ISSUE 5

Congenital
HEART NETWORK
NORTH WEST | NORTH WALES | ISLE OF MAN

SUMMER 2025

Network NEWS

COMING SOON!
NEW NETWORK
WEBSITE

2 AMAZING
PATIENT
STORIES

EXCLUSIVE!
PPV PROMOTIONAL
VIDEO
RELEASED

www.northwestchdnetwork.nhs.uk

FROM OUR CLINICAL DIRECTORS

Dear friends, families and colleagues of the North West Congenital Cardiac Network,

We hope everyone has been able to enjoy some of the North West sunshine over the summer months. This newsletter remains a source of pride and aims to keep you all informed of our latest CHD network developments.

In this issue we will highlight some of the key educational events the network has been proud to host including the learning disability day and a day focussed on Tetralogy of Fallot. Over the last year our CHD network chair Carolyn Cowperthwaite has firmly established her role and you can read more about her NHS career and aspirations for the network in this issue. Over the last year our grant funding for education has supported more nurses to enhance their knowledge with some highlights to read about here.

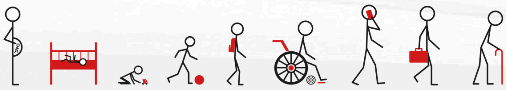
As ever thanks to our Patient and Public Voice (PPV) group, their continued commitment and dedication is evidenced in a new video they have produced this year (amongst many other endeavours). It is a fantastic watch, as an introduction to everything congenital heart disease and to inspire others to join them (it also may bring a tear to the eye).

The network achievements in the last 12 months continue to be a product of your ongoing enthusiasm and engagement so thank you all and happy reading!

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



FROM OUR NETWORK BOARD CHAIR

Carolyn Cowperthwaite
Chair - NW CHD Network Board

As Chair of the Northwest, North Wales, and The Isle of Man Congenital Heart Network, I'm honoured to support a team dedicated to improving the lives of children with heart conditions and adults with congenital heart disease.

The Clinical Leads, Network Manager, Lead Nurses and the wider team are a beacon of support, always prioritising the needs of our patients and families/carers.

I've been privileged to witness firsthand the power of patient voices at our Patient and Public Voice Group meetings. The openness and honesty with which patients and families share their experiences is truly inspiring.

Following the recent announcement regarding the planned dissolution of NHS England, I want to reassure all our colleagues, patients and families that it remains very much business as usual for the Network. We continue to be here, working together to provide high-quality, equitable care and support. Our commitment to improving outcomes and reducing variation remains unchanged.

This aligns closely with the vision set out in the new NHS 10-Year Plan, particularly the focus on delivering more integrated, person-centred care and tackling health inequalities. These priorities are at the heart of our work across the Network and will continue to guide our efforts in the months and years ahead.

By placing patients at the heart of our decision-making, I am confident that the Board will deliver on our ambitious aims:

- **Enhance Patient Experience:** Deliver exceptional care across the entire patient journey, optimising outcomes and quality.
- **Standardise Care:** Adhere to national specifications and standards to ensure consistent, high-quality service delivery.
- **Optimise Care Pathways:** Streamline referral, care, and transfer processes, minimising unnecessary travel and maximising access to specialised care.
- **Integrate Care:** Foster a collaborative, multidisciplinary approach to provide comprehensive, coordinated care.
- **Ensure Smooth Transitions:** Facilitate seamless transitions for young people moving from paediatric to adult services.
- **Support Service Development:** Identify and support the development of essential level 3 services.
- **Drive Data-Driven Improvement:** Utilise data to monitor outcomes, quality, and patient experience, and to inform service improvement initiatives.
- **Strengthen the Workforce:** Invest in training and professional development to empower our clinical teams.

Together, we can create a brighter future for patients with congenital heart disease and I look forward to our continued working together.

MEET YOUR NETWORK TEAM

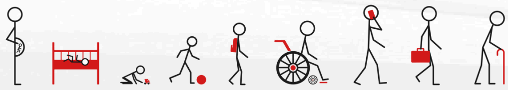
Nicola Marpole
Network Manager

Linda Griffiths
Lead Nurse

Michelle McLaren
Lead Nurse for Education, Training & Research

Elizabeth Devonport
Data Analyst

Jill Moran
Network Support Officer



Network Database UPDATE

CHD Database Project:

ON TRACK FOR 2025 LAUNCH

We're pleased to share that the North West CHD Network Database project is making strong progress. With development nearing completion the project is now moving into the implementation phase.

In partnership with....

