

Hello from our Network Clinical Directors



Dear Friends, families and colleagues of the North West Congenital Heart Disease Network,

As the summer holidays begin we are thrilled to share the latest news, stories, and updates from our network. As clinical directors we have enjoyed settling in to our new roles this year and seeing the networks accomplishments go from strength to strength.

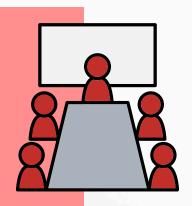
In this issue, you will find inspiring stories from our patients and families, highlights from some of the fantastic educational events we have hosted and updates on our ongoing initiatives to improve care and support for all affected by congenital heart disease. Our network thrives on the strength of our community, and we are grateful for your continued support and engagement. We hope you enjoy this edition of the newsletter and wish you a safe, healthy, and joyful summer.

Best regards

Dr Caroline Jones
Consultant Fetal and Paediatric Cardiologist
Clinical Lead for Cardiology,
Co-Director of the NW, North Wales and IoM
CHD ODN

Dr Damien Cullington
Consultant Adult Congenital Cardiologist and
Lead Medical Examiner, ACHD Clinical Lead,
Liverpool Heart and Chest Hospital,
Co-Director of the NW, North Wales and IoM
CHD ODN







New Network Board Chair

We are delighted to introduce Carolyn Cowperthwaite as our new Network Chair, a distinguished professional with a remarkable 38-year career in the NHS. Beginning as a paediatric and adult nurse, our Chair has developed a comprehensive understanding of lifetime health services. Over the past 12 years, Carolyn has excelled in senior management roles across medical and surgical divisions, refining her leadership and collaboration skills. As Chair of the Congenital Heart Disease Network, Carolyn will bring extensive experience in effective communication, management, service development, and leadership. These skills will be instrumental in achieving the network's goal of delivering the best patient and family experience across the Northwest, North Wales, and the Isle of Man.



"With a 38-year career in the NHS, I'm passionate about improving patient outcomes, especially for those with complex conditions. My journey began in paediatric and adult nursing, granting me a deep understanding of lifetime health services. In senior management roles (spanning 12 years) across medical and surgical divisions, I honed my leadership and collaboration skills.

Research has always been a driving force. I've led projects and trials and disseminated findings at regional, national, and international conferences. Currently, my focus is empowering doctors and healthcare professionals as an ILM trained Executive Coach, to excel in their roles and achieve meaningful patient outcomes whilst achieving a positive work/ life integration.

My book, "The Grief Book", is a testament to my commitment to patient well-being beyond the physical. It equips individuals with strategies for emotional resilience, a crucial skill for those coping with chronic conditions.

As Chair of the Congenital Heart Disease Network, I aim to leverage my experience in effective communication, management, service development and leadership. These skills align perfectly with the network's goals of delivering excellent care and treatment for patients with Congenital Heart Disease.

I look forward to working within an integrated, coordinated, multidisciplinary team to ensure that anyone in the Northwest, North Wales and the Isle of Man will have the best patient and family experience with regards to their care.



Network Team





Nicola Marpole Network Manager



Linda Griffiths Lead Nurse



Michelle McLaren
Lead Nurse for Education,
Training & Research



Elizabeth Devonport

Data Analyst



Jill Moran Network Support Officer

Exciting developments in the CHD North West Database Project



We are thrilled to announce significant progress in the development of an all-age database for the CHD North West Network, a crucial initiative in compliance with NHS England Special Commissioning standards. This groundbreaking project aims to streamline patient data management and improve care for paediatric cardiac and adult congenital heart disease (CHD) patients across the region.

All Level 1 and 2 centres are now on board, marking a major milestone in our collaborative efforts. Manchester Foundation Trust (MFT) will be the first to go live with their data, followed by Alder Hey Children's Hospital and Liverpool Heart and Chest Hospital (LHCH). This phased rollout ensures a smooth transition and effective integration across the network.



The network data analyst and Mindwave, our trusted partner, have started building the database architecture, laying the technical groundwork essential for the project's success. We hope to see a demonstration of the early prototype of the user portal soon, marking a significant step toward creating a unified and efficient CHD patient information system.

