13TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

Celebrating Partnerships

CYSTIC FIBROSIS Australia
On behalf of the Scientific Committee, I would like to welcome all delegates attending the conference in Perth this year. I hope that you will have time to look around & see why so many of us love living & working here in the most isolated capital city in the world.

The theme of this year’s conference is “Celebrating Partnerships” to recognise the vital role of collaboration in CF care. Few areas in medicine can boast such strong & effective partnerships as those that characterise the CF world:

(i) partnerships between clinical experts from multiple disciplines that strengthen our ability to provide care & support for people with CF
(ii) partnerships between clinicians & scientists push the boundaries to improve the level of health care we can offer to people affected by CF
(iii) partnerships between different CF centres facilitate the improvement of standards
(iv) partnerships with people with CF & their families benefit everyone.

Indeed, the present time is very hopeful in the CF world, with disease modulating therapies becoming increasingly available & many novel drugs in development. Yet, we still face challenges before everyone can live unaffected by CF. At this conference the best researchers in Australia & NZ will come together to continue the fight against CF.

Our numbers are strengthened by a formidable team of international experts & we are honoured that they have made the journey to join us. I am delighted to report we have had a record number of high quality scientific abstracts submitted. Personally, I love the vibrant interaction with likeminded people at the Australasian CF Conference who share the same commitment & passion to beat CF.

I would like to thank the members of the scientific committee - it was a privilege working with you. Finally, I would like to thank Cystic Fibrosis Australia for organising the 13th Australasian CF Conference.

Once again, a warm welcome to all the participating delegates of the 2019 Australasian Cystic Fibrosis Conference.
Acknowledgments

The organising committee for the 13th Australasian Cystic Fibrosis Conference would like to extend its thanks & appreciation to the following sponsors & exhibitors for their support.

PLATINUM SPONSOR:

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Lay Committee 2019
Nigel Barker (Chair), Nettie Burke, Caz Boyd, Jane Drumm, Tess Farrelly, Cassie Jones, Melanie Smith, Shannon Malone-Brierley, Tania Minogue, Kirsten O’Shea, Kathryn Pekin, Paula Wallace & Craig Woodrick.
Message from the President

Partnerships have always been at the centre of CF care & for many years multi-disciplinary teams in partnership with patients have improved health outcomes & extended lives. Partnerships in the CF research community have ensured rapid developments & better care & treatments for all. At its best, research in CF transcends disciplines to involve parties with different skills & perspectives in tackling the many impacts of CF on people’s lives. The Australian Cystic Fibrosis Research Trust has partnered with more than 300 researchers over the past 30 years funding over $6,000,000 worth of projects across many research disciplines. International alliances & new technologies enable the sharing of research outcomes from around the globe & we celebrate the 12 international speakers attending our CF Conference this year.

Cystic Fibrosis Australia (CFA) & CF state & territory organisations partner with the community to reduce the burden of CF & this partnership has been instrumental in the highly visible & extremely successful advocacy campaigns in recent years.

Our conference seeks to further facilitate partnerships that share best clinical practice, cutting edge research, peer support opportunities & knowledge-sharing in the expectation of further improving the lives of people affected by CF. CFA hosts this conference as part of its commitment to knowledge sharing & clinical improvement & I would like to thank the Lay & Medical Organising Committees. They have given their time, expertise & enthusiasm to the co-production of this conference & I thank them for their work & commitment to making life better for those who live with CF. I also want to thank the staff of CFA who work tirelessly to improve & host this conference.

As we celebrate partnerships I hope you enjoy the opportunity to share knowledge & expertise with your colleagues & take the chance to explore the beautiful city of Perth.

Associate Professor
Patrick O’Connor
President
Cystic Fibrosis Australia

The 13th Australasian Cystic Fibrosis Conference in Perth WA is ‘Celebrating Partnerships’ across the cystic fibrosis (CF) community.
General Information

Conference Secretariat: Registration Desk +61 414 358 028

Opening Hours:
- Saturday 3rd August: 7:30am - 5:00pm
- Sunday 4th August: 7:30am - 5:00pm
- Monday 5th August: 7:30am - 5:00pm
- Tuesday 6th August: 7:30am - 5:00pm

After the conference:
Conf. Secretariat  
Cystic Fibrosis Australia  
Rose Cottage, 2 Richardson Place  
North Ryde NSW 2113  
Ph: +61 2 9889 5171  
Email: cfa1@cfa.org.au

Lanyards & Badges:
- Lay Delegates: Black Lanyard
- Medical Delegates: Red Lanyard
- Speakers: Blue Lanyard

For security reasons:
Delegates are required to wear their lanyard & badge at all times throughout the conference & during social events.

Mobile Phones:
Please ensure your mobile phone is switched off during sessions.

Smoking:
The 13th Australasian Cystic Fibrosis Conference is strictly a smoke free event.

Conference Information:
Conference information including speaker bios, up to date schedules & much more can be accessed via the CFA website – www.cysticfibrosis.org.au

Attendance Certificates:
A certificate of attendance for delegates will be provided post event.

Location & Access:
The Conference Venue: Crown Towers, Perth  
Great Eastern Highway Burswood, Perth WA 6100  
P: (08) 9362 7777
About CFA

Cystic Fibrosis Australia (CFA), the national Australian consumer body supporting people with cystic fibrosis (CF) & their families, is committed to improving clinical practice & patient outcomes through its advocacy, clinical improvement & research. Our aim is to extend life expectancy from 37 to 50 years by 2025.

When the Australian Cystic Fibrosis Association (ACFA) was formed in March 1971 it was an important first step to alleviate the suffering of children afflicted with CF & search for better ways to cope with what was then a largely uncharted disease.

In 1998 CFA was renamed Cystic Fibrosis Australia & its remit was to facilitate & promote the provision of optimal care to all people affected by CF & ensure they have the best possible quality of life.

It was at this time that our clinical improvement work began. As the national organisation we now manage clinical improvement programs, consumer engagement initiatives & conduct CF research throughout Australia.

CFA has established a consistent approach to advocacy across Australia & supports state & territory CF bodies that provide valuable services to the CF community.

CFA works tirelessly to raise the profile of cystic fibrosis nationally & takes key messages to government, business & the health & community sectors to ensure these groups understand & appreciate the challenges facing people with CF. These include key issues such as drug affordability & availability, infection control, the financial burden of CF, gene testing & access to the best medical & allied health services.

CFA does not receive any government funding so securing grants, sponsorships & partnerships are a vital part of our work as they enable us to continue working for people with CF & their support networks.

Over 40 years on, from small first steps we have made enormous strides. But the journey & its challenges continue. Advocacy, clinical improvement & research are the key to people living healthier, longer & more fulfilling lives.

Speaker AV Information

If you are a Speaker:
Please use the following guidelines when submitting your Power Point presentations for the 13th Australasian Cystic Fibrosis Conference for both the Lay & the Medical Programs.

We strongly suggest you bring a USB with you with the presentation loaded to the Speakers Prep Room (M4 Boardroom) a minimum of one hour prior to your session. The Speakers Prep Room will be open everyday of the conference from 7:30 – 5:00pm.

Please note the following:
The screen resolution size for presentations in all sessions will be 16:9 ratio.

You should clearly label the session with meeting room number & time of session along with the presenter’s name.

The ability for the presenter to utilise their own laptop (Mac or PC) will be available. If you have a Mac laptop, please bring an adaptor.

Please indicate if presentations have embedded video or audio files. Hyperlinks to the internet, or any requirement to have internet available during the presentation will need to be advised. We strongly recommend downloading or taking screen shots of all your internet related slides as it is more reliable to show content offline. However, should you need to we can pre-arrange a connection for any live sessions.

Please be in your session room no later than 20 minutes prior to the time scheduled for your presentation.

POSTERS

Posters are displayed in the ACFC Expo area. Authors are requested to put up posters on Sunday 4th August between 1:00 – 4:00pm & to remove them on Tuesday 6th August by 3:00pm.

The Organising Committee will not be responsible for any loss of, or damage to posters left on the boards after 3:00pm.

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International Speakers
Alan is a Professor of Child Health at the University of Nottingham & Honorary Consultant in Paediatric Respiratory Medicine at Nottingham Children’s Hospital. Alan’s clinical focus is cystic fibrosis (CF). His research interests include effective ways to treat infection in CF & minimising the adverse effects of treatment. Recently he led a patient engagement exercise which defined new research priorities including research into the causes of gastrointestinal symptoms in CF. Alan is now engaged in discovery science, using MRI imaging in this area. He is joint Editor-in-Chief of the journal Thorax & Co-ordinating Editor of the Cochrane Cystic Fibrosis & Genetic Disorders Group. When not working, he is a keen cyclist & pilot.

Alistair is currently Head of Psychology Services, Leeds Teaching Hospitals, having worked there for over 23 years. He started as clinical psychologist working with children & families living with various chronic conditions but specialised in paediatric respiratory diseases, focusing on procedural-distress, adherence, motivational-interviewing & parental mental health.

Alistair was awarded Fellowship of The Royal College of Physicians of Edinburgh in 2013 & an Honorary Associate Professorship, University of Leeds in 2015. He remains active in clinical practice, teaching & research. His ECFS commitments include co-leading the Standards of Care & Psychosocial Special Interest groups. Alistair is a founding committee member of the UK Psychosocial Professionals Group & the Association of Clinical Psychologists.
INTERNATIONAL SPEAKERS

CHRIS SMITH

Chris has 15 years’ experience in clinical dietetics. Following his training in London, he worked at the Royal Free Hospital for many years then moved to the Children’s Hospital in Brighton in 2007. Currently, Chris is the clinical lead Paediatric Dietitian in a team of 10 specialist dieticians. Chris has specialised in CF for the last 11 years. He is the current joint chair for the European CF Nutrition group as part of the European Cystic Fibrosis Society (ECFS) & recently co-authored the infant nutrition section in the latest ECFS textbook. Chris also has worked over the last six years with the charity CF Europe on various projects around Eastern Europe including Latvia, Estonia, Greece, Romania & Bulgaria. This work has given him first-hand experience of the disparity of nutrition status & treatments in CF healthcare.

In his spare time Chris runs a taxi service for his two children.

BETH SMITH

Beth is an Associate Professor of Psychiatry & Pediatrics at the University at Buffalo (UB) School of Medicine & Biomedical Science. She serves as the Chief of the Division of Child & Adolescent Psychiatry at UB. Beth’s clinical work focuses on the assessment & treatment of children & adolescents with comorbid medical illness. She is the recipient of funding to conduct research on the assessment & treatment of depression, adherence & cystic fibrosis & co-authored the international guidelines on depression & anxiety in CF for the CF Foundation & European CF Society. Beth is the chair & founding member of the CF Foundation’s Mental Health Advisory Committee.

Its mission is to promote & support the mental well-being of individuals with CF & their families by partnering with CF Care Centers to provide screening, preventative interventions & ongoing innovative services.
INTERNATIONAL SPEAKERS

FELIX RATJEN

Felix is the Division Chief of Paediatric Respiratory Medicine at The Hospital for Sick Children, Professor of Paediatrics at The University of Toronto, Program Head & Senior Scientist at the Research Institute in the Translational Medicine research program & the H.E. Seller’s Chair in Cystic Fibrosis. He is co-leading the CF Centre at SickKids & is the Medical Director of the Clinical Research Unit. Felix is on the organising committees of major respiratory meetings, works on multiple grant review panels & is a member of several editorial boards. Felix conducts multiple clinical trials addressing cystic fibrosis lung disease including new therapeutic strategies to target the underlying defect, treatment of airway infections such as first infection with Pseudomonas aeruginosa, & airway inflammation. Many of these include both national & international collaborations with centres in Canada, USA, Europe & Australia.

