



Lifelong

Congenital Heart Disease Network

London | East | South East



December 2025 Network Newsletter

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

In the midst of the busy lead up to the festive season, we take stock of what we have achieved together as a Network. In this edition, we will be sharing updates on what we have been up to over the last 6 months including our in-person network meeting held in September and an introduction from David Barron, our new Chief of Cardiac Surgery.

This time reminds us not only that we are nearing the end of this calendar year, but also the end of the first 3-year board term as the Lifelong CHD Network. We know there is a degree of uncertainty with NHS England integrating into the Department for Health and Social Care, however as a Network, we remain committed with business as usual. Wheels are in motion for a new board term to commence in April 2026.

Our network centre visits have been very productive and we have enjoyed getting acquainted with centres some of us may not have known before the merger between the GSTT-ELCH and the RBH CHD Networks. With a handful of the Paediatric and Adult visits to complete, we also undertook our first Fetal network centre visit just this month.

Another first is the creation of the new ACHD Working group. We were pleased to be able to meet and set out plans for how the group will best run moving forward. This is open to all ACHD professionals in the Network. First meeting taking place on Wednesday 10 December 16:00-17:00 on MS Teams.



Aug 25 Farewell meal with Novella

We said goodbye to Novella Agyarko in August, our Assistant Network Manager (ANM) who was with us for a year and who kindly volunteered her time to support us at our Network Meeting on 17 September. We are pleased she remains in the trust for Paediatric Cardiology as Assistant Service Manager.

Finally, we hope you can join us in extending a warm welcome to Naomi Nicolae who joined this month as our new ANM. Naomi comes from an operational background with Colorectal services.



Heartfelt thanks from the Network Management Team (that's us below) for your hard work, dedication and support as always. Wishing you all a Merry Christmas and a Happy New Year with further collaboration.



Dec 25 Christmas Team Meal



Dr Natali Chung
Clinical Director



Lynda Shaughnessy
Clinical Director
& Lead Nurse



Nathalie Picaut
Lead Nurse



Susana de Sousa
Lead Nurse



Joe Eurell
Manager



Naomi Nicolae
Assistant Manager



David Taylor
Data Manager



Ilin Hayter
Business Support

New to the team

Contact Us

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

Email



gstt.chdnetwork@nhs.net

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A few words from our new Chief of Cardiac Surgery



New Chief of Cardiac Surgery, St Thomas', Evelina Children's and Royal Brompton Congenital Heart Programmes

It is a great pleasure to find myself back at St Thomas' and the Royal Brompton, where I spent many happy years during my training. The congenital heart services at these two great institutions have been brought together into a combined programme which allows us to share our expertise and facilities across both sites in central London. My appointment began in February 2025, having spent 6 years running the service in Toronto at the Sick Kids Hospital and Toronto General, which are the leading paediatric and ACHD units in Canada. Prior to this I was a consultant in Birmingham for 20 years.

These are exciting times for the service, as we are now the largest Congenital Heart Programme in the UK and can utilise all the skills and expertise from both units to strengthen the breadth and quality of the clinical service, as well as combining our research work, training and education. It provides more flexibility to create more facilities for our patients and better access for both in-patient and out-patient treatment.

I look forward to joining your Network Days and helping strengthen the links across all of our regions.

Best wishes for the holiday season to all.

David Barron



Board Meeting Updates

Hot Topic

Adult and Paediatric Psychology have been featured in our July and October meetings respectively, with patient journeys to illustrate some of the challenges faced. Michèle Puckey, Paediatric Clinical Psychology Lead provided an overview of the service and how to refer. This is especially important as data suggests CHD patients are 2-3x more likely to suffer from anxiety and depression.

The demand for psychology support continues to grow. To understand where psychological support is needed, the Network Management Team (NMT) have been tasked to undertake a mapping exercise of adult and paediatric psychology provision in the network.

End of current term approaches

As the board approaches the end of its current 3-year term, the draft version of the Terms of Reference (ToR) for the new term (April 26-March 29) has now been approved. Amendments to the new ToR includes increasing the number of Level 2 and Level 3 board positions. Expressions of Interest will be sought in January 2026, ready for the new term to start in April.

Next meeting dates

20 January 2026 and 21 April 2026 (new 2026-29 term)

Some workstream updates

ACHD Working Group meeting

New meeting to be held on Wednesday 10 December 4-5pm on MS Teams open to all ACHD colleagues

National pilot for **upskilling Cardiac Physiologists** in the Network concluded in April, however Level 1 Physiology Leads continue to support this important work at a network level.