Stay tuned for more updates as we continue to enhance CHD care through innovation and collaboration.





Patient and Public Voice Group



(PPV)

Why I became a PPV Rep?

Claire Cathcart

Jan Tate

Hello, I'm Claire and I'm a PPV Group Rep. I joined at the start 4 years ago and I love it so much, I'm staying on an extra year! The reason I became involved in the PPV is because of my amazing 9-year-old son, Jake, who was born with cardiomyopathy and is 3 years post heart transplant and of course all the other amazing children and families I have met along the way!

I work as a Sales Manager for an IT Distributor as my 'Day Job', so I am not medical, but in my 'Spare' Time I am the CEO of Team 1C, which is a charity I founded 2 years ago, with other cardiac parents.



"Our charity is dedicated to supporting cardiac families here in the North West and our less fortunate cardiac cousins in the developing world who do not have access to the NHS"

Claire with son Jake

My particular interests are in supporting families who transfer to transplant centres outside of the North West and ensuring that parents/carers/siblings are listened to and supported. I would also like to see more focus on rhythm and muscle patients in the future. It's an honour to be a PPV member, I have loved every minute and I'm really proud of everything we have achieved.

In 1964 I underwent open heart cardiac surgery for an ASD. Having always after that being interested in hearts and hospitals I decided to go into a career in cardiology. I trained as a basic grade technician, becoming a senior technician at Warrington Hospital. I then moved into the Echocardiography side of the career. I became manager of the Cardio-respiratory & Vascular department at Countess of Chester hospital. After retirement from this post I began locum work in Echo, going on to work in Sydney Australia for 8 months in a private cardiology clinic. I continued locum work until the Covid pandemic after which I retired.



and information. Most in the group (or family members) have cardiac history with first-hand knowledge and experience which we are willing to impart"

"The PPV group is important for support

lan with her son

In 2014 my son also underwent open heart surgery for ASD this was only discovered when he was 26 years of age. He also had a pacemaker implanted 3 weeks later. During this time as my son and I had very similar ECGs and history we had genetic testing for Holt Oram syndrome which we both have. My daughter was also tested and she does not have the gene for this. My son's pacemaker was removed 3 years later and he continues to do well. He now has 2 children who are well.

Claire Jan







Patient and Public Voice Group (PPV) - Join Us

We are always looking for new members especially encouraging families with children and people from diverse backgrounds to join the group.

For further information, please contact: Linda Griffiths, Lead Nurse, NW CHD ODN at linda.griffiths@alderhey.nhs.uk or call 07790976864

All Age Patient and Public Voice Group

The PPV group is made up of people from across the North West region who have experience of children with heart problems or anyone of any age affected by congenital heart disease (CHD)



WHAT WE DO:

- Represent the views and experiences of everyone affected
- Provide feedback on how services are working across the North West



WHEN DO WE MEET:

- Once a month for approx 2 hours
- Meetings are held remotely but also have face to face meetings

FOR FURTHER INFORMATION CONTACT:

northwestchdnetwork@alderhey.nhs.uk

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CHD Awareness Week 7th - 14th February 2024

The ACHD Team at Liverpool Heart and Chest Hospital had a busy week raising awareness of Congenital Heart Disease. They had a different theme for every day of the week and displayed information in the outpatient department for patients and their families.



The week culminated in some of the clinical staff from paediatrics and adults walking with the Children's Heart Association from Liverpool Heart and Chest Hospital to Alder Hey Children's Hospital and back to symbolise the journey from the children's service to the adult service. Well done to all involved in a very successful week!



ACHD Team - Liverpool Heart & Chest Hospital

This ranged from information about the importance of keeping active including what a healthy diet looks like to raising awareness of the Network and what we do to support patients and families.