MEDIWAVE

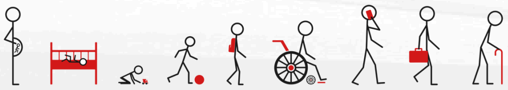
A revised timeline has been agreed with the provider trusts and our supplier, Mediwave, with first data flows scheduled to begin in July 2025.

Once the system is receiving data, it will be tested by a small pilot group before being rolled out more widely across all Level 1 and 2 centres.

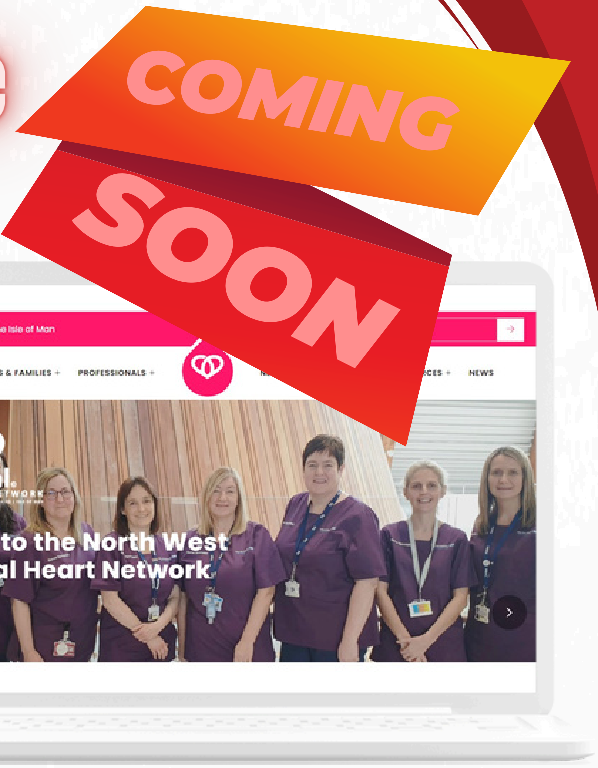
This is a major step forward for the network and will help us gain a clearer understanding of our regional CHD population, improve service planning, and take proactive steps to reduce the risk of patients being lost to follow-up. Watch this space for further updates as we move towards go-live!

WATCH THIS SPACE!

FOR UPDATES AS WE MOVE FORWARD TO GO LIVE



New Network Website

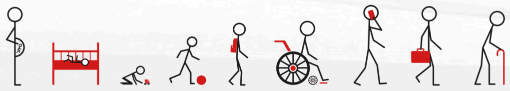


We're excited to announce that the North West CHD Network website is getting a fresh new look! The updated site has been redesigned to better reflect our work, improve accessibility, and make it easier for professionals, patients, and families to find the information they need.

The rebranded website *will feature....*

- **Clearer navigation and improved layout**
- **Dedicated sections for patients, families, and professionals**
- **Updates on projects such as the CHD database**
- **Resources, training opportunities, and upcoming events**

The new site will go live later this summer, and we'll share the official launch date soon. We hope the updated design will make it easier for everyone connected to the network, including patients, families, and healthcare teams, to stay informed and access the support they need.



Congenital HEART NETWORK

Patient & Public Voice Group (PPV)

The PPV Group have had a busy year so far. We have been concentrating on getting our group known to as many patients and families as possible. We have also been focussing on recruiting new reps to ensure continuity and sustainability for our group.

Chair
Janet Rathburn

CLINIC DROP-IN SESSIONS

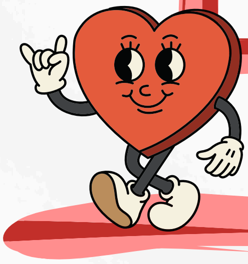
- Attended clinics at LHCH, Alder Hey, RMCH, MRI and Stepping Hill.
- Thank you to staff for allowing us to attend their clinics and to the staff who helped us on the day.
- It's been very interesting to meet patients and families and to hear their stories.
- We will continue to visit these centres and others where possible to try to ensure that as many people as possible know about the PPV Group, and the importance of Public Voice.

ZOOM DROP-IN SESSIONS

zoom

- The PPV group hosted regular informal meetings via Zoom for CHD patients or family members who wanted to chat with us.
- These sessions have been really useful, a good opportunity for patents to discuss their personal concerns and to be signposted to appropriate support.
- They have also led to two new members! We will continue with these sessions in the Autumn.

