



17 January 2023

Date: Thursday, 19th January

Time: 1pm - 2pm (AEDT) 1 hr

SESSION: A DEEP DIVE INTO THE AUSTRALIAN CYSTIC FIBROSIS DATA REGISTRY (ACFDR)

The ACFDR is a vital tool for the CF community as it stimulates ground-breaking research, supports clinical teams to improve care, monitors the safety of new medicines and through the ACFDR Annual Report, gives people with CF and their families up-to-date information about CF. As of 2021, the registry collects data from over 95% of the CF population in Australia.

Join our host CFA CEO Jo Armstrong along with Professor Susannah Ahern and ACFDR Consumer Representatives Honor Rose, Pia Sappl and Chloe Arthur.

Professor Susannah Ahern is a medical administrator and academic in health services research and management at Monash University. As the Head, Clinical Outcomes data Reporting and Research Program at Monash University, she is the Academic Lead for the ACFDR. Her areas of research interest include registry governance, secondary use of clinical registry data, registry data reporting and benchmarking, and clinical and consumer engagement with registries. Professor Ahern's registry policy and methodology-focused papers aim to inform national debate and discussion. Susannah is a recognised national expert and the Monash Academic Lead for a number of clinical quality registries.

Honor is a parent of a young child with CF. She volunteers on several hospital, and state-wide projects with a focus on patient advocacy, equitable health care and integration of digital healthcare initiatives. Honor is keen to facilitate the contribution of the wider consumer voice to the ACFDR as one of your consumer representatives.

Pia is passionate about improving CF outcomes through meaningful partnerships with people with CF and their families. Pia was diagnosed with CF at age 19 and has experienced the gruelling treatment for NTM. Pia is the founder and coordinator of the Australian CF Hub; an online community group run by 'Australian adults with CF' for 'Australian adults with CF'. She is also a former research scientist, having managed cutting-edge research projects in leading national (Monash University) and international research institutes (EMBL). Pia now works part-time as a lived-experience expert at Safer care Victoria. Pia's combination of professional scientific background and lived experience gives her a unique perspective. She hopes to use her unique perspective to elevate voices in the Australian CF community so together we can improve CF care and CF outcomes.

Chloe has spent close to 20 years seeing the impacts of CF through her husband who was diagnosed at birth. Her journey has seen CF at its best and worst, having fought for 6 years to save her husband's life while raising two daughters. Chloe understands how hard it is to fight for the smallest of things, that others may take for granted. Her professional experience in business and consulting allows her to navigate the medical system/complexities and advocate for the CF community from a place of passion and commerciality. Never backing down and fighting for those that can't fight for themselves, Chloe is motivated to continue finding and aiding new solutions and treatment options for the CF community.

We are excited to chat all about the ACFDR, its importance, how it supports ground-breaking research, and what the future holds for the registry.

We invite everyone to attend, including consumers, medical professionals, and researchers.

Please submit any questions you have by following the link [HERE](#)

We look forward to welcoming you to this great session!



The graphic features a light orange background with a grey and white geometric design on the right. In the top right corner is the Cystic Fibrosis Australia logo, which includes a stylized red bird-like icon above the text "CYSTIC FIBROSIS Australia".

Five speaker portraits are arranged in two rows:

- Top row, left: **Jo Armstrong**, Cystic Fibrosis Australia CEO.
- Top row, middle: **Susannah Ahern**, Professor at Monash University.
- Top row, right: **Pia Sappl**, ACFDR Consumer Representative.
- Bottom row, left: **Chloe Arthur**, ACFDR Consumer Representative.
- Bottom row, right: **Honor Rose**, ACFDR Consumer Representative.

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CONNECT SESSION:**
19th January | 1pm - 2pm (AEDT)
Online | Free to attend