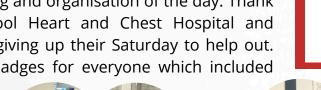


Learning Disabilities Forum Conge

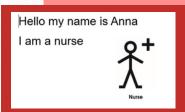
Open Day at Liverpool Heart &

Chest Hospital 15th June 2024

To celebrate the start of Learning Disability awareness week 2024 we organised an open day for people with learning disabilities and their families. Thanks to the Network Learning Disability Forum for the idea who were involved in the planning and organisation of the day. Thank you to all the staff at Liverpool Heart and Chest Hospital and Manchester Royal Infirmary for giving up their Saturday to help out. We provided easy read name badges for everyone which included Makaton signs.







Visiting the theatres

- learnt all about having a heart operation or a procedure
- getting dressed up in theatre scrubs which was great fun!

Visiting the wards

- learning how we support people with a learning disability in hospital
- supported by a Makaton Tutor to help with communications and reassurances
- visited had a clinic,

their observations took, had an ECG and heart scan, then on to see a doctor

reasonable adjustments and what this

means? mental Capacity Act and how we

Interactive talks

- support people make their own decisions and ensuring that decisions are made in their best interest when the lack capacity to make decisions for themselves
- power of attorney or deputyship advice

Click on the image below to see the video of what happened at the open day







THANK YOU To the charities and organisations who supported the day:-

The Somerville Heart Foundation / The Children's Heart Association / Down Syndrome Liverpool / People First / Healthwatch Liverpool / NW Patient & Carer Forum / SCOPE

Feedback has been amazing! We will certainly be organising another one next year - so watch this space!!





Network Events

"It has been most session & Q&A was very good."

Informative good interactive were good."

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Informative go

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"Brilliant day; I would recommend every obstetric sonographer & department leads to partake in this course."

Hands-on training for tinythers
Fetal Cardiac Sonographers

Saturday 6th April

The second hands-on fetal cardiology sonographer update day was held at the Liverpool Women's Hospital.

This was organised and delivered by Dr Joyce Lim and the North West Fetal Cardiology team, and was sponsored by GE and Tiny Tickers. It was fantastic for us to meet over 30 sonographers from all over the region and the feedback from the attendees was overwhelmingly positive.

We are planning to offer this course bi-annually alternating locations between St Marys Hospital in Manchester and Liverpool Women's Hospital and look forward to meeting many more North West sonographers at future courses.

Paediatric CHD Regional Study Day

25th April 2024

The Network were pleased to host a face-to-face study day at the Village Hotel, Whiston. The event was fully funded by the NW CHD Network and the focus of the day was our single ventricle patients; the audience consisted of nurses and allied health professionals, and welcomed over 50 delegates. It involved lots of audience participation; the workstations allowed further interaction.

Little Hearts Matter, the single ventricle support charity, attended and hosted a stand with lots of informative literature. Alder Hey Children's Hospital's Little Hearts at Home platform was represented highlighting how technology can be utilised to improve patient care and experience.



Talks were delivered by staff from both Alder Hey Children's NHS Foundation Trust and the Royal Manchester Children's Hospital involving fetal cardiac nurse specialists, paediatric cardiac nurse specialists, cardiology trainees, speech and language therapists, dieticians, palliative care nurse specialists, pharmacists and cardiac physiologists. Feedback from the event was excellent.







Network Events



13th June 2024

The inaugural Inherited Cardiac Conditions (ICC) study day was held in the beautiful location of The Reader Mansion House, Calderstones Park, Liverpool - shame that the British weather was not kind to us to really appreciate the surroundings! The event was fully funded, and organised, by the NW CHD Network.

Dr Michael Bowes, Consultant EP Cardiologist and his colleagues provided a day which involved interesting ICC case studies, this facilitated learning at different levels.

Content of the day was brilliant. Really useful & enjoyable.

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and his of ICC case

The 80 delegates included ward-based nurses, cardiac physiologists, cardiac trainees, cardiology consultants, cardiac nurse specialists, ANPs and Paediatricians with an Expertise in Cardiology (PECs) and Allied Health Professionals (AHPs).

Upcoming Network Events

Network Study Day - Focusing on 'Transposition of the great arteries (TGA)'

Friday 27th September 2024 9.00am - 5.00pm, The Reader Mansion, Calderstones Park, Liverpool

The NW CHD Network is happy to be hosting the third face-to-face study day of 2024.