DEBBIE BENETIZ

Debbie is the Nurse Coordinator & Nurse Practitioner at the Center for Cystic Fibrosis at the Keck Medical Center of USC in Los Angeles, CA. She has been in this role for the past 15 years. Debbie attended the University of Southern California School of Nursing where she received her Bachelors of Science degree in Nursing & later received her Master’s degree in Acute Care Nurse Practitioner at the University of California Los Angeles in 2003. Throughout her 15 years in Cystic Fibrosis (CF) care Debbie has been involved within the CF community in various facets. She has participated in committees such as the Partnerships for Sustaining Daily Care, Peer to Peer mentoring, Care Model of the Future, Advance Practice, Access Steering Committee & the Program Planning Committee (PPC) for the North American Cystic Fibrosis Conference (NACFC). Debbie is an active member of the CF community as a speaker & advisor for pharmaceutical companies. She has participated in educational webcasts & videos & has presented at CF education days & local chapters for the CF Foundation. Debbie has served as the Nursing Chair of the NACFC Program Planning Committee since 2015 & is the Quality Improvement coordinator for her care team involvement in the CF Pilot Learning Network. Throughout her nursing career Debbie has been honoured to receive the Nurse Patient Advocate of the Year & Advanced Practice Nurse of the Year from the Keck Medical Center of USC. Most recently she was honoured to receive the Mark Kontos Clinical Care Champion award at the 2017 NACFC.
LISA SAIMAN

Lisa is Professor of Pediatrics at Columbia University Irving Medical Center in New York, & Attending Physician & Hospital Epidemiologist at New York-Presbyterian Morgan Stanley Children’s Hospital. For over 25 years CF has been Lisa’s primary research & clinical interest as she focuses on the infectious complications & infection prevention & control for this population. She served as Co-chair for the 2003 & 2013 Guidelines for Infection Prevention & Control for CF & Co-Principal investigator for two multicenter azithromycin trials in CF. Lisa also serves on the Planning Committee for the North American CF Conference & the CF Foundation’s Patient Registry committee.

JANE DAVIES

Jane is Professor of Paediatric Respirology & Experimental Medicine at Imperial College, London & Honorary Consultant at the Royal Brompton Hospital, which cares for one of the largest groups of CF patients in Europe. The paediatric service manages children from newborns, diagnosed as part of a national screening programme, through to adolescence; the aim being to transition young people to the adult service in as optimal health as possible.

Jane has a major interest in airway infection & early airway inflammation, leading a CF Trust Strategic Research Centre on Pseudomonas aeruginosa, as part of which collaborators are researching novel detection methods suitable for young, non-expectorating patients. She co-leads the site at the ECFS Clinical Trial Network (CTN) where they are engaged in many trials in the current pipeline & closely involved in the formation of the London CF trials network as part of the CF Trust’s CTAP initiative. In an effort to accelerate the inclusion of younger children in trials, once safe & effective agents are identified, she has been working with the ECFS on the standardisation of lung clearance index & has led several drug trials in preschool children & infants.
INTERNATIONAL SPEAKERS

PAUL BERINGER

Paul is Professor & Chair of the Department of Clinical Pharmacy at the University of Southern California. He is a graduate of USC School of Pharmacy & received his postdoctoral residency in pharmacy practice & specialty residency in pharmacokinetics at the University of California, San Francisco. His clinical practice & research is conducted at the Adult CF program at Keck Medical Center of USC. Paul has been a principal investigator on a number of research studies on pharmacokinetics & pharmacodynamics of antimicrobial & anti-inflammatory therapies. His recent work has expanded to include preclinical development of host defense peptides with potential application to the treatment of CF lung disease.

MARCUS A. MALL

Marcus is Professor & Director of the Department of Pediatric Pulmonology, Immunology & Intensive Care Medicine & CF Center at the Charité – University Medical Center Berlin, Germany. He graduated from the University of Freiburg Medical School & trained at the Universities of Freiburg & Heidelberg, Germany & the University of North Carolina at Chapel Hill, USA. Marcus is board certified in Pediatrics, Pediatric Pulmonology, Allergology & Infectious Diseases & is a Fellow of ERS (FERS). He serves on the Editorial Board of the European Respiratory Journal (ERJ) & the Board of the European Cystic Fibrosis Society (ECFS), & coordinates the CF research program of the German Center for Lung Research (DZL).

Marcus’s research focus is on the pathogenesis & development of novel diagnostic approaches & therapeutic strategies for CF lung disease. He uses an interdisciplinary translational research strategy, integrating basic research with cohort studies & early phase clinical trials to improve the understanding of CF lung disease & the translation of research results into the clinic.
ZOE SAYNOR

Zoe is a Senior Lecturer in Physical Activity, Exercise & Health & the lead for the Clinical, Health & Rehabilitation research Team (CHaRT) at the University of Portsmouth (UK). She is also a Guest Lecturer on the MSc Physiotherapy course at University College London & an Honorary Researcher at the University Hospital Southampton & Queen Alexandra Hospital, Portsmouth. An athlete herself, Zoe is an active researcher & practitioner specialising in Clinical Exercise Science. Her research has focused on exercise testing, training & nutrition for individuals with chronic diseases, including cystic fibrosis (CF), joint hypermobility, Raynaud’s phenomenon, diabetes, renal disease, asthma & non-cystic fibrosis bronchiectasis. However, much work has focused on developing exercise testing guidelines & understanding the exercise (dys)function characterising children & adults with CF. Zoe is a member of the European CF Society Exercise Working Group & her recent research seeks to understand the effectiveness of exercise training in CF.

STUART ELBORN

Stuart is Professor of Respiratory Medicine at Imperial College London, & Director of the Adult CF Centre, Royal Brompton Hospital & Professor of Respiratory Medicine at Queen’s University Belfast. His clinical & research interests are in cystic fibrosis & bronchiectasis. His research group is focused on identifying new targets & diagnostics, clinical trials & developing better ways to deliver care in cystic fibrosis & bronchiectasis. Stuart currently leads programs in airway infection including antibiotic development, anti-inflammatory & mucoactive drugs. In collaboration with Helen Parrott & Su Madge he has recently started a program of co-design with adults with CF to provide care & clinical trials using digital technologies.
Local SPEAKERS
ABDULLAH TARIQUE

Abdullah is an early career fellow at the University of Queensland. Abdullah has a keen interest in immunobiology of infectious diseases. During his PhD, he focused on macrophage responses in respiratory diseases. Macrophages act as double edge sword during inflammation by initiation (pro-inflammatory) as well as resolution (anti-inflammatory) of inflammation. Abdullah developed an ex vivo model to characterise human pro-inflammatory & anti-inflammatory macrophages. With his model, Abdullah first reported that anti-inflammatory macrophages in CF were insufficient compared to healthy individuals. His contribution in CF research was recognised by awarding him the prestigious Ann Maree Bosch Fellowship from Cystic Fibrosis Australia. Currently Abdullah is investigating the molecular defects of impaired macrophage polarisation & responses in CF. As an ECR, Abdullah is open to collaborate with clinicians & other respiratory scientists.

ANGELA MATSON

Angela completed Dietetics in 1995 in the UK & has worked at The Prince Charles Hospital, Adult Cystic Fibrosis Centre in Brisbane since 1998. Angela has worked in the areas of Cystic Fibrosis, Gastroenterology, Lung Transplant & Diabetes over the past 24 years. She completed her postgraduate Diabetes Education in 2011 & became an accredited Diabetes Educator in 2014. Angela has previously been Convenor of the CF Interest group within the Dieticians’ Association Australia, a co-author of the Australasian Nutrition in Cystic Fibrosis Guidelines & Australian Standards of Care for CF related diabetes. She also provides sessional lectures for two universities.
ANNE MCKENZIE

Anne has worked as a consumer advocate in research organisations since 2004. In 2016 she led the establishment of the WA Health Translation Network’s Consumer & Community Health Research Network. Anne is now the Community Engagement Manager at the Telethon Kids Institute. Anne is a senior consumer representative for Consumers Health Forum of Australia & former Chair of Health Consumers Council WA. She serves on key state & national health & research committees such as the National Health & Medical Research Council, the Department of Health, the National Prescribing Service & the Australian Commission on Safety & Quality in Healthcare. In 2015, Anne was appointed to the Order of Australia for her work in health service & research.

ANTHONY TALBOT

Anthony is a clinical psychologist who has worked in CF care at the Alfred for seven years. He works with CF patients presenting with a range of psychological concerns, often in the context of significant illness, loss & understandable distress. Anthony’s approach is to explore a person’s own goals for achieving physical & mental wellbeing in the larger context of their life, relationships, values & strengths. Psychotherapy ideally supports adaptation, improved behavioural management of chronic illness, new coping skills & strengthened confidence to make changes. Anthony’s research is exploring the role of mindfulness & person-centred psychology in helping people achieve balance & wellness. His approach integrates cognitive behavioural therapy, mindfulness, lifespan development & existential psychotherapy. He has a background in smoking cessation. Other interests include loss & grief, motivational interviewing, developmental transitions & sexual identity.

ADAM JAFFÉ

Adam undertook his MD thesis on Gene Therapy in Children with CF at Imperial College & the Royal Brompton Hospital. He was subsequently appointed as a Consultant in Respiratory Research at Great Ormond Street Hospital for Children, London & headed up Respiratory Medicine Research at the Institute of Child Health London before moving to Sydney 13 years ago. His research career centres on translational research specifically aimed at improving child health outcomes. His research interests lie in the areas of cystic fibrosis, childhood pneumonia, emphysema, asthma & rare “orphan” lung diseases. Adam has published in excess of 170 peer reviewed publications & has been associated with more than $12 million in grant awards including two current NHMRC grants as Chief Investigator.

ANDREA BARRETT

Andrea is a Clinical Psychologist who currently works at Perth Children’s Hospital, previously known as Princess Margaret Hospital. Andrea completed her training at Victoria University, Wellington, New Zealand in 1995. In 1999, Andrea moved to Perth, & has worked as a Senior Clinical Psychologist since this time. In 2005 Andrea joined the Paediatric Consultation Liaison Program at Princess Margaret & began working closely with the Cystic Fibrosis team. In this role Andrea has provided assessment & treatment to many families who have children diagnosed with Cystic Fibrosis & provides specialist consultation & liaison services to medical, nursing & allied health teams across the organisation. Andrea is interested in early intervention & in particular, Infant Mental Health. She is the Chair of the PCH Infant Mental Health Interest Group & has trained staff across the organisation in the area of IMH practice within an acute tertiary setting. Andrea is a member of the Australian Psychological Society, Zero to Three & the Australian Association for Infant Mental Health.
ANTHONY KICIC

Anthony is currently Head of Airway Epithelial Research at the Telethon Kids Institute & is Associate Professor at the School of Public Health, Curtin University.

His current research interests include tissue engineering & cell biology, particularly focusing on the ability of the cells in the body to repair. Anthony & his research team have been investigating the reparative role of the airway epithelium & how this differs between healthy children & those with cystic fibrosis.

They are also investigating the cellular & molecular drivers of long-term lung transplant rejections which affect many recipients including those with CF.

Current funding is allowing them to explore new therapies including phage & synthetic antimicrobial peptides to treat antibiotic resistant bacterial lung infections in CF.

BARRY CLEMENTS

Barry has been a Clinical Consultant in Respiratory Medicine at Perth Children’s Hospital for over 30 years. He has many publications in peer-reviewed journals & has been the recipient of a number of research Grants.

Over the last few years, his interest in research has been rekindled, focusing on improving inhalation therapy in CF patients for which he has recently received funding for two large international projects.

BRENDA BUTTON

Brenda is an Honorary Physiotherapist at the Royal Children’s Hospital where she worked from the late 1990s. She is currently employed at the Alfred Hospital, Melbourne where she works as a senior clinician in the Department of Respiratory Medicine.

Her research interests include the effects of exercise & exercise testing, airway clearance therapy & adherence, the use of mucolytic agents, urinary incontinence & gastroesophageal reflux in adults with chronic lung disease & the prevalence of musculoskeletal problems including assessment & management in CF.

Brenda is an accredited Airway Clearance Therapy Instructor with the International Physiotherapy Group for Cystic Fibrosis & is a frequently invited speaker & course presenter in Australia, North America & Europe. She is a 2014 Winston Churchill Fellow.

