

Australian Cystic Fibrosis Data Registry

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The 6th Australasian Cystic Fibrosis Conference, held in Brisbane from 30 August to 1 September 2009, was the scene for the launch of *Cystic Fibrosis in Australia 2007: 10th Annual Report from the Australian Cystic Fibrosis Data Registry*.

After a decade of reporting, the Data Registry has reached its highest ever coverage of people with CF in Australia – over 90% of an estimated 2,900 people with CF in 2007. With annual growth of around 50 persons, that number would have grown to 3,000 today.

Although survival years are not directly estimated in the report, key indicators show that improved survival that has been reported for people with CF in other countries has occurred also in Australia – median age at death is up from 18.5 years when first reported in 1998 to over 30 years in 2007 and the proportion of people with CF who are adult (18 years and over) has reached 45%, from just 26% in 1998.

Patient outcomes related to lung function and nutrition have improved for all age groups.

With universal neonatal screening operating in Australia for almost a decade, median age at diagnosis has continued to decline and is now at 1.5 months.

Cystic Fibrosis in Australia 2007: Selected Highlights

- The Australian Cystic Fibrosis Data Registry held records of 2,639 people with Cystic Fibrosis at 31 December 2007.
- There were 69 new diagnoses reported in 2007, including 57 in infancy. Neonatal screening played a part in 51 infant diagnoses.
- Approximately one in every 3,400 babies in Australia is born with CF.
- Median age of the CF Registry population at the end of 2007 was 16.4 years, up from 16.0 years in 2006. It was 12.8 years when data were first collected in 1998.
- The proportion of adult CF patients in the registry increased to 45 per cent at 31 December 2007. Adult patients are those aged 18 years and over.
- There were 24 deaths of persons with CF reported to the registry in 2007. The median age at death was 32 years, much higher than 18.5 years for deaths that occurred in 1998.
- Of the adult with CF for whom relevant information was reported in 2007:
 - * 31 per cent of males and 39 per cent of females were married
 - * 26 per cent had tertiary qualifications
 - * 70 per cent were employed, including 34 per cent in full-time work
- Almost 20 per cent of adults with CF have Chronic Insulin-dependent Diabetes.
- About 40 per cent of the adults with CF have Osteoporosis or Osteopenia.
- Around 56 per cent of both male and female adults have lung function values below 70% of predicted values (i.e. moderate or severe impairment).

For more information, please visit: <http://www.cysticfibrosis.org.au/projects/dataregistry/>