Cystic Fibrosis Trust

UK CF Registry Annual Meeting

Thursday 12 November 2026
Leonardo Royal Hotel, Birmingham

Programme



Sponsored by

VERTEX
Gold sponsor

athera HEALTHCARE
Silver sponsor

Lifting limits
Changing lives

Welcome

I'm pleased to welcome you to the UK CF Registry Annual Meeting 2026.

We are thrilled to bring together Registry users, clinicians, researchers, and partners from across CF centres nationwide for a day of knowledge sharing, innovation, and collaboration – celebrating the vital role you play in the work of UK CF Registry. The programme features an exciting mix of Registry research, key insights from our newly published annual data report, and opportunities to connect with peers and exchange best practices.

In our interactive workshops, take an active role in shaping how we streamline data cleaning, explore and learn about our brand-new CFSPID Registry, sharpen your skills in an expert-led user masterclass, or help define the future roadmap of the UK CF Registry. Later in our spotlight sessions, discover how Registry users across the UK are innovating and ensuring best practice in their CF centres.

Throughout the day, please also take some time to explore the inspiring posters on display showcasing research supported by Registry data, quality improvement case studies, and work undertaken by the Registry team.

We extend our sincere thanks to our Gold sponsor, Vertex Pharmaceuticals, and our Silver sponsor, Athera Healthcare, for their support.

On behalf of Cystic Fibrosis Trust and the entire Registry team, thank you for your ongoing dedication and partnership supporting the work of the UK CF Registry. The impact of our data is made possible through your commitment. Every data point entered strengthens our collective knowledge and helps to accelerate progress. We hope you find today informative, engaging, and energising as we continue working together to lift limits and change lives for everyone with cystic fibrosis.

Dr Sarah Clarke
Associate Director of Data and QI,
Cystic Fibrosis Trust



We would like to thank our Gold sponsor, Vertex Pharmaceuticals, and our Silver sponsor, Athera Healthcare, for the financial support for the 2026 UK CF Registry Annual Meeting.

The sponsors have had no input or direction into the content, agenda or selection of speakers for this meeting.

Agenda

Morning session

Chaired by Susan Charman, Principal Statistician, Cystic Fibrosis Trust

9–9.30am	**Registration and refreshments**
9.30–9.45am	**Welcome and introduction** Dr Lucy Allen, Director of Research and Healthcare data, Cystic Fibrosis Trust
9.45–10.15am	**Updates and latest news from the Registry team** Dr Sarah Clarke, Associate Director of Data and Quality Improvement, Cystic Fibrosis Trust
10.15–10.45am	**Registry research and data request overview** Dr Gwyneth Davies, Vice-chair of Registry Steering Committee
10.45–11.15am	**Year in review: key highlights from the Registry annual report** Dr Jamie Duckers, Chair of Registry Steering Committee
11.15–11.45am	**Refreshment break**
11.45am–1pm	**Workshop parallel sessions 1**
WS1	**Annual data cleaning: how can we help you to help us?** Susan Charman, Principal Statistician, Cystic Fibrosis Trust
WS2	**Introduction to CFSPID registry** Kerry Laidlaw, Development Manager, Cystic Fibrosis Trust and Professor Siobhán Carr, Consultant Paediatrician, Royal Brompton Hospital
WS3	**Registry user masterclass** Elaine Gunn, Registry Clinical Data Manager, Cystic Fibrosis Trust
WS4	**Informing the future of the UK CF Registry** Dr Jana Witt, Clinical Quality Improvement Manager, Cystic Fibrosis Trust
1–2pm	**Lunch, networking and poster viewing**

Read the speaker biographies here

Agenda

2–3pm	**Workshop parallel sessions 2**

(Repeat of morning sessions)

3–3.15pm	**Refreshment break**

Afternoon session

Chaired by Elaine Gunn, Clinical Data Manager, Cystic Fibrosis Trust

3.15–4.15pm	**Spotlight sessions**
Session 1	**Every data point counts: The Co-Clinical Lead's role in ensuring accurate UK CF Registry data** Samantha Henman, Co-Clinical Lead, Papworth Adult CF Centre, Cambridge and Charlotte Dawson, Co-Clinical Lead, Great Ormond Street Paediatric CF Centre, London
Session 2	**Enhancing data collection and entry at a large Adult CF centre** Emma Winkle, CF Administrator; Nottingham University Hospitals NHS Trust
Session 3	**From genetic report to Registry: genotype entry best practice** Kerry Laidlaw, Development Manager and Mary Cerkvenik, Medical Statistician, Cystic Fibrosis Trust
Session 4	**CF Practitioner – a new way of working at a large Adult CF centre** Rebecca Heise, CF Practitioner; Kings College Hospital NHS Trust
4.15-4.30pm	**Closing remarks**
	Professor Siobhán Carr, Consultant Paediatrician, Royal Brompton Hospital, London

Posters (available to view in the main room).
Selection of poster and case studies of recent work presented at conferences. This includes research, data quality audit and quality improvement team case studies.