Data Dashboard

Recent changes have been made to simplify data collation process, allowing submissions to be made online

Pilot project for pan-London CHD-specific **PREMS*** in progress. This is a Pan-London collaboration between our Network and One-Heart CHD Network.

* Patient Reported Experience Measures

Working Group Updates



Paediatricians with Expertise in Cardiology (PEC)

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

Tosin often attends on his non-working day so thank you Tosin! It was agreed that the frequency of these meetings be reduced to three per year, with the aim that one of these will be in-person and incorporated into a PEC Study day. The format of the study day is to be decided, but suggestions so far include a mixture of education, learning from case studies, L1 updates and management discussions. If you have some other ideas, please let us know.

Under PEC Rajesh Gabani's supervision, Saduf Karim Sulaiman (ST4 at Lewisham & Greenwich), presented her excellent and concise ECG Guidelines. This will now be forwarded to the Electrophysiology leads for review, before being made available to all. A reminder that these are guidelines only.

Some PECs have put themselves forward to assist Tosin in working on Network Guidelines for referring to PEC clinics so this work can start in earnest soon.

Next meeting: Friday 30 January 2026 12:00-12:45
In-person PEC Study day tbc

"Mind the Gap" ECG Project

Presented at BCCA-PECSIG in November
1st prize for best oral presentation



The study showed that **simple, focused teaching** can significantly boost ECG confidence and supports including regular ECG training in both undergraduate and postgraduate programmes.

A national survey of 270 clinicians and medical students revealed a clear gap between confidence and competence in paediatric and neonatal ECG interpretation.

Main barriers: fear of missing a diagnosis, lack of practice and low confidence.

Preferred learning: case-based teaching, short ECG modules and quick reference guides.

Dr Reem Hussein, (ST2), Giulia Raffaele (Medical Student)
Under supervision of Dr Bikash Bhojnagarwala (PEC at Medway and PECSIG Chair)

Public and Patient Voice (PPV)

Paediatric Reps

Sean O'Grady & Kate Digby

Adult Reps

Andrea Farley Moore & Jane Western

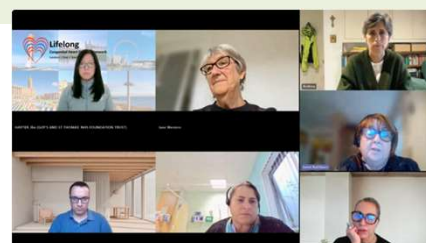
Our PPV Reps have been busy juggling the many balls that life has thrown them but are always keen to pull together issues from patients and their families to be raised and discussed at board meetings so that any necessary improvements to the service can be made.

Janet Rathburn, Chair of the Northwest, North Wales and Isle of Man CHD Network, kindly gave up some of her time to meet with Sean, Jane, Andrea and Kate. She shared her experience with setting up their PPV group which is now more established and grown to 14 members, meeting on a monthly basis.

It was reassuring to learn that they also found recruiting new members a challenge and that the approaches our PPVs have tried to attracting new members were largely aligned.

Janet has invited our reps to attend one of their working group meetings for observance which we hope to arrange in the very near future.

Next meeting: December/January tbc



Our reps will continue to request feedback of issues and views prior to board meetings via our Charity Partners and also through directly emailing our subscribers.

For our most recent board meeting, the following responses were collated:

Lack of CHD awareness within general NHS settings, particularly amongst ACHD however, once connected to the correct team, patient experience was greatly improved.

A query was raised as to whether there are any trials or investment to ACHD research. Our PPV reps would be happy to be the conduit between any CHD research groups and interested patients/families wanting to be involved.

REMINDER

New ACHD WG on MS Teams, Wednesday 10 December 16:00-17:00



Network Centre Visits

Our visits continue to take us across our Network geography and our Network Management Team have enjoyed meeting our centres. Diaries willing, we hope to be on track to complete by Summer 2026 at which point we will feed back on all the themes and findings. As mentioned at the start of this newsletter, we also completed our first visit to one of our fetal centres.