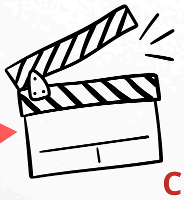
For further information to join a Zoom Drop-in Session, contact: northwestchdnetwork@alderhey.nhs.uk



CHD AWARENESS WEEK FEBRUARY 2025

As part of CHD Awareness Week, we launched a letter-writing campaign to MPs to highlight perceived inequalities in CHD service provision between the North and South. Several MPs responded, and we're especially grateful to Patrick Hurley, MP for Southport, who took an active interest after being contacted by our PPV representative, Mike Owen. Mr Hurley has raised the issue with NHS England and the Secretary of State for Health and Social Care. A key part of the campaign is around gathering data to understand whether these concerns are reflected in reality. We hope this will lead to more balanced planning and stronger national engagement.

A PPV PRODUCTION: 'JOURNEY OF HOPE'



CLICK ABOVE TO WATCH THE PPV 'JOURNEY OF HOPE'

Check out our new PPV promotional video

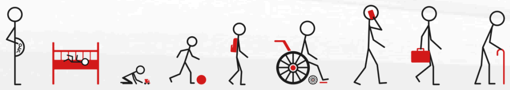
Special thanks to several PPV group volunteers for their input planning the video and taking part. Especially to Angelique and Danny for letting us film in their home, and to Heather at her holiday home. Thanks also to our other Heather in the group for the fantastic job with the voice over. And to ten year old Aurelia who was the star of the show!

I am extremely grateful to all the reps and families who took part and shared their stories with such courage and composure.

Thank you to Linda Griffith, Lead Nurse, NW CHD Network and Mark Wilkes, Wilkes Digital, for all their hard work producing the video and helping to portray the journey of a patient with CHD from cradle to older age, including bereavement.

We are extremely proud of ***'Journey of Hope'*** which has been well received and gaining significant attention on YouTube and will be used by medical professionals in various ways. It is expected to raise awareness of the PPV Group, attract new members, and enhance the patient and family experience.

For further information regarding joining the NW PPV Group contact: northwestchdnetwork@alderhey.nhs.uk



PREMS SURVEY UPDATE

North West Congenital Heart Disease Patient Survey

THANK YOU!

CLICK HERE

Does your child have a heart condition? Have you grown up with your heart condition?

How did we do?
Tell us about your care and help us improve our services

Scan Me

Speak up → Be heard → Make a difference

If you would like us to send you the link - get in touch

✉ northwestchdnetwork@alderhey.nhs.uk

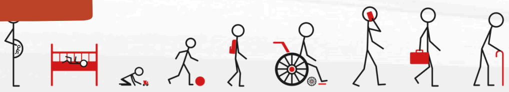
@NwchdN

www.northwestchdnetwork.nhs.uk

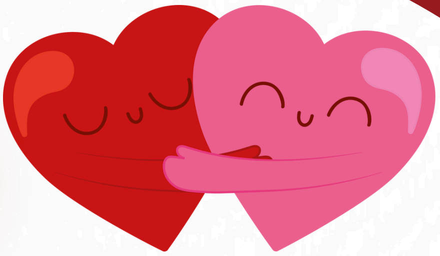
Our Patient and Public Voice (PPV) Group have been listening to patient’s stories and have used that information to help create two patient feedback surveys.

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.

***Click here** to complete the survey*



Patient Stories



SARAH'S STORY

BY JANET RATHBURN

My daughter Sarah was born with Tetralogy of Fallot (TOF) in September 1980. She was treated at RMCH (Royal Manchester Children's Hospital) Pendlebury, Myrtle Street, Alder Hey and The Heart Hospital, University College Hospital. She had a good outcome from all the procedures.

Sarah had a baby boy, Dominic, in May 2019, he had TOF and DORV and died following surgery at AH (Alder Hey Children's Hospital) in September 2019. Sarah had no heart issues in her pregnancy.

In July 2023 Sarah became pregnant again. In October at 19 weeks she felt very unwell, her heart was racing at 180bpm, she went ,via the GP, to Stepping Hill, her local hospital. The doctor on duty in A&E had an interest in cardiology. Sarah also had access to MyMFT/MyChart so share recent information from the Joint Cardiac & Obstetrics clinic she was attending at St Mary's. MRI was consulted and Dr Damien Cullington was on duty and gave his advice. Vagal manoeuvre and adenosine were utilised but failed, successfully reverted to sinus rhythm using bisoprolol. Sarah was started on a low dose of betablockers.

One A&E consultant Sarah saw at Stepping Hill, had done their training with Petra Jenkins, and had drummed into their team the importance of consulting CHD consultants. Sarah had further attacks of fast heart rate in November and December. She went straight to MRI. Again LHCH (Liverpool Heart and Chester Hospital) and Dr Damien Cullington were consulted. Her dose of betablockers was increased. The attacks were dealt with by medication.