CASSIE JONES

Working in stakeholder engagement in country NSW, Cassie juggles a full-time job & caring for her 4-year-old livewire Charlie Banjo. In 2015 Cassie’s only knowledge of Cystic Fibrosis was the Wolverines song ‘65 Roses’. Since then Cassie has whole-heartedly flung herself into a crash course to ensure her son Charlie lives his life to the fullest & healthiest. Cassie is passionate about advocating for Cystic Fibrosis & connecting with other parents who have also found themselves suddenly thrown into the deep end of parenting a child with a chronic illness.
Carmel joined the Alfred Cystic Fibrosis Service in March 2018 after working as a Credentialed Diabetes Educator for seven years. Her special interests include CF-related diabetes & gene modulator therapy as well as change management & patient education. Carmel has previously been involved in developing & implementing initiatives to improve the quality & efficiency of patient care with the Royal Melbourne Hospital & St Vincent’s Hospital & more recently with the Operations Directors at Alfred Health. In addition to her role within the CF service, Carmel consults as a Diabetes Educator at a general practice on the Mornington Peninsula.

Claire is a paediatric respiratory physician & Co-Lead for cystic fibrosis services at the Queensland Children’s Hospital in Brisbane which manages around 450 children with CF across Queensland & northern NSW. Claire is a Professor of Paediatrics & Child Health at the University of Queensland & her research interests include clinical trials, development of lung disease in CF, airway microbiology & patient reported outcomes in CF.

Craig is a born facilitator, although his wife says he likes to destroy things! Craig’s accounting career started in 1989 which was way too boring, although it took him 10 years to change. Craig found his passion working on software & implementations. He now works with clinicians to embed digital healthcare (such as Artificial Intelligence) to transform the way healthcare is provided. Craig’s turning point was the loss of his brother to CF in his early twenties. It forced Craig to be more accountable & responsible as he saw firsthand the dramatic impact it had on family & friends. Craig is married with two teenage daughters, has always been employed, & has his original lungs & he owns his home.

Cass is an Associate Professor in the Paediatric Department at the University of Auckland & a Paediatric Respiratory Specialist at the Starship Children’s Hospital. She is a leader in clinical care for children with CF with an outreach programme throughout NZ. Her research focusses on the prevention of respiratory disease progression in children with cystic fibrosis or post pneumonia bronchiectasis. She is the NZ principal investigator for a number of international trials in CF & Chair of the PORT CF: NZ registry.
CAZ BOYD

Caz is a Personal Assistant for two medical practitioners, an Associate Clinical Professor of Endocrinology & a Clinical Immunologist. She has worked in the health industry for over 34 years. Caz sits on various committees including Beat CF Project, Adult Cystic Fibrosis Consumer Advisory Committee & is Chair of the Community Advisor Council at Sir Charles Gairdner Hospital. Caz is a regular speaker & advocate for people living with CF. She has been involved with CF WA for over 36 years. Caz is President of CFWA & a Director of CFA.

Caz won the genetic lottery when she was diagnosed with CF in 1971 at the age of 4. In 1992 she underwent a successful double lung transplant. She can easily be spotted driving around by her number plate “NEWLUNGS”. In her spare time Caz can be found lazing by a pool in Bali, enjoying a cocktail or jumping out of a plane. She is a passionate West Coast Eagles supporter & enjoys a Pinot Grigio or Albarino.

DAVID ARMSTRONG

David attended the University of Auckland School of Medicine, & qualified MBChB in 1985. He obtained a FRACP in paediatrics in 1992 & trained in paediatric respiratory medicine at the Royal Children’s Hospital, Melbourne, completing his MD thesis (Longitudinal Study of Lower Airway Infection & Inflammation in Cystic Fibrosis Infants) at the University of Melbourne in 1999.

David’s clinical interest is management of children with severe asthma & all aspects of cystic fibrosis. His research focuses on the pathogenesis & treatment of early lung disease in cystic fibrosis.

DAVID PARSONS

David leads Adelaide’s CF Airway Research Group, based at the Womens & Childrens Hospital in South Australia where he is Chief Medical Scientist in the Department of Respiratory & Sleep Medicine. He also leads the CF Research section of the Robinson Research Institute, University of Adelaide.

The goal of David's group is to develop an effective & safe genetic therapy for prevention or treatment for CF airway disease, currently focussed on validating developments in normal & CF animal models.

He is supported in his research by the USA CF Foundation, the NHMRC & by local foundations & philanthropic groups. As part of the newly-formed Australian Lung Health Initiative, he recently won one of only 10 MRFF Frontiers Stage 1 grant awards to help develop revolutionary imaging-based regional lung airflow diagnostics for children under six.

DAVID REID

David is Director of the Adult CF Centre at the Prince Charles Hospital in Brisbane & Lead of the Lung infection & inflammation research group at QIMR-Berghofer Institute of Medical Research. He has >130 peer reviewed publications in the fields of CF, COPD & asthma & has been part of over $5 million dollars of research funding in the past five years.

He has been awarded Clinical Research Fellowships in Tasmania & Queensland & has been the recipient of a NHMRC Practitioner Fellowship. His studies into the role of biologically active metals, especially iron in lung diseases including CF have been at the forefront of the field & his research group together with collaborators in New Zealand were the first to develop molecular & biochemical tools to investigate how bacteria acquire metals from the host, with a focus on Pseudomonas aeruginosa in CF.

Dr. Reid’s team was also the first to examine the dynamics of the lung microbiome during the early stages of intravenous antibiotic treatment in CF.
ELIZABETH SHEVILL

Liz is the Nurse Practitioner at the QCH Cystic Fibrosis Clinic & in this role she works alongside a large multidisciplinary team, caring for 450 children with cystic fibrosis in Queensland & surrounding areas. Liz studied her Master of Nurse Practitioner at the University of Queensland. The new NP role has evolved in the last two years; prior to this Liz had worked in paediatric cystic fibrosis care as a nurse consultant for 13 years. She has a keen interest in all areas of paediatric CF family centred care.

ELISE ORANGE

Elise is a sibling of an adult Cystic Fibrosis patient. She has life long lived experience living alongside CF & has seen the highs & lows of medical intervention for patients with CF & their families, including supporting her sister through a double-lung transplant. Elise, like many siblings of those with chronic illness, also works with individuals & families in the disability sector.

As a mother, daughter & wife she understands the juggle of family life, work & trying to do something that looks like fun along the way.

GERARD KAIKO

Gerard is an NHMRC career development fellow & senior research associate at the University of Newcastle/HMRI. Gerard received his PhD in 2011 in respiratory immunology & microbiology. He worked at the MRC National Institute of Medical Research, London before receiving a CJ Martin NHMRC Fellowship to move to the USA, where he worked for five years at Washington University in St Louis. Here Gerard specialised in epithelial biology in gastrointestinal (GIT) diseases. He was part of the team that developed a new epithelial spheroid technology which was then used to create North America’s largest GIT epithelial biobank. He recently returned to Australia & setup a group which focuses on the role of the epithelium in mucosal inflammatory diseases in the GIT & lung & the use of epithelial stem cell technology in translational medicine.

HEATHER HUGO

Heather is a Senior Social Worker who has worked with children & their families in the areas of health & Child Protection for 20 years. She is currently a Senior Social Worker at Perth Children’s Hospital, working with the Respiratory Team. Heather has provided Clinical Social Work service to patients & their families with cystic fibrosis for the past 11 years. She has also worked in Paediatric Intensive Care, Neonatal Intensive Care, Acquired Brain Injury, Neurosurgery & Emergency. Heather has been a strong advocate for the psychosocial care of children & families with cystic fibrosis from newly diagnosed babies to transitioning young adults. She has worked jointly with researchers from the Telethon Institute, & is co-author of published research in the area of Bullying & Cystic Fibrosis. Heather completed her postgraduate Social Work degree at the University of Western Australia & an Arts degree in Psychology & Social Anthropology from the University of Cape Town in South Africa.
JENNA STONESTREET

Jenna is a Senior Dietitian with the Adult Cystic Fibrosis Centre at The Prince Charles Hospital & a Dietitian Team Leader within the Nutrition & Dietetics Department. She has recently been appointed to the Convenor role for the Cystic Fibrosis Interest Group with the Dietitians' Association of Australia. She holds sessional lecturer positions, delivering medical nutrition therapy presentations to students at the Queensland University of Technology & Griffith University. Jenna has a special interest in the impact of CFTR modulators on nutrition outcomes & enjoys acting as a nutrition resource person & mentor for the education, development & support of others involved in CF care.

JULIE DEPIAZZI

Julie is the Respiratory Coordinator at Perth Children’s Hospital. Her clinical work remains in evidence based physiotherapy care for children & young people with acute & chronic respiratory conditions. Her special interests include care of children with cystic fibrosis, dysfunctional breathing & tracheobronchomalacia. Julie is currently enrolled in a Masters of Philosophy at Curtin University, looking at aerobic capacity & ventilatory characteristics of children with cerebral palsy.

JODI HILTON

Jodi is a senior staff specialist at John Hunter Children’s Hospital, Newcastle & a conjoint clinical lecturer at Newcastle University. She is the Director of the Hunter New England Local Health District Paediatric Cystic Fibrosis centre. She works part time with involvement across all areas of respiratory & sleep medicine care, including acute & chronic management. However, her main clinical role involves CF care, including inpatient & outpatient management & coordination & she is PI for all CF related studies. With Prof Peter Wark, she will be implementing the CF Mental Health Initiative Trial at JHCH.

JULIET FOSTER

Juliet is a Research Psychologist with a special interest in the patient’s perspective on chronic disease & self-management. Her research interests include the adherence barriers, disease beliefs, treatment attitudes & lived experience of people with asthma, COPD & cystic fibrosis. Juliet’s publications also investigate digital behaviour change interventions & health professional-patient communication techniques. Juliet is outgoing Convenor for the Primary Care Special Interest Group for the Thoracic Society of Australia & New Zealand & serves on the Professional Advisory Council of Asthma Australia & the scientific & education committees of the European Society for Patient Adherence, Compliance & Persistence.
JOHN MASSIE

John is a Paediatric Respiratory Physician at Royal Children’s Hospital (RCH) Melbourne & Honorary Clinical Professor at the University of Melbourne. He has published extensively in the area of the diagnosis of cystic fibrosis, newborn screening & carrier screening. He is part of the federally funded Mackenzie’s Mission to study 10,000 couples for up to 1,000 conditions. John is also a member of the RCH clinical ethics service.

JOEY KAYE

Joey is a consultant endocrinologist in the Department of Endocrinology & Diabetes at Sir Charles Gairdner Hospital & is also Director of Diabetes Services for the hospital. He is a senior lecturer at the University of Western Australia & is Vice President of Diabetes Research Western Australia. He is a graduate of the University of Western Australia & completed his PhD in stress neuroendocrinology at the University of Bristol, UK.

JANE DRUMM

Jane is a parent of two young adults with CF, Chairperson of the Cystic Fibrosis NZ Board 2006 - current, Member of the NZ CF Clinical Advisory Panel, Trustee of the NZ CF Research Committee, Co-Chair of the Auckland District Health Board Patient & Whanau Centred Care Council. Jane has a background in teaching, events & community development & a great interest in governance & equity.

JUDITH MORTON

Judith leads the South Australian Adult Cystic Fibrosis Program. Judith has been involved in the care of people with CF & Lung Transplants for almost 30 years in centres across Australia.

In October 2016 Dr Morton was nominated by CFSA & awarded the inaugural Cystic Fibrosis Australia Patron’s CF Centre Star Award for her dedication, compassion & inspiration to the CF community. She is committed to improving life for people with CF & current projects include promotion & improvement of Infection Control practices & improving Transition to Adult services.

Judith attends the paediatric CF clinics in a unique partnership with The Women’s & Children’s Hospital, getting to know the adolescent patients before they transition to the Adult Service at the Royal Adelaide Hospital.
Jane is a Cystic Fibrosis Clinical Nurse Care Co-ordinator (“CF CNC”) at Monash Health, Clayton, Victoria. Jane graduated with a Bachelor of Nursing (Hons) from La Trobe University. She commenced working at Monash Health in 2000, in paediatric surgical & adolescent medicine. In 2017, Jane moved to the Cystic Fibrosis unit to work full-time as the CF CNC coordinator. The CF CNC role involves the coordination of the multi-disciplinary CF team, organising meetings, providing care for patients & families, educating health-care workers & the community. Jane has spoken nationally & internationally about her work & research. In 2017, Jane was presented with Cystic Fibrosis Australia’s CF Centre Star Award by the Governor-General for her exceptional support for people with CF.