Visit Undertaken

Date	Trust	Centre(s)	Paed/Adult
07 October 2025	East Sussex Healthcare	<ul style="list-style-type: none"> Conquest Hospital Eastbourne District General Hospital 	Paediatric & Adult
22 October 2025	Royal Papworth Hospital	Royal Papworth Hospital	Adult
27 October 2025	King's College Hospitals	Princess Royal University Hospital	Paediatric
13 November 2025	Kingston & Richmond	Kingston Hospital	Paediatric
21 November 2025	Norfolk & Norwich University	Norfolk & Norwich University Hospital	Adult
02 December 2025	King's College Hospitals	King's College Hospital	Fetal

Planned

Date	Trust	Centre(s)	Paed/Adult
28 January 2026	The Hillingdon Hospitals	Hillingdon Hospital	Paediatric
27 February 2026	The Princess Alexandra Hospital	Princess Alexandra Hospital	Paediatric

Education & Training

Heart to Heart: QE Hospital (Woolwich)/ Darent Valley Hospital Study Day

More than 30 participants attended a successful regional paediatric cardiac study day held at Queen Elizabeth Hospital (Woolwich) on 29 August 2025. This was jointly organised by Tessa Shewan, Children's Nurse with an interest in Cardiology (Darent Valley Hospital) and Charley Weston, Practice Development Nurse (Queen Elizabeth Hospital, Woolwich) and supported by the Lead Nurses from the Lifelong CHD Network. The aim of the event was to increase the knowledge and skills of local nurses and Allied Health Professionals to care for cardiac patients presenting at local hospitals and its community.

The programme covered fetal and post-natal circulation, septal defects, coarctation of aorta, tetralogy of Fallot, hypoplastic left heart syndrome, psychology considerations in congenital heart disease and transition (moving from paediatric to adult services). A mother shared their experience with her son's diagnosis and living with a heart condition which was very moving.

"That was really good. Gave me an insight on how to deal with cardiac patients and their carers"



"...good teaching on understanding different types of defects and both its diagnosis and treatment"

Changes to dates for regular teaching over the festive period

Visit <https://www.lifelong.nhs.uk/education-training/> to see our education page

Formal Echo Teaching

Weekly: Mondays 1230-1330

There will be no teaching on 08/22/29 December.
15 December session on Ao Pul Window Spectrum;
Recognition and Management will run as normal.
Regular sessions will resume on Monday 05 January.

Paediatric CHD Teaching

Weekly: Tues/Weds/Thu 0800-0830

There will be no teaching from 22 December and will resume on Tuesday 06 January.

ACHD Clinical Cases Series

Monthly: Last Tuesday of the month

There is no December session and will resume on Tuesday 27 January 08:00-09:00 with Structural Valve Intervention in ACHD Patients.

PEC Echo Education sessions

Monthly: 3rd Wednesday of the month

There is no December session and will resume on Wednesday 21 January 17:05-18:00 with a PEC Case Study.



In-Person Network Meeting Wednesday 17 September 2025



Dr Marilyn McDougall Level 1 Update

We welcome any network centre who would like to work with us to host a future in-person meeting. If you are interested, please email us at gstt.chdnetwork@nhs.net

"I felt like the most helpful aspect was talking through some of the issues"

Thank you to everyone who organised, attended or presented at our in-person Network Meeting in Governor's Hall, part of the St Thomas' Hospital Campus. It is always great to be able to connect with our Network Colleagues when we are able and to provide an opportunity for everyone to meet. We appreciate everyone had taken time from their schedules in order to attend.

The day featured separate paediatric and adult programmes, and a joint session for all. Colleagues from all parts of our network attended including from Guy's and St Thomas' Hospitals, with the exception of centres in the East of England whose travel was disrupted by trees on the tracks!

Joint Session

Dr Marilyn McDougall provided a **Level 1 Update** including a timeline of planned work since the GSTT-RBH merger in 2021.

Joe Eurell & David Taylor delved into the topic of **Health Inequalities**, highlighting the correlation between areas of deprivation and access to healthcare.

We were pleased to welcome Noëlle Wolvaardt-Gavin from Royal Papworth Hospital presenting the topic of **Upskilling Physiology Workforce in the Network**. Beth Wilson from Norfolk & Norwich was due to present results from the **Endocarditis Prophylaxis in the Network audit** but unfortunately was unable to attend due to aforementioned travel issues.

Paediatric Session

Dr Aaron Bell and Lynda Shaughnessy facilitated a themed discussion on some of the issues that have been raised regarding **Communication**. This session was very much welcomed by our PECs and one to continue. This is just the beginning...

This was followed by excellent talks from Dr Alistair Baker (King's College London) on **Fontan associated with Liver Disease** and Dr Leonie Wong on **Arrhythmia (Long QT)**, a regularly requested topic within our network.