Read the speaker biographies here

What did you think of the Registry Annual Meeting?
Let us know by scanning the QR code and filling out a quick evaluation form.

Your feedback is really useful and will help us make next year's event even better. Thank you.

Speakers

Dr Lucy Allen

Cystic Fibrosis Trust



Lucy Allen joined Cystic Fibrosis Trust in late 2019. Lucy's previous experience includes building and leading research collaborations with industry, other research charities and clinical academics across a wide range of disease areas such a respiratory, mental health, and cancer and nutrition for the National Institute of Health Research (NIHR). She has also lead R&D projects for GE Healthcare developing radiopharmaceuticals for cancer and Alzheimer's disease. Lucy also has a PhD in lung inflammation and infection.

Dr Sarah Clarke

Cystic Fibrosis Trust



Sarah joined Cystic Fibrosis Trust in 2020 and leads the UK CF Registry and Quality Improvement teams. Sarah is the UK CF Registry Data Controller and Caldicott Guardian, the UK representative on the ECFS Patient Registry Steering Committee and is part of the global CF Registry collaboration. Prior to joining the Trust, Sarah worked in clinical research, leading the R&D department in an acute NHS Trust in the South of England and worked for the National Institute for Health and Care Research Clinical Research Network. Sarah has also worked within pharmacovigilance and pharmacoepidemiology, managing a large observational post authorisation safety study. Sarah began her career with a Cystic Fibrosis Trust-funded PhD, investigating novel neutrophil elastase inhibitors in the treatment of airway inflammation in CF.

Dr Gwyneth Davies

UCL Great Ormond Street Institute of Child Health



Gwyneth is a clinical associate professor at the UCL Great Ormond Street Institute of Child Health, and honorary consultant paediatrician at Great Ormond Street Hospital, London. She was the joint lead for the CF STORM Registry-based clinical trial, which has recently completed. Gwyneth chaired the UK Cystic Fibrosis Conference in 2025, which brought together basic science, clinical trials and Registry research relevant to the CF community. She joined the Registry steering committee in 2020 and was appointed Vice Chair in 2025.

Dr Jamie Duckers

Health and Care Research Wales



Jamie is a Respiratory Consultant based in Cardiff and Vale as well as being National Clinical lead for Rare Disease. He is Health and Care Research Wales Respiratory Specialty Lead and has been chair of the UK CF Registry Steering Committee since 2023.

Speakers

Susan Charman
Cystic Fibrosis Trust



Susan has led the Registry statistics and analytical team since 2017, and now oversees a team of five including statisticians, analysts and a data manager. Susan's team is responsible for preparing and clearing our annual data, producing the annual report, supporting provision of data for data requests and leading the analysis for studies with the pharmaceutical industry. Susan has extensive experience with medical statistics in both academia and teaching. Susan is a voting member of the Data Request Review Group.

Kerry Laidlaw
Cystic Fibrosis Trust



Since November 2023, Kerry has served as Registry Development Manager at Cystic Fibrosis Trust, leading the development and maintenance of the CF Registry to ensure it remains relevant to changes in clinical care, regulation, and system health. As the parent of a son with cystic fibrosis, Kerry brings both professional expertise and personal insight to supporting improvements in care through high-quality registry data.

Professor Siobhán Carr
Royal Brompton Hospital



Siobhán is a Consultant in Paediatric Respiratory Medicine based at Royal Brompton Hospital for 10 years after having already been a consultant at Royal London Hospital for 15 years with a special interest in cystic fibrosis. In addition, Siobhán is Professor of Practice at Imperial College London integrating professional expertise into higher education. Siobhán chaired the Registry Steering Committee for over 10 years.

Elaine Gunn
Cystic Fibrosis Trust



Elaine trained as a cardio-thoracic nurse and worked as CF Research Manager at Papworth Hospital between 1994–2005. She then came to the Registry and for the last 21 years has worked relentlessly to ensure good quality data is entered for the benefit of all living with cystic fibrosis. Elaine manages the Registry Data Request Process and Data Request Review Group Meetings and is a key point of contact with CF centres.

Speakers

Dr Jana Witt

Cystic Fibrosis Trust



Jana leads the Quality Improvement team at Cystic Fibrosis Trust, which supports CF services across the UK to monitor and explore quality of care, as well as plan and evaluate targeted quality improvement activities. Her background is in clinical audit, outcome measurement, patient experience research, and clinical quality improvement. She holds a PhD from Cardiff University and previously worked at King's College London, Cancer Research UK, and NHS England, before joining Cystic Fibrosis Trust.