José Caparrós-Martín

In 2002 José graduated in Biology from the University of Alicante (Spain) & completed his PhD at the Institute for Molecular & Cellular Biology (Valencia, Spain). In 2007 he was appointed as postdoctoral scientist to the CIBER of rare diseases (Spain). There he improved his skills in molecular genetics & bioinformatics applied to the analysis of NGS data. In 2015 he joined the Human Microbiome Programme at Curtin University to investigate the dynamics & interaction of functional diversity on different human microbial communities in health & disease. José makes use of different omics integrative approaches & genetic animal models to decode host-microbiota interaction in the gut & lung. He is a founding member of the Western Australia Human Microbiome Collaborating Centre.

Jamie Wood

Jamie has been a physiotherapist at Sir Charles Gardiner Hospital for over 14 years & has worked with adults with CF for the past 11 years. In 2010 Jamie was awarded a Sir Winston Churchill Memorial Fellowship to study physiotherapy for people with CF & bronchiectasis in England, Sweden & Belgium. He is an International Physiotherapy Group for CF Accredited Airway Clearance Instructor & has presented at numerous airway clearance courses nationally & internationally. Since 2010 Jamie has been a sessional academic at Curtin University, & is currently undertaking a PhD investigating the integration of telehealth with usual care in adults with CF.

Judith Glazner

Judith is both a psychologist & nurse. She has worked at The Royal Children’s Hospital in Melbourne for over 35 years. Judith joined the hospital’s Cystic Fibrosis (CF) team in 1991 as the Clinical Nurse Consultant in a clinic that cares for 250 children & adolescents.

Judith recently completed her PhD through the Department of Paediatrics at The University of Melbourne, investigating the impact of CF on parental differential treatment & the social & emotional adjustment of siblings. She has spoken nationally & internationally about her work & research. In 2017 Judith was presented with Cystic Fibrosis Australia’s CF Centre Star Award by the Governor-General for her exceptional support for people with CF.

Joan Caparrós-Martín
**Julia Moore**

Julia is a Consultant Child & Adolescent Psychiatrist at Perth Children’s Hospital, working in the Paediatric Consultation Liaison Program since 2014. Julia has experience working with children & adolescents who have CF & their families, as well as with children who have other complex medical problems. She is a graduate of the University of Western Australia. She has a strong interest in family therapy, infant mental health, & supporting parent-child relationships. She also has experience working with children who have autism. Julia is involved in clinical research regarding medication safety & antidepressant treatments for adolescents. She is also the Consultant Psychiatrist for the PCH Gender Diversity Service & is involved in a number of research projects in transgender health.

**Kate Baumwol**

Kate is a Certified Practising Speech Pathologist. She holds positions at Sir Charles Gairdner Hospital & the Lung Health Clinic. Her specialist interest is in the management of voice disorders, chronic cough & vocal cord dysfunction. Kate currently co-ordinates the Sir Charles Gairdner Hospital chronic cough clinic & combined ENT & Speech Pathology Voice Clinic. Kate is an adjunct lecturer at Curtin University, teaching in the area of voice. She is also the WA representative for the Laryngology Society of Australasia.

**Keith Ooi**

Keith is a clinical academic & a Professor of Medicine at the University of New South Wales (UNSW) & Senior Specialist Paediatric Gastroenterologist at Sydney Children’s Hospital Randwick, Australia. Keith is an international & national expert in cystic fibrosis-related gastroenterology & nutrition, as well as childhood pancreatic diseases. He has over 100 journal article & textbook chapter publications, including in high impact journals in the fields of gastroenterology (e.g. Gastroenterology), cystic fibrosis (e.g. Thorax, Chest) & paediatrics (e.g. Pediatrics, JAMA Peds). He has received more than $7 million as chief investigator in research funding, regularly presents at prestigious conferences & has won multiple research awards, including the Dean’s Rising Star Award (UNSW Medicine). Keith’s PhD, supervised by Professor Jane C Davies at Imperial College, London, focused on further defining the utility of Lung clearance Index, measured by Multiple Breath Washout, as a surrogate endpoint for CF intervention studies.

“Standardisation & synergy of clinical outcome measures, especially in difficult-to-detect early lung disease, is an emerging paradigm in a landscape of small molecule treatments & personalised medicine.

**Katie Bayfield**

Katie has established expertise in respiratory physiology & clinical trials co-ordination. Her current research studies focus on defining optimal monitoring tools for early lung disease detection in CF & other important paediatric respiratory diseases, under the supervision of A/Professor Paul Robinson. Katie’s PhD, supervised by Professor Jane C Davies at Imperial College, London, focused on further defining the utility of Lung clearance Index, measured by Multiple Breath Washout, as a surrogate endpoint for CF intervention studies.

“Standardisation & synergy of clinical outcome measures, especially in difficult-to-detect early lung disease, is an emerging paradigm in a landscape of small molecule treatments & personalised medicine.
LUKE GARRATT

Luke is a career medical research scientist with a special interest in the cellular pathobiology of early CF lung disease. His undergraduate studies were biomedical science/microbiology & in 2007 he joined ARREST CF as a research assistant. Luke graduated with a PhD from the University of Western Australia in 2015, where he demonstrated the adverse effects CF inflammation has on airway tissue. In 2017, he was awarded a NHMRC Early Career Fellowship & Project Grant to investigate how early events like infection can initiate CF inflammatory lung disease & characterise the phenotypes of lung & immune cells as chronic inflammation develops. Luke’s purpose is to discover new therapies that advance management of CF lung infections & to expand clinical biomarkers.

MICHAEL KELSO

Michael graduated from the University of Wollongong (B. Med. Chem. Hons 1, 1996) & received his PhD from the University of Queensland (2002). After a 1-year postdoc with Prof Claudio Palomo (Universidad del Pais Vasco, Spain) studying asymmetric catalysis, he moved to The Scripps Research Institute (CA, USA) to study medicinal chemistry as an NHMRC CJ Martin Fellow with Professor Dale Boger. In 2006-2007 he completed his NHMRC Fellowship at the University of Wollongong, where he was subsequently appointed as a lecturer in 2008 & A/Prof in 2014. His research focuses on the design, synthesis & evaluation of new antibiotics acting via novel mechanisms. He has received support from the Australian Cystic Fibrosis Research Trust (ACFRT) to develop biofilm-dispersing antibiotics for chronic Pseudomonas aeruginosa respiratory infections in CF.

LOUISE HESKETH

Louise has been working as the Senior Dietitian for the Advanced Lung Disease & Lung Transplant unit at Fiona Stanley Hospital, WA since the Hospital opened in early 2015. Her role also includes managing Advanced Heart Failure & Cardiac Transplant as well as cardiothoracic patients. Louise also has extensive experience in Critical Care nutrition which has been a valuable asset to her role in managing patients post-transplant. Louise meets with all CF patients undergoing lung transplant workup assessments & ensures any nutrition-related issues are optimised prior to transplant. Post-transplant, Louise provides nutrition care to ensure patients receive adequate & appropriate nutrition support to meet the complex demands of CF patients having undergone transplant. Louise has a passion for medical nutrition therapy & enjoys seeing the improvements that dietetic interventions can make in overall care of our patients.

MITCHELL MESSER

Mitch has been a consumer advocate for over 40 years & has been actively involved with CF organisations throughout the world. He is a vice president of CF Australia, a Trustee of the Australian CF Research Trust & a past Executive Director of CFWA. He has been a board member of many state & national consumer organisations. Mitch was a member of the PBAC for almost 12 years & was a member of the Research Committee of the NHMRC from 2009 – 2012. In 2018, Mitch took on the role of consumer advisor for BEAT CF at Telethon Kids Institute providing a resource for the project’s consumer reference group members & a link between the research team, consumers & the CF community.
MICHAEL WARD

Michael is the Managing Director of Leda Financial Advice Ltd, a not-for-profit financial advice practice.

Leda’s primary focus is on developing a thorough understanding of a client’s position, concerns & goals, before carefully implementing appropriate strategies to reach an agreed financial outcome.

Michael’s passion for financial literacy & education has resulted in Leda partnering with Kaplan Professional to deliver education scholarships to regional high school leavers.

Michael has been in financial services for over 17 years & been a licensed financial adviser for 12 years. His qualifications include but are not limited to a Masters of Financial Planning, Graduate Certificate of Applied Finance, SMSF Specialist Adviser, & registered Tax (Financial) Agent. Michael sits on a number of education committees for the Financial Planning Association, as well as Curtin University & Kaplan Professional.

MICHELLE WOOD

Michelle has over 15 years as a clinical Physiotherapist in the area of cystic fibrosis. Since 2009 she has worked as the Clinical Research Co-ordinator at the Adult CF Centre at The Prince Charles Hospital, which includes managing & conducting the clinical drug trial portfolio. She has a special interest in infection control & this year completed a Master of Philosophy researching potential airborne transmission of CF pathogens & mitigation strategies including the effectiveness of face masks.

MICHAELA LUCAS

Michaela is a Consultant Clinical Immunologist/Immunopathologist at Sir Charles Gairdner & Perth Children’s Hospitals in Western Australia, where she leads the drug allergy services. She is a research group leader at the Harry Perkins Institute, University of Western Australia. She is currently the President Elect of the Australasian Society of Immunology & Clinical Immunology (ASClA) & Chair of the ASCIA Drug Allergy Committee.

Michaela has a strong background in T-cell immunology, notably in describing the role of classical & non-classical T-cell responses to the pathogenesis of infections and, most recently, in drug allergy & transplantation. Michaela is currently playing a key role in the development of national Australian guidelines concerning the management of drug allergy.

NATHAN WARD

Nathan is the Principal Physiotherapist for Respiratory at the Royal Adelaide Hospital where he has worked as part of the CF team for the last 11 years after having previously worked for the Tasmanian Adult CF Service.

Nathan is also a PhD candidate at La Trobe University where his research is investigating the role of exercise as a form of airway clearance in people with cystic fibrosis & the development of a method for objectively monitoring adherence & technique performance with positive pressure airway clearance devices.
Natalia Popowicz

Natalia is a Senior Clinical Pharmacist in Cystic Fibrosis at Sir Charles Gairdner Hospital, Perth, a lecturer of Clinical Pharmacy at the University of Western Australia (UWA) & leads the Respiratory Research unit at the Centre for Optimisation of Medicine at UWA. Her PhD on optimising therapy in pleural infection includes both laboratory & translational clinical research. In clinical practice, Natalia has a research interest in the pharmacokinetics of antibiotics and the impact of adherence on health outcomes in patients with cystic fibrosis.

Natalie Van der HaaK

Natalie has worked in the area of CF since 2007 & has been involved in many projects including timing of pancreatic enzyme replacement therapy, audits of nutritional & vitamin D status & implementation of nutrition annual review clinics. Natalie has published in the Journal of CF & has presented project findings at the North American & European CF conferences. Natalie was a project facilitator for the 2017 NHMRC approved Nutrition Guidelines for CF in Australia & New Zealand & presented these at the 2017 European & Australasian CF conferences. Natalie is currently the vice-convener of the Dieticians’ Association of Australia CF Special Interest Group & enjoys working with CF dieticians to progress nutrition work in CF.

Pamela Scarborough

Since qualifying as a physiotherapist in 2001, Pamela has spent over 15 years working as a physiotherapist in the NHS, predominantly working with adults with cystic fibrosis. Pamela is passionate about the role of exercise in improving physical & emotional wellbeing & looking at ways to help individuals manage treatments more effectively so they can each live their best life. Having personally benefited from a regular yoga practice, Pamela trained as a yoga teacher to share the disciplines & benefits with people with CF. Pamela researched ‘Yoga for Thoracic Kyphosis & Low Back Pain in adults with CF’ for her Masters dissertation, has gone on to present internationally on ‘Yoga & CF’ & co-authored the ‘Complementary Therapies’ chapter in the UK ‘Standards of Care & Good Clinical Practice for the Physiotherapy Management of Cystic Fibrosis’. Pamela hosts live yoga sessions for the CF community weekly on Beam where she has also created tailored on-demand yoga videos. Her practice is alignment-focused & specifically aims to improve breathing pattern, relaxation, posture & continence.