The focus of the day is TGA patients from womb to adulthood. We welcome delegates from paediatric CHD and ACHD backgrounds, PECs, allied health professionals, cardiology trainees and cardiac physiologists. Registration is open and there are a few remaining places; there are 80 places in total. Please see flyer for further details.



Click here to register





Empowering Excellence: Cong **Expanding Horizons in CHD Education**

The Network is pleased to have been in a position to provide numerous funding opportunities this summer. Our colleagues have had the incredible chance to attend a variety of specialised training and educational events focused on congenital heart disease (CHD) and paediatric cardiology. This support has enabled them to participate in esteemed programs such as the John Moore's University CHD master's module, the BCCA conference, and specialised courses Echocardiography in CHD. Additionally, they have international gatherings, including the Association for European Paediatric and Congenital Cardiology Conference and the advanced Ultrasound in the Fetal Cardiovascular Examination course. These opportunities, which would have otherwise been out of reach, have significantly enriched their knowledge and skills, ultimately enhancing the quality of care we provide to our patients.

AEPC (Association for **European Paediatric** and Congenital Cardiology) Porto 8th-11th May 24

Maria Hollingsworth, Paediatric Cardiologist Specialist Nurse & Nicole Almond, Cardiology Specialist Nurse, **Royal Manchester Children's Hospital**

- Reading up to date research and relevant cases from around the world through the poster gallery
- Florence Nightingale Lecture presented by Kathleen Mussatto (USA).
- Fetal cases and what different teams put in place to support expectant mothers.
- 'Puzzle the Experts' led by our own RMCH consultant N. Dzhelepova.
- Heart failure through the lifespan and how to manage cases of failing fontan, and awareness of heart transplantation.
- 'Long Term Survival of Antenatally Diagnosed Functionally Single Ventricle Congenital Heart Disease' led by AHCH Fetal Cardiologist Dr Lim.
- Genetics and how they can contribute to sudden infant death.
- The importance of fitness challenges in young people with a heart condition and how to build up their exercise tolerance (particularly the idea of fitness prescriptions).
- Research carried out on Aortopathies, including therapies used such as beta blockers or angiotensin receptor blockers.









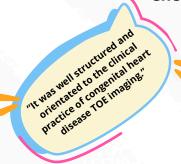


Empowering Excellence: Expanding Horizons in CHD Education

European Transoesophageal Echocardiography in CHD London 4th & 5th April 24

Liam Corbett, ACHD Physiologist, Liverpool Heart & Chest Hospital





I really enjoyed this face-to-face hands-on course. It was a great collaboration of experts sharing science, knowledge, clinical practice, and imaging review knowledge. There were many practical elements with lots of hands-on / practice permitting a detailed overview of basic to complex TOE assessment when reviewing cardiac morphology, congenital heart pathology and its TOE imaging correlates, which after years of practice largely within the TTE world really demonstrated its additive role in the diagnosis and management of these patients.

Adult and Paediatric Cardiovascular Pathology London 19th & 20th June 24

Kathryn Houghton, Inherited Cardiac Conditions Nurse Specialist, Alder Hey Children's Hospital



The Congenital Heart Network kindly funded me to attend the Adult and Paediatric Cardiovascular Pathology Event. The Event was hosted By Professor Mary Sheppard and Dr Joe Westaby at St Georges Hospital London and funded by Cardiac Risk In the Young Charity.

I found the event invaluable as an Inherited Cardiac Conditions (ICC) nurse specialist I often spend time talking with families about the circumstances before and at the time of death of loved ones, looking at any findings at autopsy that might be useful to aid diagnosis and help assess risk for surviving 1st degree relatives and the wider family.

The event covered everything from the role of the medical examiner, coroner, the postmortem findings for all the ICC's, interestingly the Cardiac findings that are not inherited along with stressing the importance of obtaining DNA samples especially when the cause of death is unknown. We were given the opportunity to review the histories and view what is seen at autopsy we also viewed 2 live cardiac autopsies. Over the 2-day event we were given ample opportunity to question the experts.







