transplantation

Number of people with CF living with a lung transplant

At-A-Glance report 2013