Paul Hodges

Paul is a National Health & Medical Research Council Senior Principal Research Fellow & Director of the Centre of Clinical Research Excellence in Spinal Pain, Injury & Health at The University of Queensland. He is a Fellow of the Australian Academy of Science & the Australian College of Physiotherapists & Honoured member of the Australian Physiotherapy Association. His research interests in movement, pain, respiration, continence & rehabilitation span from cells to humans, clinical trials & knowledge translation. He has authored more than 400 peer reviewed papers that have been cited more than 21,000 times (Scopus), in addition to 36 book chapters & four books.
Peter Middleton

Peter is Senior Staff Specialist & CF Centre Director at Westmead Hospital & Clinical Professor at Sydney Medical School. Following training at Royal Prince Alfred Hospital, he went to the Royal Brompton Hospital, London where he completed a PhD in CF Gene Therapy at the University of London. He is Co-Chair, CF Centre Directors Group & CF Special Interest Group & also a member of the Steering Committees of the Australian CF Data Registry, BEAT CF & the CF AVATAR study. Peter is a member of the European CF Society Diagnostic Network & he set up the CF laboratory at Westmead to measure Nasal Potential Difference.

Peter’s interests include clinical aspects of CF care, development of new treatments for CF, surrogate markers of CFTR activity & the role of bacterial & fungal infections in the CF airway.

Peter Wark

Peter is a Senior Investigator with the Priority Research Centre for Healthy Lungs at the Hunter Medical Research Institute. He is also a chief investigator in the NHMRC Centre of Excellence in Severe Asthma. His research interests are airway inflammation in the context of chronic airways disease, innate immunity & the role of infection in chronic airways disease. His group has developed expertise in identifying respiratory viruses in airway secretions & developing an in-vitro cell culture models of the airway epithelium to model the effect of infection & inflammation. His research focuses upon factors that increase susceptibility to viral infection in asthma, COPD, Cystic Fibrosis & bronchiectasis.

Peter is a board member of Cystic Fibrosis Australia. He qualified as a Bachelor of Medicine at the University of Newcastle, Australia in 1991 & qualified as a specialist in Respiratory & Sleep Medicine as a Fellow of the Royal Australasian College of Physicians in 1999.

Phil Robinson

Phil has been a consultant respiratory physician in the Department of Respiratory & Sleep Medicine at the Royal Children’s Hospital for 27 years & is currently the acting head of the department. He was head of the Hospitals’ CF unit for 14 years & during that time helped edit the first edition of the Australian Standards of Care for CF & is presently an editor developing the second edition. He has run a respiratory clinical drug trial unit for 20 years & has been involved in over 60 such trials including most of the mutational specific drug trials over the past 10 years. He conducts regional CF clinics in Albury, Hobart & the Northern part of Tasmania & helped establish the Royal Children’s Cystic Fibrosis Research Trust in 1999 which since then has raised over $3 million for CF Research at the hospital.

Ruth Dentine

Ruth is the senior physiotherapist in the department of respiratory medicine at Royal Prince Alfred Hospital in Sydney. Ruth coordinates the adult CF clinic, including inpatient & outpatient care & research (25 publications). Ruth has extensive experience in respiratory medicine (over 20 years) with particular interest in CF, airway clearance techniques & inhalation therapies, management post ICU, tracheostomy weaning & NIV. She enjoys the challenge of applying evidence based reasoning to clinical practice; the continuum of questioning, learning & teaching.
**RASA RUSECKAITE**

With an undergraduate degree in Science, Rasa has a Master of Science & two PhDs - one in Applied Computer Science & the other in Neuroscience. Rasa has always maintained a strong interest in human health, patient outcomes & clinical registries. As a Senior Research Fellow & Data Manager of the Australian Cystic Fibrosis Data Registry, Rasa is responsible for all aspects of the registry data management including acquisition of good quality data, also analysis, interpretation & reporting. Rasa also has a strong interest in quality of life research & patient reported outcomes. She is currently leading an initiative aiming to develop guidelines for PROMs inclusion in clinical quality registries.

**SHANNON MALONE-BRIERLEY**

Shannon is a highly experienced & respected educator with over 14 years’ experience. Shannon has worked with all age groups of children from preschool all the way through secondary school. Shannon has a Bachelor Degree in Education, a Master’s Degree in Education (Behaviour Management) & is currently enrolled in post-graduate studies in Inclusive Education. Coming from a background of working with children, Shannon has channelled her experience & expertise to intelligently, respectfully & actively advocate for the rights of children to have access to the drugs & services that they require to live a life unaffected by their disease.

She credits her love of advocacy & raising awareness for children with diverse needs for helping her to achieve some wonderful personal goals including running the New York Marathon to raise awareness.

**SUSANNAH KING**

Susannah is a senior dietician at The Alfred Hospital in Melbourne, & leads the nutrition service for CF & respiratory illness. With over 20 years’ experience in CF, she was a lead author for both the 2006 & the 2017 Nutrition Guidelines for CF in Australia & New Zealand. With key interests in body composition, nutrition assessment, malnutrition & nutrition support she is active in research in CF & acute & chronic disease fields including gastroenterology & critical illness. She is also a Senior Lecturer at La Trobe University, supervising Masters & PhD students. Susannah is currently an Associate Editor for the Journal of Cystic Fibrosis & a member of the Australian CF Data Registry Steering Committee.

Sarath is Head of the Department of Paediatrics at the University of Melbourne, Director of Respiratory & Sleep Medicine at the Royal Children’s Hospital & Group Leader at the Murdoch Children’s Research Institute in Melbourne. Professor Ranganathan was recently elected Fellow of the American Thoracic Society. He is a leading authority on infant respiratory physiology & early lung disease.

**SARATH RANGANATHAN**

Sarath is Head of the Department of Paediatrics at the University of Melbourne, Director of Respiratory & Sleep Medicine at the Royal Children’s Hospital & Group Leader at the Murdoch Children’s Research Institute in Melbourne. Professor Ranganathan was recently elected Fellow of the American Thoracic Society. He is a leading authority on infant respiratory physiology & early lung disease.
SHAFAGH WATERS

Shafagh is a Senior Research Associate in the School of Woman & Children’s health, & heads the miCF research Laboratory at UNSW, Sydney, Australia. She received her PhD in RNA biology from Australian National University (ANU), & undertook postdoctoral training at UNSW. Shafagh’s current research activities have a strong translational focus in three key areas of (i) stem cell biology involving culture & biobanking of primary respiratory spheroids & rectal organoids from patients with cystic fibrosis (ii) prognostic & diagnostic exosomal biobanker discovery for CF related diabetes, & (iii) CFTR restoring therapeutics in patient derived organoids using a variety of delivery approaches.

TIMOTHY JAMES-KIDD

Tim is an NHMRC-funded Research Fellow currently undertaking infectious diseases research at The University of Queensland (UQ).

Tim completed his undergraduate studies in 1992 & thereafter worked within various clinical microbiology laboratories. During this time he established Australia’s first Burkholderia reference laboratory & developed high-level expertise in CF microbiology.

In 2007 he commenced full-time research working across both clinical & basic science research fields in Australia & the UK. His current research focuses on the acquisition, epidemiology, antimicrobial resistance (AMR) & pathogenesis of acute & chronic Gram-negative infections.

Tim’s research has resulted in over 65 publications & his findings have extended to development of international patient management guidelines. He also currently serves as a member of the AMR International Working Group in CF & ERS College of Experts.

SUSANNAH AHERN

Susannah is a Medical Administrator academic in health services research & management.

She is the Academic Lead for six clinical registries including those in dementia, cystic fibrosis, thyroid & bowel cancer. Her areas of interest include registry governance & policies/guidelines, quality of clinical registry data, registry data analysis & reporting including risk adjustment & benchmarking, external data access to registry data & communication of registry outcomes to a broad range of stakeholders.

STEVE ALLSOP

Steve has worked for almost 40 years in the alcohol & other drugs field. He is currently employed as Professor at the National Drug Research Institute Curtin University.

He has previously worked as the Director of two National Centres in Adelaide & most recently at the National Drug Research Institute. He also worked for many years in senior roles in the Drug & Alcohol Office.

Steve is currently chair of the WA Network of Alcohol & Other Drug Agencies & Deputy Chair of the Australian National Advisory Council on Alcohol & other Drugs, the principal advisory group on drugs to the Australian Government.
SCOTT BELL

Scott is a Senior Physician of the Adult Cystic Fibrosis Centre at TPCH (>320 patients) where he has worked since 1996. He is currently the Editor-in-Chief of the Journal of Cystic Fibrosis & leads the Lung Bacteria Laboratory at QIMR Berghofer Medical Research Institute. Scott has over 230 peer-reviewed publications & has received grant support totalling more than $16 million over the past 10 years. His research interests include the CF microbiology & acquisition pathways for human infection & he has a long history of supporting multi-disciplinary research. He has been PI on numerous pivotal CFTR modulator trials & is global PI on a novel approach to combination therapies for CFTR correction.

SIOBHAIN MULRENNAN

Siobhain is a Clinical Associate Professor, trained as a Consultant in Respiratory & General Medicine in Yorkshire, UK & as an Adult CF Physician at the Manchester Adult CF unit, UK.

Siobhain has been a full time Respiratory Consultant at Sir Charles Gairdner Hospital, Perth since 2008 & Director of the Adult CF Service.

She is a Clinical Associate Professor in the Faculty of Health & Medical Sciences, University of Western Australia & affiliated with the Institute of Respiratory Health & the Busselton Population Medical Research Institute.

SHARON LAWRENCE

Sharon currently works as the Clinical Nurse Consultant for the Advanced Lung Disease & Lung Transplant Unit at Fiona Stanley Hospital. She has worked with the program from its inception at Royal Perth Hospital in 2000 & transitioned to Fiona Stanley Hospital in 2015. Like the program, Sharon’s role has evolved to include transplant coordination, patient case management both pre & post-transplant, inpatient & outpatient education, clinical trial coordination & staff education. For the past three years Sharon has also been the Chairperson of the Heart & Lung Transplant Foundation of WA Inc.

STEPHEN STICK

Stephen is the Director of the Kids Respiratory Research Centre at the Telethon Kids Institute & Specialist in paediatric respiratory medicine at Perth Children’s Hospital, Perth & NHMRC Practitioner Fellow.

Stephen graduated in medicine from Cambridge University, UK, has a PhD in physiology from University of WA & is Chief Investigator with the Australian Respiratory Early Surveillance Team for cystic fibrosis.

His interests include precision medicine as a framework for approaching early childhood disease & the role of the epithelium in chronic respiratory disease.
SHIVANTHAN SHANTHIKUMAR

Shiv has nearly completed his training as a Paediatric Respiratory Physician at the Royal Children’s Hospital, Melbourne. He is midway through his PhD, which is attempting to identify biomarkers which can be used in early life to predict lung disease severity in later life. In particular he is focusing on epigenetic biomarkers. In addition to this he also has a strong interest in CF systems improvement & quality improvement initiatives, having developed ‘at risk’ & antibiotic protocols for the CF team.

SHANE LING

Shane completed his medical degree at the University of Western Australia & completed his advanced surgical training in Perth. He went on to complete a clinical fellowship at the Queen Elizabeth Hospital, Birmingham, focusing on advanced endoscopic sinus surgery & endoscopic pituitary & anterior skull base surgery.

Shane’s main interests are in diseases of the sinonasal region & anterior skull base & he frequently works together in a multidisciplinary team treating these complex conditions. He is active in teaching, frequently teaching on surgical courses & involved in training registrars.

SUE MOREY

Sue is a Nurse Practitioner in Respiratory Medicine at Sir Charles Gardiner Hospital. Her special interests include cystic fibrosis. In the early 1980s Dr Gerard Ryan established a formal cystic fibrosis clinic, which Sue has been intrinsically involved with. Since that time the numbers have evolved to 190 adults with CF. Gerard Ryan & Sue have fostered an open door policy to allow patients early access & early intervention.

This state-wide adult CF clinic offers home IVs & a transition clinic from the Perth Children’s Hospital. The CF multidisciplinary team regularly attends outpatient clinics at the hospital to meet the young patients prior to their transition to the adult CF centre.

