

PRESS RELEASE

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Cystic Fibrosis on the increase

The Cystic Fibrosis Trust has today published the Annual UK CF Registry Report based on patient's clinical outcome data for the year 2010. The UK CF Registry is the only national database of information on people with Cystic Fibrosis (CF) in the UK.

The data, used by clinicians, policy makers and scientists, provides an overview of 9300 of people living with CF in the UK. The registry has complete data on 85% of these people.

Some points to note from this data:

- The median predicted survival rate is 41, an increasing trend
- Only 37.5 % of the whole population of people with CF had chronic *Pseudomonas Aeruginosa* infection

Speaking about the data in the report **Jo Osmond, Director of Clinical Care and Commissioning** said:

“The CF Registry is a key indicator of how children and adults with CF have responded to the care they are receiving. We can see that there is a trend towards people living longer but there is still a long way to go. There is still room for improvement. During the next year the CF Trust will be looking to find ways - through its standards of care and rigorous Peer review process - to continue the trend of longer median predicted survival and better lung function in children and young adults .

We are also monitoring carefully the numbers of people with CPA infection. We know that early intervention can prevent or delay chronic infection and we wish to see the numbers of people with CF and chronic *Pseudomonas Aeruginosa* decreasing.

The CF Registry is in its fifth year and 2010 is its fourth annual report. A copy of the report is available to view on the CF Trust's website:

[http://www.cftrust.org.uk/aboutcf/publications/cfregistryreports/UK_CF_Registry -
_Annual Data Report 2010.pdf](http://www.cftrust.org.uk/aboutcf/publications/cfregistryreports/UK_CF_Registry_-_Annual_Data_Report_2010.pdf)

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For all media inquiries and interviews please contact: Louise Banks on 0208 290 7912 or email lbanks@cftrust.org.uk

Notes to Editors

- A copy of the CF Trust's Standards of Care document can be found at www.cftrust.org.uk
- The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). It funds research to treat and cure CF and aims to ensure appropriate clinical care and support for people with Cystic Fibrosis.
- Cystic Fibrosis (CF) is one of the UK's most common life-threatening inherited diseases. Cystic Fibrosis is caused by a single defective gene. As a result, the internal organs, especially the lungs and digestive system, become clogged with thick sticky mucus resulting in chronic infections and inflammation in the lungs and difficulty digesting food.
- Each week five babies are born with Cystic Fibrosis and two young people die – 90% from lung damage. Only half of those living with Cystic Fibrosis are likely to live past their late 30s, although improvements in treatments mean a baby born today is expected to live even longer.
- Further information can be found on our website www.cftrust.org.uk. Help and advice for those affected by Cystic Fibrosis is available through our Helpline on 0300 373 1000. For further information, media should contact Louise Banks on 0208 290 7912 or email lbanks@cftrust.org.uk