'Being a PEC' Paediatrician with Expertise in Cardiology

Based at Ysbyty Glan Clwyd for over seven years, I work as a "PEC" - a paediatrician with expertise in cardiology. When it comes to introducing myself to my patients, I prefer to use the term "cardiac paediatrician" - partly because even after all this time, I'm still reluctant to acknowledge any sort of "expertise" in a field as complex as paediatric cardiology. But chiefly, I feel it provides patients and their families with a better idea of what my role entails - primarily as a general paediatrician, but with the skills to manage congenital and acquired cardiac disease in our local population.

Clearly, many of the more complex patients need the skills and experience of a real consultant paediatric cardiologist. To ensure that the cardiologist can focus on those patients with known pathology, I also run my own weekly clinics where I aim to see patients with asymptomatic murmurs. The majority of these young people can be discharged with the reassurance that they have a normal heart.



Dr Matthew Sandman FRCPCH Ymgynhorydd Pediatreg • Paediatric Consultant Ysbyty Glan Clwyd Hospital Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

Occasionally, after examining the child, it's apparent that the murmur heard and referred with the letter stating "I think it's likely to be innocent" is no such thing - the grade 3/6 pansystolic murmur heard as soon as the stethoscope touches the chest ensures I will focus for that bit longer on the ventricular septum when performing the echo, hunting down the defect responsible for the noise. With the diagnosis made, I have come to realise that sharing with a family the finding of the smallest congenital heart defect often brings about tears and upset, despite my best efforts to reassure that this is "unlikely to cause any problems.

The pressure of the role - the point at which I might reluctantly acknowledge any slight degree of "expertise" - comes in the emergency situation. The phone call to let me know of a collapsed infant being brought to the ED: "We've covered for sepsis" (good!), "but we're worried this could be cardiac". At those times, amongst the controlled chaos of a paediatric resuscitation, there is a recognition that the minutes after placing the echo probe on the chest could be crucial to the outcome for that child. Decisions being made by the team, "do we start prostaglandin?", "do we give more fluid?", rely on a rapid and accurate assessment and diagnosis. Each view of the heart revealing a clue to the eventual diagnosis. I'll confess to a palpable sense of relief when, having noted weak femoral pulses and a poorly functioning left ventricle on echo in an infant, I've switched to focusing my views on the distal aortic arch to see the characteristic doppler swirl of blue and yellow signifying flow acceleration across a critical coarctation. From that point the management is clarified, and the focus can shift onto stabilising the child for a safe transfer, for definitive treatment by the team at Alder Hey.

Ultimately, it's that tertiary support which ensures the role remains rewarding. Despite working over an hour away from Alder Hey in rural North Wales, I still feel that I am part of a team caring for our patients. The ongoing support and input from the tertiary team means there is never a sense of isolation. It allows me to offer the best care for our patients, to continually learn, and possibly, one day, I might even acknowledge a degree of "expertise".

"It's clear that the heart is unique in how society views it – much more than simply an organ in the body."

"Something about what heart stands for reflects who you are as a person; a strong and healthy heart representing the same of the individual."

Dr Matthew Sandman







PREMS Survey Update

Our Patient and Public Voice (PPV) Group have been listening to patient's stories and have used that information to help create two patient feedback surveys.

We have one that is for adult patients and their families or carers who are living with congenital heart disease, and we have a separate one for families who are living with a child with a heart problem. These surveys help us to learn what we are doing well and how we can improve.

We had our first Patient Experience Forum on 6th June. A team of doctors, nurses, managers and patient reps met to review the first 6 months of data and agreed on what actions we should take. Here is a brief summary of what we discovered:

Between 15th May and 31st December 2023 57 people completed the adult survey 25 people completed the paediatric survey



<u>Click here</u> to complete the survey

It was clear that everyone 100% who had an encounter with one of the nurse specialists found it helpful. 100% of people who came to visit the hospital as part of their pre-admission process found it helpful.

Suggestions we are putting in place:

- Let the ECG departments know about the results of the surveys so they can start offering a copy of the ECG to the patient
- Make sure the link and QR code to the surveys is shared regularly.
- Developing a suite of 5 short videos to help families including - what support is available and how to access it? / how to use play to help children who need to come to hospital / how to talk to your child about their heart problem.