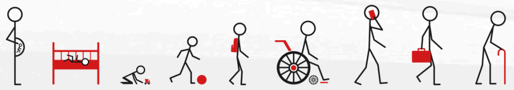
On 4th February Sarah had another attack and went to MRI. Her baby was scheduled to be born by C section on 14th February. The attack on Sunday 4th February couldn't be controlled by medication, and through consultation with Petra Jenkins and the on call Obstetrics team it was decided Sarah had to be cardioverted under general anaesthetic. Baby Benjamin was born at the same time! Benjamin was premature by 1 day so was in NICU at St Mary's. 5 days later mother and baby were reunited on Friday evening. Early on Saturday morning Sarah had another attack. Sarah's heart reverted just as the doctors were about to give the medication to revert. She ended up on the acute cardiac ward in MRI , with baby and dad on the post-natal ward!

Both mother and baby were eventually reunited at home. Sarah continued to suffer from a very high heart rate. She had an cardioversion, under general anaesthetic, at LHCH 3 and a half weeks after Benjamin's birth but it didn't last long. Sarah was extremely tired and unable to do very much other than feed the baby. She had an ablation on April 16th by Rezza at LHCH. Since then she has been back to normal!

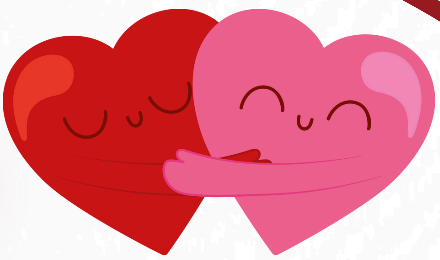
Positives and negatives

- All district hospital cardiac staff should be aware of the importance of consulting with CHD consultants.
- After Benjamin's birth when she was dealing with LHCH she was waiting for an appointment, however, she didn't receive the letter until after the appointment date and therefore didn't attend. Sarah contacted LHCH and received another appointment the following week.
- When she was in LHCH her treatment was second to none from the whole team, including catering. Sarah's view is that if you could combine MRI's MyMFT/MyChart information with LHCH facilities and care it would be brilliant.
- Also that GP's need regular reminding that with Heart related issues the local hospital may not be the right place to send ACHD patients to.

thank you



Patient Stories



ALISTAIR'S STORY

BY HEATHER LAWSON

My brother Alistair was born in February 1976 with Down's Syndrome and congenital heart disease. During his first few months my parents were informed that his life expectancy would be approximately 16 years.

Alistair lived a full and active life up to and well beyond his sixteenth birthday, living in the moment, appreciating life and always, always finding joy.

On 29th November 2023, aged 47, Alistair collapsed at home. From regular three-monthly consultations at Manchester Royal Infirmary, as a family, we were aware that Alistair's heart condition was deteriorating. Fluid was building around his right ventricle and it was felt that any invasive surgery would just be too much for his body to take.

Having been initially admitted to our local district hospital, it was agreed shortly afterwards that Alistair could be safely transferred to Liverpool Heart and Chest Hospital where his cardiologist was now based.

The roads were thick with snow, my brother was wrapped in blankets along with his favourite dressing gown, his bobble hat and gloves. My eyes were fixed on Alistair as we made this final journey together.

Within minutes upon our arrival at LHCH, Alistair was taken to his own room where very quickly he was examined by one of the ACHD cardiologists, following this, regular monitoring ensued. We, that is, my mum, late father, husband and I, were always so very grateful for the honest, open conversations that took place with the cardiologist alongside the ACHD lead nurse, someone who had been part of and contributed hugely to Alistair's positive outcomes during hospital stays over the previous 13 years.

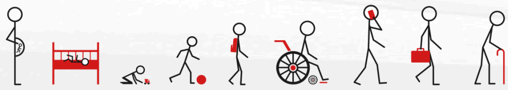
The nature of a Patient Story, I imagine, is to share an insight into the lived experiences of patients and their families, so I hope that this, Alistair's story, provides you with a window into the experience of caring for someone you love more than anything, whilst navigating the world of hospitals and processing the devastating reality that life for your loved one is soon to come to an end.

Time is a commodity often in short supply but when shared valued immensely. Time to listen, to share expertise and advice, to ask questions and time to spend precious moments with Alistair after he had taken his final breath, without being rushed was appreciated beyond belief. Time taken by Alistair's own ACHD cardiologist whom he was very fond of, to come and sit with us as well as Alistair after his passing, is something we will never forget. A relatively simple gesture but one that will live in the memories of us as a family.

The irony of writing this patient story on behalf of my amazing brother, is that the NHS were ultimately unable to save his life. It is a story that unfortunately does not have a happy ending. However, it is a story filled with admiration for the expertise, commitment and compassion the cardiologists and nursing staff displayed throughout Alistair's treatment during the 13 years he was under their care.

