

NEWSLETTER

July 2025



Lifelong

Congenital Heart Disease Network

London | East | South East

Welcome to the summer edition of the Lifelong Congenital Heart Disease (CHD) Network Newsletter

As we enjoy the summer season, we are taking a moment to reflect on the work, achievements and stories that have shaped the first half of the year within our network. We appreciate everyone in our network for being part of our journey. Your continued involvement, care and commitment help our network grow stronger and more connected every day.

Thank you for everything you do!

In this edition, we will be sharing updates from our network working groups, highlights from the latest board meeting and a few exciting developments in education and training. We're also celebrating some recent milestones across the network and giving you a glimpse of what's coming up next. Plus, don't miss our special feature on the summer patient engagement event held in June — see below for a visual preview of the day.



We'd like to take this opportunity to remind our **NHS Professionals** across the network about our upcoming **In-Person Network Meeting**, taking place on **Wednesday 17th September 2025 on St Thomas' Campus**. Email invitations have already been sent. Please register if you are able to attend and have yet to do so. You'll find more details about the event later in this newsletter — we hope to see as many of you there as possible.

And of course, here's a reminder of our brilliant management team behind the scenes...



Dr Natali Chung
Clinical Director



Lynda Shaughnessy
Clinical Director
& Lead Nurse



Nathalie Picaut
Lead Nurse



Susana de Sousa
Lead Nurse



Joe Eurell
Manager



Novelle Agyarko
Assistant Manager



Ilin Hayter
Business Support

We wish you and yours a wonderful summer!

Best wishes, Lifelong CHD Network Management Team (LCHDNMT)

If you have any comments or would like to get involved with PPV we would love to hear from you

Contact Us

Email



gstt.chdnetwork@nhs.net

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Board Meeting Updates

Board meetings now feature a **Hot Topic** on the agenda, as suggested by Dr Angela Tillett our Board Chair, to raise awareness and understanding of burning issues that have been highlighted to the Network Management Team. Following input from our PPV Board Reps and discussions with Piers McCleery, our Deputy Chair, the aim is for each board meeting to be themed around this topic.

At the January board meeting, we discussed Access to dental care. Dr Mina Vaidyanathan, Clinical Lead for Paediatric Dentistry at the Evelina London, subsequently attended April's meeting to talk about the role of dentistry in CHD, difficulties accessing dental care and dental deserts, including issues encountered by their team and patients. Mina and her team run screening clinics to identify cardiology patients who may be at a higher risk to dental issues. This may also result in accelerating treatment if needed. This service has been welcomed by both Paediatric Cardiologists and patients and relieves some burden on administrative teams. This is an important service to our patient population and one that requires further investment at a trust, regional and national level.

We have also re-structured our **Work Plan**, reducing the number of workstreams contained within for the 2025-26 reporting period. The Work Plan is an NHS England requirement and sets out our annual plan to address priorities, the expected benefits and where best to focus resources. A reduction in workstreams in should allow for a more concentrated approach to work in key areas.

Finally, we have completed one full year of data dashboard submissions and are building a wealth of information. We have moved this to allow input via our website.

Next meeting dates: 10 July 2025, 16 October 2025, 20 January 2026



Working Group Updates

Paediatricians with Expertise in Cardiology (PEC)

These meetings are chaired by Dr Tosin Otunla, Ashford & St. Peter's PEC and also our Network PEC on the board.

With the increase in referrals to PEC clinics there have been discussions on referral criteria and when cardiac screening is required. Part of these discussions included referrals from Geneticists. Clinical genetics colleagues from GSTT, attended a recent working group meeting to provide their points of view and inform guidelines. They agreed that there is a lot of over-screening for PECs adding to their workload.

We heard, whilst PECs enjoy and benefit from online training, they would welcome a return to in-person sessions.

There was concern that the teaching of basic skills to general paediatricians, such as interpreting ECGs, is being lost. Dr Bikash Bhojnagarwala, PEC at Medway and South-East of England Network Partner on the board, hopes to undertake a project to understand the barriers to learning this skill.

Next meeting date: Autumn 2025 TBC

Patient and Public Voice (PPV)

Early this year, the Network Management Team met with our representatives in-person to reflect on their roles and expectations of the role.

Their primary aim is to provide views from a patient or public voice perspective to be raised and discussed at board meetings to inform operational improvements.

However, they also get involved with leaflet reviews, patient engagement (as seen at our recent Patient Engagement and Support Event at the Kia Oval) and have had several meetings with us to discuss these.

As ever, they are keen to enlist the help of our L1 and network colleagues to grow the PPV subscriber base who can then be approached for thoughts, feedback and discussions. This continues to be one of our biggest challenges.

We also say thank you and farewell to Katie Jackson who stepped down from her role last month.