The CF clinic has been recognised by the Health Department for pioneering telehealth clinics, which provide regular consultations for country patients. The CF team liaise regularly with the Fiona Stanley Hospital lung transplant team to ‘work patients up’ for lung transplants. This has been achieved through a multidisciplinary approach, which is coordinated by the nurse practitioner.
TARYN BARRETT

Taryn is a mother of three boys, the youngest of which has cystic fibrosis. Since having her son Connor in 2015, Taryn has become an advocate for research & the placement of breakthrough medicines on the PBS. She advocated for the placement of Orkambi on the PBS & received the 2017 Cystic Fibrosis Australia Award which was presented by the Governor General of Australia. Taryn also established a South West chapter of Conquer Cystic Fibrosis, a volunteer-run charity focussed on research. For the past 16 years the charity has hosted many events including the Capel Vale Conquer Cystic Fibrosis Grand Ball in Perth & raised more $3.5 million. Armed with her past experience in media, research & government relations, Taryn ensures she will continue to advocate for the cause until the day a cure is found.

TAMARAH KATZ

Tamarah received her Masters in Nutrition & Dietetics at the University of Sydney in 2001. She has been working as Paediatric Dietician at Sydney Children’s Hospital since & as a member of the Cystic Fibrosis Team for 12 years. During that time she has partnered with her multidisciplinary care team in over 20 publications.

Tonia is a Paediatric Respiratory & Sleep Physician & Co-director for Cystic Fibrosis services at the Queensland Children’s Hospital. Tonia is a senior clinical lecturer with the University of Queensland, School of Medicine & her research interests include early CF lung disease & psychosocial determinants of health in CF.

TOM SNELLING

Tom is a Paediatric Infectious Diseases physician, & Director of the Wesfarmers Centre of Vaccines & Infectious Diseases at the Telethon Kids Institute. In addition, he is an Honorary Fellow at the Menzies School of Health Research, & Adjunct Associate Professor with the School of Public Health at Curtin University. Tom is also Team leader of Infectious Diseases Implementation Research at the Telethon Kids Institute with an aim to implement treatment & preventative strategies to reduce the burden of infectious diseases in children.

He is one of Australia’s leading proponents of pragmatic & adaptive clinical trials, being the chief investigator of four competitively funded Bayesian adaptive clinical trials.

TONIA DOUGLAS

Tonia is a Paediatric Respiratory & Sleep Physician & Co-director for Cystic Fibrosis services at the Queensland Children’s Hospital. Tonia is a senior clinical lecturer with the University of Queensland, School of Medicine & her research interests include early CF lung disease & psychosocial determinants of health in CF.
TREVOR WILLIAMS

Trevor is a Director of Respiratory Medicine at The Alfred Hospital & Adjunct Professor at Monash University in Melbourne. Trevor is a Melbourne trained Respiratory Physician who was a Clinical Research Fellow for the Toronto Lung Transplant Program. Upon his return to Melbourne he helped establish The Alfred Hospital Lung Transplant Program, which in the ensuing 29 years has performed almost 1,500 lung transplant procedures.

His main clinical research interests are in the area of severe lung diseases including lung transplantation - particularly immunopathology of chronic rejection, pulmonary hypertension, exercise limitation in severe lung disease & development of novel bronchoscopic approaches to emphysema. He has been a principal investigator on many Phase 1, 2 & 3 clinical trials of pharmacological & non-pharmacological therapies for COPD & Pulmonary Hypertension.

Trevor serves as a reviewer for all major international respiratory medicine journals & is the immediate past President of the Pulmonary Hypertension Society of Australia & New Zealand. His work has produced over 200 peer review publications, book chapters or reviews.

Trevor presently leads the largest most comprehensive Department of Respiratory Medicine in Australia including the National Centre for Paediatric Lung Transplantation, State Centre for Cystic Fibrosis, State Centre for Pulmonary Hypertension (including CTEPH), Allergy & Immunology Program, Interstitial Lung Disease Program, Sleep & Ventilatory Failure program & the medical support team for one of the most active lung transplant programs (>100 LTx/year) worldwide.

TOM RILEY

Tom divides his time in Perth, Western Australia, between PathWest Laboratory Medicine, WA’s public sector pathology service provider where he is a Senior Clinical Scientist, Edith Cowan University where he is a Professorial Research Fellow, & Murdoch University where he is Professor of Public Health. He has had a long standing interest in healthcare-related infections, particularly the diagnosis, pathogenesis & epidemiology of Clostridium difficile infection. He is a Fellow of the Royal College of Pathologists, the Australian Society for Microbiology, the American Academy of Microbiology, the Society for Healthcare Epidemiology of America & the Faculty of Science of the Royal College of Pathologists of Australasia & has published >400 book chapters & refereed journal articles, including >170 on C. difficile.

VERONICA YOZGHATLIANG

Veronica is a Respiratory & Sleep Physician at St. George Hospital & Visiting Medical Officer at Royal Prince Alfred Hospital working in the Adult Cystic Fibrosis Clinic. She completed her PhD studies at University of Sydney studying microbiology resistance & antibiotic treatment focussing on Adult Cystic Fibrosis patients. Her special interests include respiratory infectious diseases, with a focus on both cystic fibrosis (CF) & non-CF bronchiectasis. She also has a special interest in severe asthma & expertise in a broad variety of sleep disorders including complicated ventilation patients.
As the CEO of Cystic Fibrosis Australia, Nettie brings experience & expertise shaped in senior management roles in both the corporate & not-for-profit sectors in the United Kingdom & Australia. Nettie is a passionate advocate for the cystic fibrosis community & in recent years she has focused on gaining access to cutting edge drugs & treatments, supporting better mental health services through training & technology & reducing the burden of the disease.

Her stewardship of key initiatives including partnership development, consumer engagement & brand strategies has attracted collaborations with the community, corporate sector & government. Nettie is responsible for ensuring that key target markets are aware of the milestones achieved by CFA & that the expectations of corporate partners, government, donors & supporters are met all while fiscal targets are not only reached but exceeded.

Nettie spent almost three decades in corporate advertising working at high profile agencies including Saatchi & Saatchi & Adcorp Australia. In these roles she was tasked with unifying eclectic talents & far-flung regional resources to create a truly compelling & distinctive service offering in an increasingly competitive marketplace.

Restructuring & change management are key skills in Nettie’s armoury & she employs these to streamline processes, improve effectiveness & balance budgets. Nettie has a successful track record in liaising at the highest level of corporate management & government, presenting major initiatives to large groups of stakeholders & delivering defined & effective partnerships that get results.

Nettie was formally a Board Member of Fashion Targets Breast Cancer, Muscular Dystrophy NSW & The Kid’s Cancer Project. She is currently researching avenues of support, advocacy & increased funding to help CFA achieve its significant goals, tackling an insidious disease & giving a greater voice to people with cystic fibrosis.

Patrick’s professional life revolves around running a consulting company specialising in the design, creation, implementation and evaluation of markets for ecosystem services. Patrick designs & researches approaches to overcoming negative environmental externalities from agricultural production systems & has created markets for the conservation of soil, wetlands, biodiversity & for carbon sequestration. He also works in program evaluation, designing & implementing evaluations to improve decisions in environmental programs in the government & not-for-profit sector.

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Patrick is a board member of the National Landcare Network, former Vice President of the Nature Conservation Society SA & life member of Trees for Life. Patrick began his voluntary involvement with cystic fibrosis organisations in 1982 when he raised money & helped lead a recreation camp for young people living with CF. Patrick was a Board member of CFSA for 15 years & has been on the CFA Board for five years. Patrick was elected President of CFA on the 2nd May 2015.
Awards & Prizes

Prizes
Prizes will be awarded & presented in the following categories:
1. Best Abstract
2. Best Poster (Medical/Scientific)
3. Best Poster (Allied Health)

CF Allied Health Fellowship
“The Abbie Fennessy Memorial Fellowship”
Technipro-PuloMed Pty Ltd sponsors this Allied Health Award with the aim of improving the knowledge & skills of those multidisciplinary teams working in cystic fibrosis care. The award is presented annually. Information can be obtained at Cystic Fibrosis Australia.

CFA Life Time Achievement Award
All awards & prizes will be presented on Tuesday 8th August (2:30-3:00pm).

Social Program

Official Opening & Keynote Address
Sunday 4th August 2019 at 1:00pm.
All registered lay & medical conference delegates are welcome in Crown 1.

Welcome Drinks
Sunday 4th August 2019 at 5:00pm.
All registered lay & medical conference delegates are welcome in the ACFC Expo.

Lay Dinner 6:30pm, Saturday 3rd August at Market & Co, Crown Promenade, for registered lay delegates to share experiences in a relaxed & friendly environment.

Conference Celebration 7:00pm, Monday 5th August 2019 at The Camfield, Roger MacKay Drive, Burswood for registered medical conference delegates. The Camfield is a short 5-minute walk from The Crown Complex.

ACFRT

In 1989 the Australian Cystic Fibrosis Research Trust (ACFRT) was founded by the members of The ACFA, parents, patients & doctors to secure resources to support cystic fibrosis research in Australia. They believed that setting up an entity to implement best practice in assessing research projects & aggregating research funds was vital. Their goal was to provide more & better opportunities to support improving the treatment & quality of life for people facing the daily challenges of living with CF. The founding Trustees were Wal Riddell, Conrad Guerra & Mitch Messer.
The ACFRT’s remit is to secure funding from public, private & corporate entities & allocate funds for high quality peer & consumer reviewed research. This year the ACFRT celebrates its 30th anniversary & to date the Trust has funded more than 300 research projects valued at over $6 million. The ACFRT is recognised as Australia’s largest & most prolific independent CF research funding body & is passionate about ground breaking, innovative research concepts that consider new treatments & models of care that ultimately improve life expectancy & quality of life for people with CF. Attracting the brightest young minds into cystic fibrosis medicine, allied health, mental health & research is also a key priority & former ACFRT grant recipients are a testament to this.
It is important to note that 100% of the funds raised or donated to the ACFRT are used to fund research. The ACFRT is administrated by Cystic Fibrosis Australia & supported by CF organisations from all states & territories.
# Lay Program

