# History of Cystic Fibrosis WA 1975 - 2017

In July 1975, 3-4 parents of children living with cystic fibrosis (CF) came together and established, with the help of the Perth Jaycees, a self-help group. The group was formally incorporated under the Associations Act of WA on 29June 1976.

In the 1990’s, we continued to develop our services and to develop links with the cystic fibrosis clinics based at Princess Margaret Hospital for Sick Children (PMH) and Sir Charles Gairdner Hospital (SCGH).

In the late 1990s, we obtained funding from the Department of Health WA to begin a Comprehensive Homecare Service which allowed us to provide support for people with CF in their own homes. This service, which continues today, provides amongst other things, education, nursing, physio/airway clearance and home help.

In the early 2000s, we moved into our current home, ‘The Niche’, which is on the QEII Medical Centre campus. The services provided have continued to grow and develop. We have also become the largest contributor in the CF Federation to CF research in Australia through the Australian Cystic Fibrosis Research Trust (ACFRT).

The regular surveying of our members continues to ensure that our services meet their needs, particularly as more and more children are surviving into adulthood. We have also contributed to the national CF agenda by helping to establish and fund Cystic Fibrosis Australia (CFA) and its work in areas such as advocacy, the Australian CF data registry, centre directors group, standards of care working party, national website development, advocacy and the Australasian Conference.

In 2009, we were successful in negotiating a new three year contract with the Minister for Health providing a significant increase in funding to better meet the needs of those living with CF and their carers.

In 2010, we launched our first PhD Top Up Scholarship which sought to address some of the workforce legacy issues particularly in the area of adult CF, recognizing that for the first time in our history, increases in life expectancy meant that we have more adults living with CF than children.

In 2011, working closely with CFA and the ACFRT, we called upon researchers from around the world to submit expressions of interest to undertake an ambitious $10-$20m collaborative research project. The Collaborative Research Project, became known as Little Lungs Big Futures.

Thanks to support from Lotterywest, the refurbishment of our offices in 2014 future-proofed our association for the next 15 years and provided much needed room for expansion.

In 2015, we secured a further contract with the HDWA for $5.4m to deliver services to people living with CF over a five-year period.

2014 also saw the listing of a new drug, Kalydeco®, on the PBS following many hours of lobbying by CF associations around the country. This is the first drug to treat the underlying cause of the disease rather than the symptoms and represents the first in a whole new class of drugs currently under investigation. In 2015, we started implementing a strategy to support access to a new combination therapy, Orkambi®, which will bring relief to approximately half the people living with CF with the more common homozygous F508del mutation.

In 2016, the total raised in WA for the Little Lungs Big Futures collaborative research project reached over $2.6m with major donations from the Stan Perron Charitable Trust, the Allingame family, Conquer Cystic Fibrosis and John and Denise Rothwell.

Since May 2015, CF researchers from the Telethon Kids Institute and Institute for Respiratory Health have presented their latest results at an annual forum hosted jointly by TKI and CFWA. It was at the 2016 forum that we described CF for the first time ever as a lifetime manageable disease rather than a premature life shortening sentence.

In July 2016, our success was publicly recognised when we won the prestigious State Telstra Business Awards charity category.

In July 2017 CF researchers and CFWA took the research forum to the Southwest and we funded two additional WA PhD Top Up scholarships, taking the total number of PhD Top up Scholarships to 8. We also provided $30,000 seed funding to help establish an adaptive platform trial to help shorten the time taken in clinical trials to bring new drugs to market and provide the very best outcomes to people on clinical trials.

In July 2017, thanks again to Lotterywest, we upgraded our software and hardware to reduce time spent on administration and improve service delivery, efficiency and transparency.

In August 2017. we won the opportunity to host the 13th Australasian Cystic Fibrosis Conference here in Perth in 2019. We look forward to seeing you there.