Adult Session

The day started for adult colleagues with their regular weekly MDT & **Network Activity Update** provided by Thomas Witter. This was followed by sharing of updates from network centres.

The main discussion session was centred around **Improving Pathways**, led by Dr Natali Chung, concluding with an education session on **Menopause** from Nathalie Picaut.

"Suggest more clinical topics included"



Noëlle Wolvaardt-Gavin
Upskilling Physiology Workforce

"Informative and useful day...thank you!"



Joe Eurell & David Taylor
Health Inequalities



Our Charity Partners ECHO Heart and Brompton Fountain always join us when they can to showcase the many ways they can offer support

Special Mentions



We'd like to take this opportunity to extend a warm welcome to all the new starters who have joined our network since our last newsletter and a massive thank you to those who have moved onto to pastures new.



Congratulations to Tessa Shewan, Children's Nurse with Interest in Cardiology, Darent Valley Hospital who won an award for the best poster at the Children's Cardiology Nurses Association (CCNA) in November. Tessa has since left the trust but we thank her for the impact she made whilst in post.

BCCA Award

Congratulations to Dario Freitas who won the service development and physiologist led services competition during the BCCP oral competition on 03 November.



Rothschild and Co and the Evelina London Charity Scholarship award

In a previous newsletter, we shared the good news that Lynda Shaughnessy and Susana De Sousa were awarded a scholarship providing financial support and mentorship for their project titled 'Transition provision: a holistic approach'. It aims to look at how to ensure transition services develop to provide all the needs for the patient, reducing the numbers of appointments and preventing lost to follow-up when moving from paediatric to adult services.

Currently in phase 1, they are collecting and reviewing data on patients with Hypoplastic Left Heart Syndrome born since 1995 to identify which services they may also require other than cardiology when moving from paediatric to adult services. This update was presented at a Rothschild event in London on 06 November. Watch this space for more updates soon.

Transition provision: a holistic approach

- Address complex healthcare transition for Young People (YP) with cardiac conditions and other co-morbidities
- Deep dive to the services currently provided in acute and community settings
- Design a service along with the young people to ensure that services are working together to provide truly holistic and joined up care.



Film stars in the making?

Echo have been working with some of our clinicians to produce a short film highlighting what to expect at a network clinic and how specialist centres (e.g. Evelina London) and network centres (e.g. St George's, West Suffolk) work together to provide the specialist care to patients and their families, at a location closer to home. Filming took place at the Evelina London in November and should be ready for viewing soon!

Our film stars:

Caroline Reeve	Children's Nurse with Interest in Cardiology, West Suffolk Hospital
Dr Irina Luca	Paediatrician with Expertise in Cardiology, St George's Hospital, London
Dr Aaron Bell	Joint Head of Service for Paediatric Cardiology, Evelina London
Alex Savis	Specialist Echocardiographer/Physiologist lead in Research & Training, Evelina London



Image courtesy of Echo

Congratulations

to Susana de Sousa, one of our Network Lead Nurses who completed her Masters degree in Leadership and Management in November. The hard work finally paid off. Well done Susana!



Huge congratulations to **Katie Haines, Cardiac Clinical Scientist**, from East Sussex Healthcare, on passing her European Association of Cardiovascular Imaging Echo CHD exam. Her colleague, **Cathy Tojo**, is also progressing towards accreditation, the result of both of their hard work and dedication. Thank you to GSTT Cardiac Physiology Leads, Dario Freitas, Kelly Peacock and Alex Savis, and other colleagues who have supported them. We are delighted to be growing the number of accredited clinicians in our network!

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. Contact us via our [website](#).

Nursing Contact Cards

Paediatrics

**Paediatric
Clinical Nurse Specialist
Team**



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**



(For patients > 21 years old)

Monday to Friday 09:00 – 17:00

Tel: 0330 128 8764

Email: gstt.achd-rbh@nhs.net

**Adult Cardiac
Clinical Nurse
Specialist Team**

Royal Brompton and
Harefield hospitals

Monday to Friday 08:30 – 17:30

Tel: 0207 188 9172

Email: gst-tr.ACHD@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

Our Charity Partners

[Brompton Foundation](#)



[ECHO](#)



[Little Heart Matters](#)



[Somerville Heart Foundation](#)



Thank you for your continuous support

**Taking this opportunity once again to
wish everyone a Merry Christmas
and a Happy New Year from all of us
in the Lifelong Congenital Heart
Disease Network.**