The memories at the end of life for your loved one live with you forever, so ensuring that the experience is as positive as possible is vital. Despite losing Alistair, our precious gift, our family are indebted to the dedication of a truly inspirational team of people who looked after him during his final days at Liverpool Heart and Chest Hospital.

thank you



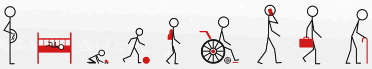
PATIENT STORIES

Congenital
HEART NETWORK
NORTH WEST | NORTH WALES | ISLE OF MAN

WITH CONSENT, YOUR STORY COULD BE......

- READ AT OUR BOARD MEETINGS
- PUBLISHED ON OUR WEBSITE
- PUBLISHED IN OUR NEWLETTER

Interested? Fill in the form via the QR code below and a member of the NW CHD Network will contact you.



Learning Disabilities Forum

Do you or your child have a heart problem?

Do you look after someone with a learning disability and heart problem?

Do you or your child also have a learning disability or autism?

You are *not alone....*

The Learning Disability Forum is a group of patients, carers and family members, and charities who want to improve the experience of people with learning disabilities who need to come to hospital. They want to share experiences and find understanding from others who truly get it!

The group meets once a month via Zoom at 7pm email: northwestchdnetwork@alderhey.nhs.uk to be sent the Zoom link

Learning Disabilities' Forum Study Day

Friday 13th June,
Alder Hey Children's Hospital

We held our first Learning Disabilities' Forum Study Day in June, which was a great success.

Thank you to everyone that attended and to our fabulous guest speakers.

We hope to see you all at a future event

A special thank you to 'Afta Thought Training Consultants' for their scenarios and lived experience performance.

Delegates at our first Learning Disabilities' Forum Study Day

RAISING AWARENESS OF THE LEARNING DISABILITIES FORUM

LD and PPV group member, Heather Lawson was recently interviewed by the Cumbria Daily Mail. Heather's interview focuses on the new PPV promotional video in which she talks about the great work of the Learning Disabilities Forum, along with her CHD story.

Click here to read the article.

ON AIR

mencap

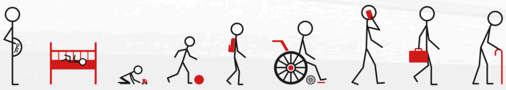
The New Sound Of The City
LCR
www.l-c-r.co.uk

Our Lead Nurse, Linda Griffiths was recently invited to be interviewed by members of Mencap Liverpool, on LCR 106.7FM (Liverpool Community Radio) as part of Mencap Wednesday to raise awareness of CHD and the Learning Disabilities Forum.

Linda Griffiths (second left) pictured with members of Mencap Liverpool

CLICK IMAGE ABOVE TO LISTEN

NB: Adverts precede the start of the programme, which begins at 1:44)



Congenital HEART NETWORK

NETWORK STUDY DAYS 2025

Fetal, Neonatal & Paediatric Cardiac Palliative Care Study Day

Tuesday 29th April

Alder Hey Children's Hospital

The event was led by Gill McBurney, Fetal Cardiac Nurse Specialist, and Patricia Coyle, Cardiac Nurse Specialist, both of Alder Hey Children's Hospital and Linda Griffiths, Lead Nurse, NW CHD Network. We welcomed over 60 delegates consisting of nurses and allied health professionals.

What our **DELEGATES** said

- Really informative study day with interesting presentations.
- I really enjoyed hearing people's feedback and discussion between professionals!
- Very educational and informative day.

Tetralogy of Fallot Study Day

Tuesday 8th July

Alder Hey Children's Hospital

Our recent NW CHD Network Study Day on 8th July focused on Fallot's Tetralogy, taking us on a journey from antenatal diagnosis right through to adult palliative care. With engaging talks from local and national experts, we covered treatment options, lifestyle issues, and support through transition.

We were also joined by the Children's Heart Federation and Max Appeal, who shared the vital support they offer to families. A real highlight was hearing a powerful lived experience from a patient living with congenital heart disease. It was a brilliant day of learning and networking for nurses across the region!

What our **DELEGATES** said

- Brilliant day! Learnt loads!!
- It has to be one of the most interesting study days I have been on with such a variety of information.
- Thank you for facilitating such a comprehensive and useful session

THANK YOU!

