

29 May 2020

Longer Lives But Still More To Do



As we come to the end of Cystic Fibrosis Month, Cystic Fibrosis Australia (CFA) would like to share some outstanding breaking news ... ***people with cystic fibrosis (CF) are living longer.***

Monash University's Registry Science Unit has determined an overall predicted (median) survival of people with CF in Australia of **47 years**. This allows for a statistical margin of error, and therefore estimated survival is in the range of 45-50 years.

I know that this announcement will mean a great deal to the CF community and we are lucky to have world class CF and Transplant Centres, CFTR modulators and cutting edge treatments for infection and inflammation that have improved survival.

Professor Scott Bell, Medical Lead of the ACFDR Steering Committee attributes this increase in median survival to advances in many key aspects of clinical care including improved approaches to diagnosing and treating infection and advances in nutritional support, airway clearance and long-term maintenance therapies.

Professor Bell anticipates further improvement in clinical outcomes over the coming years including reduced need for hospitalisation, improved lung function and nutritional status with the roll out of CFTR modulators for many of our patients.

Professor Susannah Ahern, Head, Registry Science and Research at Monash said that the ACFDR had been an incredibly valuable resource in the monitoring and reporting of outcomes of people with CF. The ACFDR was increasingly focusing on quality assurance of its data, so that more complex analysis could be undertaken with increasing certainty.

Professor Ahern added that the ACFDR has reported consistent improvement over time and the latest survival data show that improved clinical outcomes are translating into improved survival. With increased access to CFTR modulators, it is anticipated that the ACFDR will continue to report improved health and wellbeing for Australians with CF.

Survival rates around the world have increased over the last decade and the Australian performance is similar to that of the United Kingdom, Canada and the United States.

We still have more to do and CFA will continue to advocate for improved treatments for all. Vertex's Trikafta, a triple therapy is currently being evaluated by the TGA. AbbVie and Proteostasis Therapeutics are also developing triple combination therapies and we encourage them to bring their clinical trials to Australia. But for now we celebrate an estimated median survival of 47 years.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke".

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