Samantha Henman

Royal Papworth Hospital



Samantha Henman is Lead Nurse for Cystic Fibrosis and Co-Clinical Lead for the Cambridge Centre for Lung Infection (CCLI) at Royal Papworth Hospital. Having worked in cystic fibrosis care for 28 years, Samantha joined Royal Papworth as one of the junior nurses on the newly opened adult CF unit and has contributed to the service's development throughout her career. Her interests include nurse-led care, service development, remote monitoring and transition services. Samantha also supports international collaboration through the European Cystic Fibrosis Society (ECFS) Twinning Programme.

Charlotte Dawson

Great Ormond Street Hospital



Following a successful completion of Registered Sick Children's Nursing training at Great Ormond Street (GOSH) and Queen Elizabeth Hospital, London, Charlotte received her RSCN qualification in 1994. She joined the CF team at GOSH as the Clinical Nurse Specialist in 2004 having completed 10 years clinical nursing on the specialist respiratory unit at GOSH and during this time completed the BSc Hons Health and Nursing Degree from South Bank University in 2016.

Charlotte is the Co-Lead for the CF Service and coordinates the care and support for approx 200 CF patients between the ages of 0–18 at Great Ormond Street Hospital (CF specialist centre), local hospitals and within the community as lead CF CNS for the nurses and clinicians' assistant within the team.

Charlotte was the chair of the UK National CF Nurses Association (CFNA) and a member of the ECFS Scientific Committee for four years.

Speakers

Emma Winkle

Nottingham University Hospitals NHS Trust



Emma has been a part of the Nottingham adult CF team for nearly four years, working as a CF Administrator.

Before moving into the NHS Emma spent many years in the private sector, and then ending up in Finance at Boots head office for nine years.

Mary Cerkvenik

Cystic Fibrosis Trust



Mary has worked for Cystic Fibrosis Trust since November 2023, originally a member of the CTAP team, she joined the Registry team as a medical statistician in February 2025. Her work has included a variety of projects including producing the annual Registry data report, conducting analyses for real-world outcomes of those treated with Kaftrio, and improving the free-text cleaning of genotype data on the Registry. Mary is also a member of the CTAP Research and Scientific Oversight Board. She holds a MSc in Public Health from the University of Bristol.

Rebecca Heise

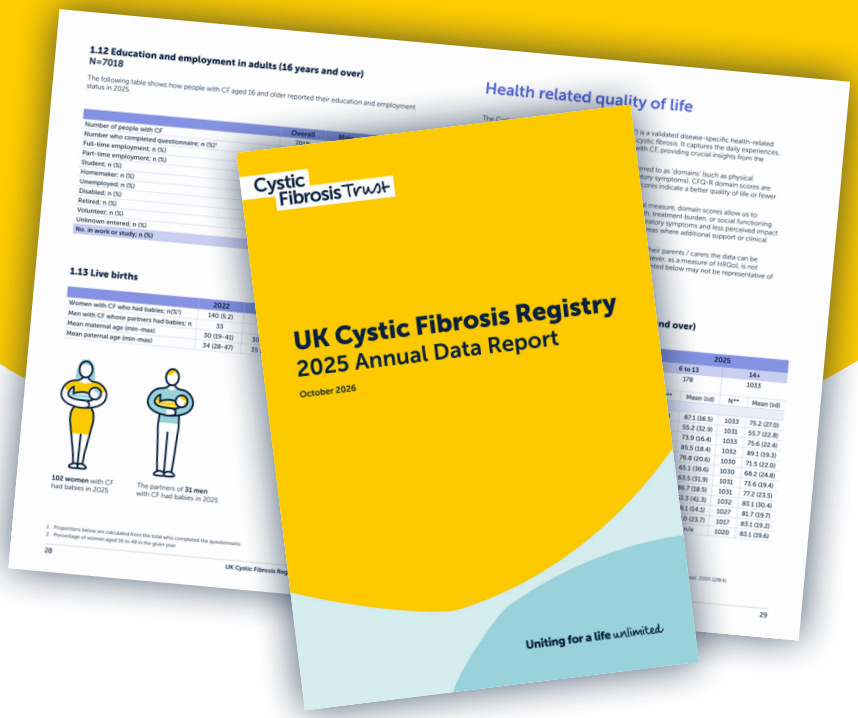
Kings College Hospital NHS Trust



Rebecca has worked in cystic fibrosis for 17 years and has really enjoyed seeing the significant changes and advances in CF care over this time. In particular she has found it rewarding to see the transformative impact of CFTR modulators on patients' health, quality of life and long-term outcomes.

Cystic Fibrosis Trust

We are delighted to have the 2025 Annual Registry Report available for you to take, along with the 'at a glance' report.



If you would prefer to view the reports online visit **cysticfibrosis.org.uk** or scan the QR codes below.

Scan for the full 2025 Annual Data Report

Scan for the 2025 at a glance report

We hope you enjoyed the day and would love you to complete the feedback form which can be found by scanning the QR code.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2026. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 33 Creechurch Lane, London EC3A 5EB.

Lifting limits
Changing lives