To all our speakers and charities for their support at all our events

4th Fetal Cardiac Sonographers Hands-on Training

Saturday 14th June

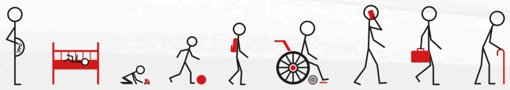
Liverpool Women's Hospital

This is hands-on obstetric sonographer cardiac update was attended by 30 sonographers and obstetric trainees to upskill attendees on the 5 standard fetal cardiac views. Since the 1st hands-on course, we have up-skilled at least 120 attendees from the North West and around the UK. We hope to continue with annual update courses.

Event organiser Joyce Lim (L) with guest speakers

What our **DELEGATES** said

- This course would be extremely helpful for sonographers a few years after qualification.
- Live examples of the heart videos were very helpful.
- The practical (hands-on) sessions were very helpful. I would love to attend again next year!
- Good facilitators during hands-on session. Thank you for organising such a fantastic course.
- Please consider senior O&G trainees from across the region to the course.



Supporting Education for our staff

UK Maternal Cardiology Society

Melanie Menzies, ACHD CNS, Manchester University NHS FT
'UK Maternity Cardiology Society Annual Conference 2024'

On Wednesday 20th November 2024 I attended the UK Maternal Cardiology Society (UKMCS) annual conference in Birmingham. This was made possible by the support of the North West CHD Network who funded my place at the conference as well as my travel costs to and from Birmingham.

Part of my role as an ACHD clinical nurse specialist involves supporting the Joint Obstetric Cardiac clinic at St Mary's Hospital in Manchester. This is a clinic where patient's with any kind of cardiac diagnosis, who are pregnant or considering pregnancy, can be reviewed by an Obstetrician and a Cardiologist. Many of the patients who attend have CHD.

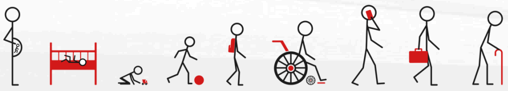
This was my first opportunity to attend any maternal cardiology specific training since joining the team over 2 years ago. I thoroughly enjoyed the day and listened to various, interesting presentations including case studies and hot topics related to maternal cardiology. I learnt a lot, and will be able to use my new knowledge in practice.

BRITISH SOCIETY FOR HEART FAILURE

Lorraine English, ACHD Nurse,
Liverpool Heart & Chest Hospital NHS FT
'British Society Heart Failure Annual Meeting'

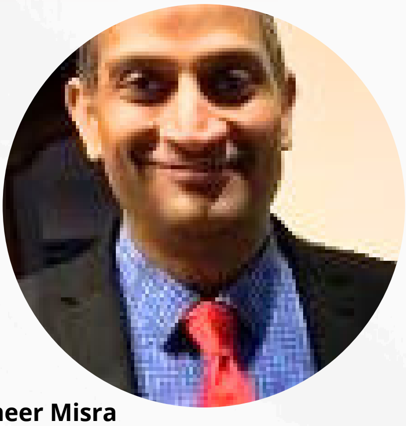
Many thanks for the opportunity to attend, this was a great event organised by leading experts and well attended by a passionate audience. It provided not only the latest guidelines but also time to debate and explore the nuances surrounding complex increasing progressive disease management in the context of a financially constrained NHS.

On a personal level I felt privileged to attend in person to see the high level of leadership displayed by members of the BSH and to witness first hand a Northwest colleague receive a nomination for the prestigious Lynda Blue Award and a former patient deliver a fantastic talk on her journey and how the support she received from healthcare professionals has spurred her to become an advocate.



PECs
(Paediatricians with Expertise in Cardiology)

Meet our CHAIRS



Dr Sameer Misra
Consultant Paediatrician and Lead for Paediatric Cardiology
Bolton NHS Foundation Trust
Associate Postgraduate Dean
NHS England Workforce Training and Education

Dr Sameer Misra is a general paediatrician with paediatric cardiology expertise at Royal Bolton Hospital, he is a member of the national Paediatricians with expertise in cardiology special interest group (PECSIG). He has been in post since 2010 and completed his training in the Mersey region which included cardiology and PICU placements at Alder Hey.

Dr Harriet Riggs,
Paediatric Consultant
Specialist Interest in Cardiology
Royal Oldham Hospital
Northern Care Alliance NHS Foundation Trust

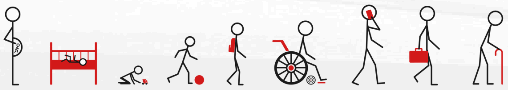
I am a Paediatrician with Expertise in Cardiology working at Royal Oldham Hospital. I completed my paediatric training in the North West Deanery in 2022, having completed a cardiology SPIN at Alder Hey.