Next meeting date: Autumn 2025 TBC





Network Events

CHD Summer Patient Engagement & Support Event

On Saturday, 14th June, we were delighted to welcome patients, families and healthcare professionals to our Summer Patient Engagement and Support Event at the iconic Kia Oval, London. It was a great day of connection, support and shared learning, bringing together people from across the network. Under the sunshine, attendees enjoyed three focused sessions exploring different aspects of living with CHD - making for an inspiring and meaningful day for all involved.

The day began with a practical and informative session on welfare benefits, led by **Patricia McNamara, Welfare Advisor** for Harefield, Royal Brompton, St Thomas' and Guy's Hospital. Patricia offered valuable guidance and answered key questions to help attendees navigate financial support more confidently.

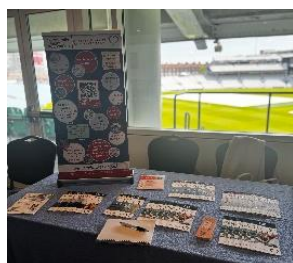
This was followed by an energising talk on exercise and heart health delivered by **Dr Ioannis Kasouridis, Consultant Cardiologist** at the Royal Brompton Hospital, who spoke about the benefits and considerations of physical activity for people living with CHD.



In the afternoon, we concluded with a powerful and insightful session titled *"The Emotional Journey: Living with CHD"*. This session was led by **Andrea Farley-Moore**, one of our **Patient and Public Voice (PPV) Representatives** and a **trained counsellor** and facilitated by **Dr Mina Arvanitopoulou, Lead ACHD Clinical Psychologist**, and **Dr Belinda Hemingway, Lead ACHD Health Psychologist**—both from St Thomas' Hospital—alongside. Together, they explored the emotional and psychological impact of living with a lifelong condition. The session offered a safe, reflective space for open discussion and shared experiences. There was also an expert Q&A Panel, giving attendees the chance to ask questions on a wide range of topics to a panel of professionals from across the network.

It was an enriching day, full of valuable insights, meaningful conversations and a renewed sense of connection across our CHD community.

Here's a look back at some of the highlights...



We have collected valuable feedback from attendees, which will be carefully reviewed and reflected upon to identify what worked well and where there are opportunities for improvement. This insight will be instrumental in shaping and enhancing the quality and impact of our future events.

A Heartfelt Thank You 'Thank you' - To our incredible charity partners who joined us with stalls, our speakers and other health care professionals across the network, your presence and support were valued. Most importantly, **thank you to every patient and their loved ones who attended**. Your voices and experiences are at the heart of everything we do. We're proud to be on this journey with such a dedicated and inspiring community.



Education & Training



Alex Savis, Senior Chief Cardiac Physiologist for Fetal and Paediatric Echocardiography (*pictured left*), has recently returned from a two-week placement at the **Instituto da Criança e do Adolescente** in **São Paulo, Brazil**. During her visit, she worked closely with Dr Gabriela Leal to explore best practices in strain imaging for children with acquired heart disease. The placement was a great success, and Alex has returned inspired and eager to incorporate her learning into our echocardiography practice. Well done to Alex on this fantastic achievement! We're excited to see the positive impact her learning will bring to our echocardiography service.



Monthly PEC Echo Education Course (Wednesdays)

Thank you to all those who dial in every month to attend these sessions, and to our faculty members and speakers who give up their time to organise and present.

Big shout out to PECs **Dr Adam Carter** (Epsom & St Helier), **Dr Nader Elgharably** (Kingston Hospital) and **Dr Anshoo Dhelaria**, plus Registrar **Mabel Thu** (Lister Hospital), presenting their cases at the PEC-Led sessions.

Please note: There will be no session in August for the summer break.

We welcomed **Katy Haines** from Eastbourne who started her ACHD ECHO training with us on 23rd April to work towards her CHD accreditation. Katy is an experienced sonographer and regularly helps us in all the ACHD network clinics at Eastbourne.

We have delivered a cardiac study day at **Frimley Park Hospital** that was very well attended by Nurses, Doctors and Allied Health Professionals. Thank you to all speakers that contributed for the day and to Frimley Park education team for hosting.

We want to take this opportunity to congratulate **Dario Freitas**, Lead for ACHD Echocardiography at GSTT (*pictured right*) and **Noëlle Wolvaardt-Gavin**, Lead Cardiac Physiologist for ACHD Echo at Royal Papworth Hospital (*pictured right*). They were recognised in the June issue of the journal of the British Society of Echocardiography about their collaborative work in the Lifelong CHD Network. Well done to them both!



Network Centre Visits

Our visits continue to take is across our Network's geography and we have enjoyed meeting more colleagues this year. We have reached our halfway point and with a few more lined up for the autumn, we hope to complete these visits by 2026.

