

UK CF REGISTRY ANNUAL DATA REPORT 2009 – SUMMARY

The CF Registry Report is a comprehensive set of clinical data from all the CF Centres in the UK and over 80 clinics. The Registry helps clinicians and patients build up a picture of how people with CF are doing all over the UK.

Here are some of the key points from this year's report:

- There are 9029 patients registered, so the number of people living with CF is continuing to increase. 82% of these patients have their annual review data entered into the registry.
- There were 261 new diagnoses in 2009, five a week.
- The average age of diagnosis is now 3 months old.
- 55% of those registered are over 16 years old, and there are over 500 people with CF who are over 40 years old. The oldest man on the registry is 78 years old and the oldest woman is 82.
- 69% of those over 16 are working or studying.
- The median BMI (Body Mass Index) for paediatric patients is 51.2 and for adults, 21.8.
- The median FEV₁% for patients over 6 years old (Forced expiratory volume in one second) is 74%.
- 24 patients with CF received a transplant in 2009.
- There were 141 deaths reported in 2009, an increase of 41% on the previous year. Detailed analyses over a longer time period will help us evaluate whether this shift is a random fluctuation.
- Due to the increase in number of deaths, median predicted survival is now 34.4 years, compared to 38.8 in 2008.
- Patients can now view the information in the registry that relates to their hospital.

ENDS

If you are a patient or parent and have further questions:

Email helpdesk@portcf.org.uk or call the CF Trust helpline on 0300 373 1000

For all media enquiries, please contact:

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