- First consultant post in Oldham in 2022, role created to setup a level 3 paediatric cardiology service.
- I have enjoyed the challenge of setting up a service at Oldham. With the amazing support of neonatal colleagues with expertise in cardiology and my fantastic operational manager, we have been able to setup a weekly PEC clinic and provide numerous inpatient cardiology assessments.
- When taking on this role as co-chair; I discussed with Sameer whether I was the right person for the job, with only 3 years of consultant experience. He reassured me; “you will be fantastic, we need more energy, not experience”. I hope I can fulfil the brief and live up to Sameer’s kind words. I look forward to meeting you all through my role as co-chair.

SAVE THE DATE

NEXT FACE-TO-FACE PECs MEETING

Innovation Park, Liverpool



Other News

Around our region

VEIN FINDER
LIVERPOOL HEART AND CHEST HOSPITAL

“Patients feel more at ease when we use the vein finder”

The ACHD Team at Liverpool Heart and Chest Hospital were delighted to receive £5000 funding to buy a new vein finder. This was donated by the team at the Amazon fulfilment centre in Knowsley. The vein finder is a helpful tool for drawing blood, especially for patients who have trouble with their veins. I’ve found it particularly useful for patients with heart failure who have swelling in their arms and legs. It can be hard to find a vein in these cases, but the vein finder makes it easier.

Many patients feel more at ease when we use the vein finder, especially those who are nervous about getting their blood taken. A lot of them have said it’s a great new technology.

I've also noticed that healthcare assistants from other departments are borrowing our vein finder, which shows they find it useful too.

Linsha George
ACHD Nurse Specialist
Liverpool Heart and Chest Hospital NHS FT

CARE BOX
HEARTS & MINDS FOUNDATION

www.heartsandmindsfoundation.com

We’re delighted to share that the Hearts & Minds Foundation, chaired and founded by Tajinder Banwait MBE, has made a special donation to the paediatric cardiology team at Royal Manchester Children’s Hospital.

The Foundation, which supports children and young adults with congenital heart disease, launched a care box initiative earlier this year to provide thoughtful, comforting items to young patients and their families during hospital stays. The first set of boxes at RMCH brought smiles all around — including to young Elijah and his grandmother, pictured below opening their care box together.

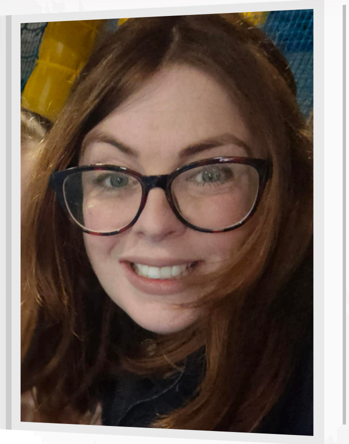
These moments bring a little light during what can be a very challenging time, and we’re so grateful to the Manchester Foundation Trust Charity for their support in helping to coordinate the donation with the clinical team.

We look forward to seeing the initiative grow across our region and continue making a positive difference to families on the ward.

Spreading a little joy!

Young Elijah and his grandmother opening their care box

Day in the life of....



> *"I can honestly say that it is an absolute privilege to work alongside the cardiac families at Alder Hey."*

DR JESS MOORE

CLINICAL PSYCHOLOGIST (CARDIOLOGY)
CLINICAL HEALTH PSYCHOLOGY
ALDER HEY CHILDREN'S HOSPITAL NHS FT

I have worked in the Clinical Health Psychology Team at Alder Hey Children's Hospital since 2017, working specifically in the cardiac team.

As a clinical psychologist within the cardiac team, my role focuses on supporting the emotional wellbeing of children and young people with congenital heart disease (CHD), as well as their families. Living with a heart condition can be challenging—not only physically, but emotionally too. From diagnosis, surgery, recovery, through to the longer-term management, each stage can bring up a range of difficulties for families to contend with. My job is to help children, and their parents/caregivers to make sense of these experiences and develop strategies to help them cope.

I work closely with the wider cardiac multi-disciplinary team (MDT), which includes cardiologists, cardiac nurse specialists, health play specialists and our complex care team. Part of my role within the MDT is ensuring that a patient's (and/or their parent/caregiver's) psychological wellbeing is considered as part of a holistic approach to their care.

I offer one-to-one work with children and young people who are experiencing a range of challenging emotions, such as: anxiety, sadness, fear, or difficulties adjusting to their condition and the limitations it might bring. Some of this work might be done as an inpatient, or on an outpatient basis. I also support those young people who are due to transition to adult services, linking them in with psychology colleagues at adult centres if needed.

For parents/caregivers, I provide space for them to reflect on the impact of having a child with CHD, such as challenges with sitting (and coping) with the uncertainty of their child's condition, making difficult decisions, or managing the demands of hospital life.