Key Themes emerging from these visits thus far include:

- Communication – clinical documentation, dialogue
- Workforce in the current financial climate
- Job Planning – competing demands of time
- Referrals – in particular, those to PEC clinics
- Admin – waiting lists & appointment reminders

Visit undertaken

| Date | Trust | Centres | Paed/Adult |
|-----------|------------------------------|--|--------------------|
| 27 Jan 25 | Medway | • Medway | Paediatric |
| 28 Feb 25 | Surrey and Sussex Healthcare | • East Surrey | Paediatric |
| 14 May 25 | Lewisham and Greenwich | • Lewisham • QE Woolwich | Paediatric & Adult |
| 24 Jun 25 | University Hospitals Sussex | • Royal Alexandra • Worthing • Royal Sussex County | Paediatric & Adult |
| 09 Jul 25 | Guy's & St Thomas' | • St Thomas' • Royal Brompton & Harefield | Adult |

Planned

| Date | Trust | Centres | Paed/Adult |
|-----------|---------------------|--|--------------------|
| 07 Oct 25 | East Sussex | • Conquest Hospita • Eastbourne DGH | Paediatric & Adult |
| 22 Oct 25 | Royal Papworth | • Royal Papworth | Adult |
| 13 Nov 25 | Kingston & Richmond | • Kingston Hospital | Paediatric |



Special Mentions

We'd like to take this opportunity to say a big **CONGRATULATIONS** and extend a warm welcome to all the new starters who have joined our network since our last newsletter.

We have new PEC Tesha-Dawn Brathwaite (Queen Elizabeth Hospital – Woolwich), a new Locum PEC Dr Dinapoor Desilva (West Suffolk Hospital) and new Nurse with Interest in Cardiology Tessa Shewan (Darent Valley Hospital). We are thrilled to have you on board!

It's wonderful to hear about the amazing work you've already been doing since joining the team. We're excited to see all the great contributions you'll continue to make and look forward to hearing even more about your achievements.

Welcome to the team!

We want to share a special welcome to Professor David Barron, who started his role earlier this year as Chief of Paediatric and Congenital Cardiac Surgery at Guy's and St Thomas' NHS Foundation Trust. Professor Barron operates cross-site at the St Thomas' and Royal Brompton campuses, treating our Paediatric and Adult Congenital Heart Disease (ACHD) patients. Another special welcome to **Dr Sara Thorne**, who started in April as a Consultant Adult Congenital Heart Disease Cardiologist across all STH and RBH sites.

Wishing **Dr Beverly Tsai-Goodman** a joyful and fulfilling retirement—thank you for your outstanding dedication and care in fetal cardiology at RBH.

In-Person Network Meeting Wednesday 17 September 2025 from 10:00. Governor's Hall, St Thomas' Hospital, London

This meeting is open to all our network colleagues (NHS Professionals) and registration emails have been sent. If you are intending to attend but have yet to register, please do so via the following link or scan the QR code. Diary invites will then be sent on registration.



<https://forms.office.com/e/iQSnZMa4zg>

WE WANT TO HEAR FROM YOU

We continue to welcome any suggestions of what you would like to see in the “For Patients” and “For Professionals”. To help us make this a site both useful and interesting to all our readers, please share any ideas for suggested news items that we can add. This could be a story of a patient journey, a poem/painting/drawing/photo from a patient/family/carer or news of events happening in and around your centre related to Congenital Heart Disease. You can get in touch with us via our [website](#)

Nursing Contact Cards

Paediatrics

Paediatric Clinical Nurse Specialist Team

 **Evelina London**

Monday to Friday 09:00 – 17:00
Tel: 0207 188 4546
Email: gstt.paediatriccardiologycns@nhs.net


Paediatric Clinical Nurse Specialist Team

Royal Brompton and Harefield hospitals

Monday to Friday 08:30 – 17:30
Tel: 0330 128 7727
Email: gstt.ccln@nhs.net

Adults

Adult Cardiac Clinical Nurse Specialist Team

 **Guy's and St Thomas' NHS Foundation Trust**

Monday to Friday 08:30 – 17:30
Tel: 0207 188 9172
Email: gst-tr.ACHD@nhs.net

Adult Cardiac Clinical Nurse Specialist Team

Royal Brompton and Harefield hospitals

(For patients > 21 years old)
Monday to Friday 09:00 – 17:00
Tel: 0330 128 8764
Email: gstt.achd-rbh@nhs.net

Transition

Transition Nurse Specialist Team

Royal Brompton and Harefield hospitals

(For patients 12-21 years old)

Monday to Friday 09:00 – 17:00
Tel: 0330 128 8772
Email: gstt.transitionchd-rbh@nhs.net

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