Some comments received:

"I had to contact the **ACHD Team myself** as the local hospital refused to call them"

" The care I received was outstanding!"

The care I continue to receive is fantastic. I have a great relationship with my cardiac team. They often feel like my family. I wouldn't be where I am today without their care and support over many years."

"I have never been given a copy of my ECG"



Other news around the region

NEW TEAM MEMBERS ACROSS OUR CENTRES

ROYAL MANCHESTER
CHILDREN'S
HOSPITAL

Ali Jeylani, Paediatric Cardiac Physiologist

ALDER HEY

CONSULTANTS
Bernadette Khodaghalian
Tommaso Generali



LIVERPOOL HEART & CHEST HOSPITAL

CONSULTANT Jonathan Senior, Clinical Fellow in ACHD/Paediatrician Intervention

I am a post CCT fellow in congenital structural intervention, trained in adult congenital cardiology at the Queen Elizabeth Hospital, Birmingham. I live with my young family in Leamington Spa and travel to Liverpool to gain further skills in congenital structural heart interventions, including percutaneous (keyhole) valve replacements and ASD closure. When time allows, I enjoy keeping active by running, cycling and playing golf (but not as much as I would like 2)

Learning Disability Forum Distraction Bags

FLOME

Our Network Learning Disability Forum have created a checklist of what they feel are important reasonable adjustments that hospitals should be able to provide for a patient with learning disabilities or other additional needs. They have been visiting hospitals to go through this checklist and helping providers to identify where they have gaps. The need for distraction toys to be available to help support people coming into hospital and especially during procedures was identified as being essential.

These types of toys are not always available at the time they are needed. Our LD Forum decided to do something about this. They came up with the idea of providing a distraction bag full of helpful toys to our main hospitals. They told us what types of toys can be used for distraction purposes. We then used that list to buy the items they had recommended. Together the Network, Team 1c and the Children's Heart Association have all contributed to the creation of these bags.



We think they will make a massive difference and want to thank our LD Forum for helping us with this project.





L-R: Lisa Mawdsley, CHA / Linda Griffiths, Lead Nurse, NW CHD ODN / Michelle McLaren, Lead Nurse, NW CHD ODN / Lorna O'Brien, Play Specialist, Alder Hey



So far bags have been provided to:

4.50	
ACHD Teams Liverpool Heart & Chest Hospital	ACHD Team Manchester Royal Infirmary
Cardiac Team Alder Hey Children's Hospital	Coming Soon! Manchester Children's Hospital

Alistair from the LD Forum handing the bags to LHCH and MRI teams







Useful links & information

Email us at: NorthWestCHDNetwork@alderhey.nhs.uk

Join the NWACH Support Group



@NwchdN
now has 941
followers



Click here to join the Adults CHD Support Group

Congenital Heart Helplines:

If you need any personal advice about you or your child's congenital heart problem our Congenital Heart Nurse Specialists are very skilled and experienced and able to help with any queries. Please ring and **leave a message** with the patients name and hospital/NHS number and the Nurse Specialists will call you back to help with your query.

Adult Congenital Heart Patients

The helpline is based at Liverpool Heart and Chest Hospital and is available for everyone living in the North West, North Wales and Isle of Man

For non-urgent enquiries: Cardiac Help Line: 0151 254 3333

For Urgent queries outside of normal working hours:

Please call the hospital switchboard on 0151 600 1616 and ask to speak to the hospital co-ordinator on bleep 2707. If the hospital coordinator is busy please identify yourself as a congenital heart patient and **leave a message** to ask for a call back. Make sure you leave your contact telephone number with switchboard.

Royal Manchester Children's Hospital For non-urgent enquiries:

Cardiac Help Line: 0161 701 0664

For Urgent queries outside of normal working hours:

Contact ward 85 on 0161 701 8500/8501

Alder Hey Children's Hospital For non-urgent enquiries: Cardiac Help Line: 0151 252 5291

For Urgent queries outside of normal working hours:

Contact ward 1C on on 0151 252 5740/5418