Again some of this work might be done on an inpatient, or outpatient, basis. Much of the more formal therapy I offer to parents/caregivers (for instance, trauma therapy) would be offered as an outpatient.

The parents/carers and young people I meet are incredibly resilient, with stories that are extraordinary and inspiring.

Indeed, the work I often do involves encouraging young people and their families to acknowledge the positives and strengths within their lives, helping to embolden the narrative around these in order to bolster their resilience.

I can honestly say that it is an absolute privilege to work alongside the cardiac families at Alder Hey. Witnessing the quiet strength, and remarkable resilience, of these families often leaves me in awe and with total admiration.

I look forward to continuing my work in the cardiology team and supporting more of our incredible families.

Dr Jessica Moore
Clinical Psychologist (Cardiology)
Clinical Health Psychology

Round up/looking ahead

Stronger together:
this year and beyond

As we look back over the last 12 months, the North West CHD Network is proud of the progress made across our shared priorities. We've seen strong collaboration between centres, renewed focus on levelling up services, and steady momentum on key projects that support high-quality, equitable care.

HIGHLIGHTS THIS YEAR INCLUDE........

- Securing financial support for the CHD Database for the next three years, helping ensure sustainability beyond the initial rollout.
- Finalising the design of the CHD Database, with first data flows expected in July 2025.
- Enhancing clinical governance and professional leadership through the appointment of new PEC co-chairs and ongoing engagement across all provider levels.
- Preparing for the launch of our rebranded website, designed to improve communication and accessibility for patients, families and professionals.

WHAT'S NEXT

LOOKING AHEAD TO 2025, OUR FOCUS WILL BE ON:

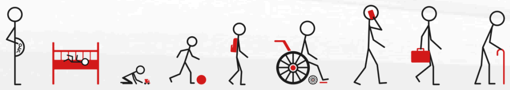
- **Rolling out the CHD database to Level 1 and 2 centres following successful pilot testing.**
- **Supporting workforce development through training, education, and shared learning events.**
- **Launching work to address gaps in level 3 paediatric cardiology provision in parts of the region.**
- **Strengthening our work with ICBs and providers to ensure that care is equitable, sustainable, and closer to home wherever possible.**
- **Laying the groundwork to extend the database to Level 3 centres, subject to future funding.**

As the new NHS 10-Year Plan places emphasis on integrated care, improved outcomes, and reducing health inequalities, we remain firmly aligned with this national direction. Our work to connect services across the region, invest in data-led improvements, and support local access to specialist care is helping to turn these ambitions into reality for the congenital heart population.

Thank you to all the teams, clinicians, patients, and families who continue to contribute to the success of the network. Your commitment and collaboration are what drive improvements in CHD care across the North West.

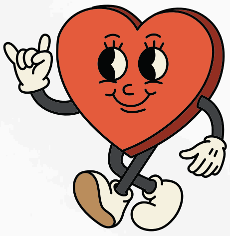
We look forward to working with you in the year ahead.

Nicola Marpole
Network Manager
NW CHD Network



Congenital HEART NETWORK

Useful Information



Congenital Heart Helplines:

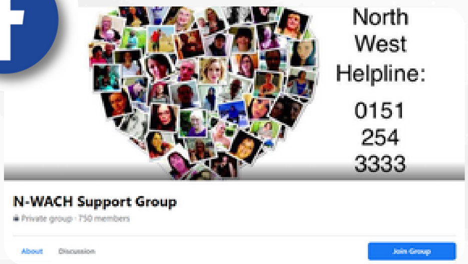
If you need any personal advice about you or your child's congenital heart problem our Congenital Heart Nurse Specialists are very skilled and experienced and able to help with any queries. Please ring and **leave a message** with the patients name and hospital/NHS number **and the Nurse Specialists 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 0151 252 5740/5418

Join the NWACH Support Group on Facebook



N-WACH Support Group
Private group · 750 members

Click here to join the Adult CHD Support Group

@NwchdN

now has 961 followers

NWCHDNetwork
@NwchdN Follows you
CHD Network - Committed to providing high quality care for everyone affected by Congenital Heart Disease in the North West of England, North Wales & Isle of Man
North West, England
northwestchdnetwork.nhs.uk
Joined May 2020
1.1K Following 822 Followers
Followed by The Heart Centre @AlderHey 💙, Dr Caroline Jone...

Pinned
NWCHDNetwork · 05/09/2023
📣 calling all parents/carers/ families affected by cardiac disease in children. Have you grown up with a congenital heart ❤️ problem

Email us at:
NorthWestCHDNetwork@alderhey.nhs.uk