## Saturday 3rd August 2019

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:30 - 5:00pm</td>
<td>Registration</td>
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<tr>
<td>8:30 - 8:45am</td>
<td>Opening Address - Crown 3A &amp; 3B</td>
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<tr>
<td></td>
<td>MC: Nigel Barker</td>
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<td></td>
<td>CEO, Cystic Fibrosis Western Australia</td>
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<td>Acknowledgement of Country</td>
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<td></td>
<td>Speaker: Patrick O’Connor</td>
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<td></td>
<td>President, Cystic Fibrosis Australia</td>
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<td></td>
<td>André Schultz</td>
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<td>13th Australasian Cystic Fibrosis Conference Chair</td>
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<td></td>
<td>Opening Remarks: “Partnerships”</td>
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<tr>
<td>9:00 - 10:00am</td>
<td>Key Note Plenary - Crown 3A &amp; 3B</td>
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<td></td>
<td>CELEBRATING PARTNERSHIPS</td>
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<tr>
<td></td>
<td>Speaker: Debbie Benitez</td>
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<td></td>
<td>Chair: André Schultz</td>
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<tr>
<td>10:00 - 10:30am</td>
<td>Morning Tea</td>
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<tr>
<td>10:30 - 11:30am</td>
<td>Plenary 2 - Crown 3A &amp; 3B</td>
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<tr>
<td></td>
<td>THE FUTURE OF CYSTIC FIBROSIS - THE DISEASE</td>
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<td></td>
<td>Speaker: Jane Davies</td>
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<td>Chair: Jane Drumm</td>
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<tr>
<td>11:30 - 12:30pm</td>
<td>Plenary 3 - Crown 3A &amp; 3B</td>
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<tr>
<td></td>
<td>INFECTION CONTROL IN THE REAL WORLD</td>
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<tr>
<td></td>
<td>Speaker: Lisa Saiman</td>
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<td></td>
<td>Chair: Julia Langrehr</td>
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<tr>
<td>12:30 - 12:45pm</td>
<td>YOGA</td>
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<td></td>
<td>Yoga for Relaxation (seated session) with Pamela Scarborough, CF Physiotherapist &amp; Yoga Instructor</td>
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<tr>
<td>12:45 - 1:30pm</td>
<td>Lunch</td>
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<tr>
<td>1:30 - 2:30pm</td>
<td>Concurrent Session 1</td>
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<tr>
<td>Crown 3A</td>
<td>Chair: Karin Knoester</td>
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<tr>
<td></td>
<td>Cystic Fibrosis Genetics &amp; Fertility</td>
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<td></td>
<td>Speakers: John Massie &amp; Siobhain Mulrennan</td>
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<tr>
<td>Crown 3B</td>
<td>Chair: Shannon Malone-Brierley</td>
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<td></td>
<td>Personalised Cystic Fibrosis Treatments</td>
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<td></td>
<td>Speakers: Stuart Elborn &amp; Marcus Mall</td>
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<tr>
<td>Crown 3C</td>
<td>Chair: Caz Boyd</td>
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<td></td>
<td>Personal Advocacy &amp; Being Involved</td>
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<td></td>
<td>Speakers: Mitch Hesser - Cystic Fibrosis Adult</td>
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<td></td>
<td>Taryn Barrett - Mother of Cystic Fibrosis Child</td>
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<td></td>
<td>Anne Mackenzie - Consumers in Research</td>
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<td>2:30 - 3:00pm</td>
<td>Afternoon Tea</td>
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<tr>
<td>3:00 - 4:00pm</td>
<td>Concurrent Session 2 “Through the Ages”</td>
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<tr>
<td>Crown 3A</td>
<td>Chair: Claire Leonard</td>
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<td>Living With CF</td>
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<td>Through the Ages - Child</td>
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<td>Speakers: Cassie Jones &amp; Julia Moore</td>
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<tr>
<td>Crown 3B</td>
<td>Chair: Julia Langrehr</td>
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<td>Living With CF</td>
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<td>Through the Ages - Teens</td>
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<td>Speakers: Jane Drumm &amp; Judith Morton</td>
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<tr>
<td>Crown 3C</td>
<td>Chair: Wendy Endebrock-Brown</td>
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<td>Living With CF</td>
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<td>Through the Ages - Adult</td>
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<td>Speakers: Siobhain Mulrennan &amp; Caz Boyd</td>
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<td>4:00 - 5:00pm</td>
<td>Concurrent Session 3</td>
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<td></td>
<td>Chair: Paula Wreidt</td>
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<td></td>
<td>The Financial Burden of CF</td>
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<td>Speakers: Craig Woodrick &amp; Michael Ward</td>
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<td></td>
<td>Chair: Cassie Jones</td>
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<td>Positive Partnering: Focus on Partnerships That Facilitate Positive Mindsets</td>
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<tr>
<td></td>
<td>Speakers: Shannon Malone-Brierley, Elizabeth Shevill &amp; Peta Yarrow</td>
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<td>Chair: Nigel Barker</td>
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<td>Transplant</td>
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<td>Speakers: Caz Boyd &amp; Sharon Lawrence</td>
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<tr>
<td>6:30pm</td>
<td>LAY DINNER</td>
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<td>Market &amp; Co, Crown Promenade</td>
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Lay Program

Sunday 4th August 2019

7:15 - 8:00am | Wake Up Yoga
Wake Up Yoga with Focus on Postural Awareness (all levels welcome) with Pamela Scarborough. Meet at Registration.

7:30 - 5:00pm | Registration

9:00 - 10:00am | Plenary 4 - Crown 3A & 3B
THERE'S NO HEALTH WITHOUT MENTAL HEALTH
Speakers: Alistair Duff & Beth Smith Chair: Petrina Fraccaro

10:00 - 10:30am | Morning Tea

10:30 - 11:30am | Concurrent Session 4
Chair: Jane Bollard Maximising Your Medications
Speaker: Paul Beringer
Chair: Kathryn Pekin Sinus Disease
Speakers: Caz Boyd & Shane Ling
Sponsored by Cystic Fibrosis SA
Chair: Craig Woodrick Australian Clinical Trials Including BEAT CF
Speakers: Stephen Stick, Tom Snelling & Phil Robinson

11:30 - 12:30pm | Concurrent Session 5
Chair: Petrina Fraccaro Nutrition: A Fat Lot of Good
Speaker: Chris Smith
Chair: Karin Knoester Considering Siblings in a CF Family
Speakers: Judith Glazner & Elise Orange
Chair: Taryn Barrett All Things Exercise
Speaker: Zoe Saynor

12:30 - 1:00pm | Lunch

1:00 - 1:30pm | Conference - Official Opening
1:30 - 2:30pm | Key Note Address Plenary 1
2:30 - 3:30pm | Key Note Address Plenary 2
3:30 - 4:00pm | Afternoon Tea
4:00 - 5:00pm | Key Note Address Plenary 3
5:00 - 6:00pm | WELCOME COCKTAIL PARTY
Medical PROGRAM

SUNDAY 4TH - TUESDAY 6TH AUGUST 2019
**Medical Program**

**Sunday 4th August 2019**

<table>
<thead>
<tr>
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<tr>
<td>7:15 - 8:00am</td>
<td><strong>Wake Up Yoga - Meet at Registration</strong>&lt;br&gt;Wake Up Yoga with Focus on Postural Awareness (all levels welcome) with Pamela Scarborough, CF Physiotherapist &amp; Yoga Instructor</td>
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<tr>
<td>7:30 - 5:00pm</td>
<td><strong>Registration</strong>&lt;br&gt;Room M3&lt;br&gt;<strong>SIG Scientists</strong>&lt;br&gt;Coordinators: Anthony Kicic &amp; Luke Garratt&lt;br&gt;<strong>SIG Nurses</strong>&lt;br&gt;Coordinator: Judith Glazner&lt;br&gt;<strong>SIG Physiotherapists</strong>&lt;br&gt;Coordinator: Jamie Wood</td>
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<td>9:00 - 12:00pm</td>
<td><strong>SIG Scientists</strong>&lt;br&gt;Coordinators: Anthony Kicic &amp; Luke Garratt&lt;br&gt;<strong>SIG Nurses</strong>&lt;br&gt;Coordinator: Judith Glazner&lt;br&gt;<strong>SIG Physiotherapists</strong>&lt;br&gt;Coordinator: Jamie Wood</td>
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<td>12:00 - 1:00pm</td>
<td><strong>Australian Cystic Fibrosis Research Trust</strong>&lt;br&gt;30th Anniversary Researcher Luncheon - ACFC Expo, Grand Ballroom&lt;br&gt;By Invitation</td>
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<td>1:00 - 1:30pm</td>
<td><strong>Conference - Official Opening - Crown 1</strong>&lt;br&gt;CELEBRATING PARTNERSHIPS&lt;br&gt;<strong>MC:</strong> Nettie Burke, CEO Cystic Fibrosis Australia&lt;br&gt;<strong>Welcome to Country:</strong> Richard Walley&lt;br&gt;<strong>Speakers:</strong>&lt;br&gt;- Patrick O’Connor, President, Cystic Fibrosis Australia Board&lt;br&gt;- André Schultz, Chair, 13th Australasian Cystic Fibrosis Conference&lt;br&gt;- Louise Pratt, WA Senator</td>
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<tr>
<td>1:30 - 2:30pm</td>
<td><strong>Key Note Address Plenary 1 - Crown 1</strong>&lt;br&gt;FUTURE CYSTIC FIBROSIS THERAPIES&lt;br&gt;<strong>Speaker:</strong> Jane Davies&lt;br&gt;<strong>Chair:</strong> André Schultz</td>
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<tr>
<td>2:30 - 3:30pm</td>
<td><strong>Plenary 2 - Crown 1</strong>&lt;br INTERNATIONAL PARTNERSHIPS THAT IMPROVE CARE - CLINICAL TRIALS &amp; MODELS OF CARE&lt;br&gt;<strong>Speakers:</strong> Stuart Elborn &amp; Scott Bell&lt;br&gt;<strong>Chair:</strong> Adam Jaffé</td>
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<tr>
<td>3:30 - 4:00pm</td>
<td><strong>Afternoon Tea - ACFC EXPO</strong></td>
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<tr>
<td>4:00 - 5:00pm</td>
<td><strong>Plenary 3 - Crown 1</strong>&lt;br&gt;MENTAL HEALTH ACROSS THE SPECTRUM&lt;br&gt;<strong>Speaker:</strong> Beth Smith&lt;br&gt;<strong>Chair:</strong> Peter Wark</td>
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<tr>
<td>5:00 - 6:00pm</td>
<td><strong>WELCOME COCKTAIL PARTY - ACFC EXPO</strong></td>
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**Room M1B**<br>SIG Psychosocial<br>Coordinators: Heather Hugo & Andrea Barrett<br>SIG Pharmacists<br>Coordinator: Natalia Popowicz

**Room M1A**<br>SIG Dietitians<br>Coordinator: Natalie van der Haak

**Botanical 2**

**Botanical 3**
### Medical Program

**Monday 5th August 2019**

**6:00 - 6:45am | Wake Up Yoga - Meet at Registration**
Wake Up Yoga with Focus on Breath Awareness with Pamela Scarborough. Meet at Registration.

**7:30 - 5:00pm | Registration**

**7:00 - 8:30am | VERTEX Sponsored Breakfast Session - Crown 1**
C FurTheR

**8:30 - 9:15am | Plenary 4 - Crown 1**
**IMPROVING OUTCOME OF INFECTIONS IN THE AGE OF CFTR MODULATORS**
Speaker: Lisa Saiman Chair: Phil Robinson

**9:15 - 10:00am | Plenary 5 - Crown 1**
**TRANSITIONING FROM PAEDIATRICS TO ADULT CARE & PRE & POST TRANSPLANT**
Speakers: Stuart Elborn & Tonia Douglas Chairs: Siobhain Mulrennan & Rachel Collins

**10:00 - 10:30am | Morning Tea - ACFC EXPO**

**10:30 - 12:00pm | Concurrent Sessions 1**

**CHALLENGING INFECTIONS**
Chairs: Anna Tai & Tim Kidd
- Update on NTM Speaker: Scott Bell
- Treatment of Difficult NTM Speaker: Tonia Douglas
- How to Manage Stenotrophomonas & Achromobacter Speaker: Barry Clements
- Making the Most of Tobramycin Speaker: Paul Beringer
- How to Manage Aspergillus Speaker: Peter Warik

**TRANSLATING MENTAL HEALTH INTO BETTER OUTCOMES**
Chairs: Peter Warik & Jodi Hilton
- The Australian Mental Health Trial Update Speakers: Peter Warik & Jodi Hilton
- Disordered Eating in CF Speaker: Alistair Duff
- Mental Health of Siblings Speakers: Judith Glazner & Elise Orange
- Drug & Alcohol Addiction in CF Speaker: Steve Allsop

**PHYSICAL FUNCTIONING & PHYSIOTHERAPY**
Chairs: Michael Dounit & Tiffany Dwyer
- The Challenge to Coordinate the Multiple Functions of the Diaphragm: Implications for Living with CF Speaker: Paul Hodges
- Chronic Cough & Inducible Laryngeal Obstruction (ILO) Speaker: Kate Baumwol
- Malacia & ACT Considerations in CF Speaker: Julie Depiazzi
- CFTR Modulator Therapy & Physical Function: A Physiotherapy Perspective Speaker: Michelle Wood
- The Impact of Exercise Training on the Whole Body Speaker: Zoe Saynor

**TRANSPLANT**
Chairs: Siobhain Mulrennan & Sharon Lawrence
- Overview of Multiple Organ Transplant Speaker: Trevor Williams
- Sponsored by Cystic Fibrosis Community Care -VIC Optimising Nutrition Around Transplant Speaker: Louise Hesketh
- Sponsored by Cystic Fibrosis Queensland Negotiating Transition Around Transplant Professional to Professional Speaker: Anthony Talbot
- Body Composition in CF Speaker: Susannah King & Chris Smith
- The Future of Nutrition in CF Speaker: Natalie van der Haak & Jenna Stonestreet

**DIETETICS & NUTRITION**
Chairs: Natalie van der Haak & Susannah King
- Optimising Nutrition in CF Speaker: Chris Smith
- Are We Achieving Energy Demands at the Expense of Diet Quality? Speaker: Tamarah Katz
- Body Composition in CF Speaker: Susannah King & Chris Smith

**STANDARDS OF CARE**
Chairs: Natalie van der Haak & Susannah King
- Optimising Nutrition in CF Speaker: Chris Smith
- Are We Achieving Energy Demands at the Expense of Diet Quality? Speaker: Tamarah Katz
- Body Composition in CF Speaker: Susannah King & Chris Smith
- The Future of Nutrition in CF Speaker: Natalie van der Haak & Jenna Stonestreet

**12:00 - 1:00pm | Lunch - ACFC EXPO**
Monday 5th August 2019

12:15pm Lunchtime Debate 1 | (20mins) - Crown 1

**INFECTION CONTROL**
We Are Not Doing Enough vs. Have We Lost Perspective?
Speakers: Sarath Ranganathan vs. Adam Jaffé Chair: Tonia Douglas

12:40pm Lunchtime Debate 2 | (20mins) - Crown 1

**ANTENATAL DIAGNOSIS & POPULATION SCREENING**
Speakers: John Massie vs. Claire Wainwright Chair: Judith Morton

1:00 - 2:00pm | Thematic Posters - ACFC EXPO

Crown 1 Crown 2 Crown 3A
2:00 - 3:00pm | ePoster Discussion

Infection/Microbiology/ Immunology
Chair: Stephen Stick

Physiotherapy
Chair: Michael Doumit

Psychosocial/Nursing/ Education
Chair: Judith Glazner

Molecular Biology/ Physiology
Chair: Anthony Kicic

Gi/Nutrition
Chair: Natalie van der Haak

Clinical/Clinical Trials/ Quality Improvement
Chair: Adam Jaffé

2:00 - 3:00pm | Thematic Posters - ACFC EXPO

3:00 - 3:30pm | Afternoon Tea - ACFC Expo

3:30 - 5:00pm | Concurrent Sessions 2

**THE DRUG DEVELOPMENT PIPELINE**
Chair: Peter Wark
The Drug Development Process from Molecule to Medicine
Speaker: Jane Davies
Managing the Burden of CF Drug Development
Speaker: Barry Clements
Glucose Altering Therapy - Time to Implement Into Practice?
Speaker: Shihab Hameed
Gene Therapy Update
Speaker: David Parsons
Emerging Antibiotic & Anti-Inflammatory Therapies
Speaker: Felix Ratjen

**TARGETING INFLAMMATION & INFECTION**
Chair: Anthony Kicic & Luke Garratt
Novel Strategies to Fight Infection
Speaker: David Reid
Targeting Infection
Speaker: Lisa Saiman
Targeting Inflammation
Speaker: Paul Beringer
Increased Elastase Activity on the Surface of Airway Neutrophils: Is it Relevant & How Can We Measure It?
Speaker: Marcus Mall
Understanding Antimicrobial Resistance in People With CF
Speaker: Tim Kidd
The Molecular Mechanism of Defective Anti-Inflammatory Responses by Macrophages in CF
Speaker: Abdullah Tarique
Antimicrobial Resistance in CF - International Taskforce
Speaker: Scott Bell

**LATE COMPLICATIONS**
Chair: Anna Tai
Optimising Nutrition with CFARD
Speaker: Angela Matson
CFRD & Microvascular Disease in CF
Speaker: Joey Kaye
Antibiotic Allergy in CF - A Way Forward
Speaker: Michaela Lucas
Sinus Disease
Speaker: Shane Ling
The Ageing Lung in CF
Speaker: David Reid
The Importance of Consumer Engagement in Research
Speaker: Anne McKenzie

**CYSTIC FIBROSIS GASTROENTEROLOGY**
Chair: Adam Jaffé
Why the Gut Microbiome is Important in CF & the Role of Probiotics
Speaker: Keith Ooi
How Bile Salt Aspiration Drives CF Lung Disease
Speaker: Jose Caparrós-Martín
Enteral Feeding in CF
Speaker: Chris Smith
Clostridium difficile
Speaker: Thomas Riley
The Risk of GI Malignancy & How to Screen
Speaker: Keith Ooi
Pancreatic Enzyme Replacement Therapy (PERT)
Speaker: Natalie van der Haak

**THE CHALLENGE OF ADHERENCE TO TREATMENT**
Chair: Natalia Popowicz & Andrea Barrett
How to Measure Adherence
Speaker: Juliet Foster
How the MDT Can Help Improve Adherence to Prescribed Treatment
Speaker: Alistair Duff
Social & Mental Health Focus to Improve Adherence
Speaker: Beth Smith
PERX Health - Using Behavioural Science to Improve Adherence & Engagement in CF
Speakers: Scott Taylor
Adherence to Treatment During Pregnancy
Speaker: Judith Morton

7:00pm - Late | The Conference Celebration - The Hall @ Camfield, Roger MacKay Dr, Burswood
Just a 5min walk from The Crown
# Medical Program

## Tuesday 6th August 2019

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:30 - 3:00pm</td>
<td>Registration</td>
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</table>
| 7:00 - 8:00am | X-RAY VELOCIMETRY: THE FUTURE OF LUNG HEALTH MEASUREMENT & MONITORING IN CF  
  Speaker: David Parsons  
  Chair: Phil Robinson |
| 8:00 - 9:30am | Concurrent Sessions 3                                                |
|              | EARLY LUNG DISEASE                                                  |
|              | Chair: Stephen Stick  
  Using MRI to Determine the Nature of Early Lung Disease  
  Speaker: Marcus Mall  
  Physiology Functional Consequences of Early Lung Disease Severity  
  Speaker: Felix Ratjen  
  Epigenetics: Markers From Early Life Which Predict Future Lung Disease Severity  
  Speaker: Shantikumar  
  When Partnerships Go Bad: Neutrophil Inflammation in Early Life  
  Speaker: Luke Garratt  
  Early Lung Disease, What Should Be Our Treatment Goals?  
  Speaker: Stephen Stick |
|              | CARE PARTNERSHIPS                                                   |
|              | Chairs: Judith Glazner  
  & Charlotte Burr  
  A Standardised Approach to Acute FEV1 Decline  
  Speaker: Debbie Benitez  
  The Rollout of Orkambi in a Large Adult CF Clinic  
  Speaker: Carmel Parlapiano  
  CF Professional Development Day For Educators  
  Speaker: Jane Willis  
  Improving Clinical Care Around Diagnosis & Early Infancy. Assessment of the Parent-Child Relationship in the Context of a CF Diagnosis  
  Speaker: Andrea Barrett  
  Transitioning Aboriginal Patients to Adult Care Using Culturally Safe Practises  
  Speaker: Heather Hugo  
  Open Door Policy for Managing CF  
  Speaker: Sue Morey |
|              | NOVEL STRATEGIES TO ADDRESS ANTIMICROBIAL RESISTANCE               |
|              | Chairs: Sarah Ranganathan  
  & Andrew Tai  
  Pharmacokinetics & Pharmacodynamics with Antibiotic Use  
  Speaker: Paul Beringer  
  Resisting Challenging Bugs: How to Address Antibiotic Resistance  
  Speaker: Lisa Saiman  
  Novel Antimicrobials: Including Small Molecules & Phages  
  Speaker: Anthony Kicic  
  Back Against the Wall: Using Therapies That Do Not Yet Have the Weight of Evidence Behind Them  
  Speaker: Veronica Yozghatlian  
  Azithromycin Benefits verses Risks  
  Speaker: Sarath Ranganathan |
|              | PRECISION MEDICINE                                                 |
|              | Chairs: Judith Morton  
  & Adam Jaffé  
  Rare Mutations  
  Speaker: Jane Davies  
  Organoids & Individual Mutations  
  Speakers: Adam Jaffé  
  & Shafagh Waters  
  Treatable Traits & CF  
  Speaker: Peter Wark  
  The MDT Role in Precision Medicine  
  Speakers: Peter Middleton  
  & Catherine Byrnes |
|              | LOOKING FORWARD IN PHYSIOTHERAPY                                   |
|              | Chairs: Anna Middleton  
  & Angela Potter  
  Airway Clearance in the Next Decade  
  Speaker: Brenda Button  
  The Evolution of Inhalation Therapy  
  Speaker: Ruth Dentice  
  The Future of Exercise Testing  
  Speaker: Zoe Saynor  
  PRO/CON DEBATE: Exercise Can Be Used As Airway Clearance  
  Speakers: Nathan Ward vs. Jamie Wood |
|              | QUALITY IMPROVEMENT & REGISTRIES                                   |
|              | Chair: Tom Snelling  
  The Australian Peer Review Platform  
  Speaker: Claire Wainwright  
  Utilising the ACFDR for Real World Outcomes  
  Speakers: Scott Bell & Susannah Ahern  
  Patient Reported Outcomes - PROs  
  Speaker: Rasa Ruseckaitė  
  Rationale for an Adaptive Platform Trial for Improving Outcomes in Exacerbations of CF  
  Speaker: André Schultz  
  BEAT CF - Challenges & Progress in Setting Up an Adaptive Platform Trial in CF  
  Speaker: Tom Snelling |
| 9:30 - 10:00am| Morning Tea - ACFC EXPO                                             |
| 10:00 - 11:30am| Oral Abstracts                                                        |
| 11:30 - 12:00pm| Lunch - ACFC EXPO                                                     |

### Crown 1

- **Physiotherapy**  
  Chair: Jamie Wood
- **Clinical/ Clinical Trials/ Quality Improvement**  
  Chair: Siobhain Mulrennan
- **Molecular Biology/ Physiology**  
  Chair: Anthony Kicic

### Crown 2

### Crown 3

### Room 3A

### Room 3B

- **GI/ Nutrition**  
  Chair: Natalie van der Haak

### Room 3C

- **Psychosocial/ Nursing/ Education**  
  Chair: Judith Glazner

### ACFC Theatre

- **Infection/ Microbiology/ Immunology**
Medical & Scientific Program

12:00 - 1:00pm | Celebrating 30 Years of The Australian Cystic Fibrosis Research Trust - Crown 1
Chairs: Mitch Messer & Nettie Burke
An Australia Wide Alliance to Test CFTR Modulators on Personal Organoids From People With Rare CF
Speaker: Shafagh Waters
Multi-Action Antibiotics to Treat Chronic Biofilm Infections
Speaker: Michael Kelso
Characterisation of Structure-Function Relationships in Mild Cystic Fibrosis Lung Disease
Speaker: Katie Bayfield
Novel Multi-Omic Insight into Evolution of Antibiotic Resistance in Pseudomonas Aeruginosa in Cystic Fibrosis & Relationship to Clinical Outcomes
Speaker: David Reid
Cystic Fibrosis Airway Gene Therapy
Speaker: Alexandra McCarron
Optimising Patient-derived Stem Cell Technology in Cystic Fibrosis to Predict CFTR Modulator Response
Speaker: Gerard Kaiko

1:00 - 2:30pm | Plenary 6 - Crown 1
PARTNERSHIPS IN CARE
Speakers: Debbie Benitez & Alan Smyth Chair: Peter Middleton

2:30 - 3:00pm | Awards - Crown 1
Best Abstract
Best Poster (Medical/Scientific)
Best Poster (Allied Health)
Abbie Fennessy Memorial Fellowship
CFA Lifetime Achievement Award
Chairs: André Schultz & Nettie Burke

3:00 - 4:00pm | Closing Plenary 7 - Crown 1
NOVEL CLINICAL TRIALS TO OPTIMISE CYSTIC FIBROSIS CARE
Speakers: Stuart Elborn - Adults | Felix Ratjen - Paediatrics
Chairs: Sarath Ranganathan & André Schultz
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Cystic Fibrosis Australia would like to thank the Lay & Medical attendees for supporting the 13th Australasian Cystic Fibrosis Conference.

The Lay & Medical Conference Committees generously gave their time & shared their knowledge & expertise to create two outstanding programs.

The theme ‘Celebrating Partnerships’ was the vision of Conference Chairman, Dr André Schultz & he was inspirational in the way he orchestrated the outstanding content of the Conference.

More than 80 Australian CF experts & 12 international luminaries presented at our Conference & they must be thanked for sharing their knowledge & adding to the expertise of all attendees.

Finally, thanks must go to our Conference sponsors who make it possible to hold an international event of this scale with the highest calibre speakers.

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