



# NEWSLETTER



## FAREWELL AND 'THANK YOU' TO OUR CLINICAL DIRECTOR

In 2003, the concept of a 'joint paediatric cardiology network arrangement' between the two regional Children's Trusts evolved with the ultimate aim of achieving a 'single paediatric cardiology service' for the North-West. NHS England's Heart Disease Standards & Specifications (2016) identified that a more robust regional 'network' was required to oversee the provision of 'all age congenital heart disease' services.

The initial small group of committed individuals interested in progressing 'joint working arrangements' between two Trusts, evolved into today's CHD Network, with membership including any provider of clinical care for a patient with congenital heart disease, in addition to representatives of the families/patients themselves.

Currently, there is a single, region wide network covering the whole lifetime pathway of care including prenatal diagnosis, obstetric and neonatal services, children's services, transition, adult congenital cardiac services and palliative care. The network aims to support both providers of care and families/patients, improving patient experience and outcomes wherever possible.

The 'regional network' now forms part of a 'national CHD network collaboration' with regional groups supporting each other, sharing ideas and helping facilitate patient care between providers. The need for this 'national collaborative' overview was evident during the Covid-19 pandemic, which created significant difficulties in provision of clinical care for CHD patients and highlighted marked variations in the ability of different regions to respond to the challenges they faced.

Although many of the difficulties that confronted our 'small working group' in 2003 remain, I am encouraged that much has been achieved and I feel confident that the network structures that are in place, will continue to ensure that the 'best possible clinical care' that can be provided, is achieved for those requiring it within the region. Finally, it only remains for me to say thank you to all the colleagues, patients and their families that I have had the privilege of being associated with over the past 41 years ..... best wishes to all for the future.

### Dr Gordon Gladman



# WELCOME TO OUR NEW NETWORK CLINICAL DIRECTORS

## WELCOME ✨ to the TEAM

*We would like to welcome our two new Network Clinical Directors, Dr Caroline Jones and Dr Damien Cullington to the Network Team, taking the reins from Dr Gordon Gladman.*



**Dr Damien Cullington,**  
Consultant Adult Congenital  
Cardiologist, Liverpool Heart  
& Chest Hospital



**Dr Caroline Jones,**  
Consultant Paediatric  
Cardiologist, Alder Hey  
Children's Hospital

"We are delighted to have been appointed as co-directors for the CHD Network and would like to give thanks to Dr Gladman for his service and guidance over the last 3 years. I think there is a unique opportunity here for Dr Jones and I are to work collaboratively as the new Network co-directors to comprehensively help address the needs of patients of the whole spectrum of congenital heart disease in the North West, North Wales and the Isle of Man.

We are actively working on our new 3 year Network strategy and themes for education and will unveil these in the New Year.

On a final note, we would like to wish you and your families and friends a happy, peaceful and restful holiday period. Christmas can sometimes be a difficult time of year for many reasons. As the late, great adult congenital cardiologist Gary Webb said: **'Be good to yourself and be good to others'** this holiday season."

## FOREWORD FROM OUR BOARD CHAIR

I have had the privilege of chairing the North West Congenital Heart Disease Network Board for over four years. During this time, in parallel, the ACHD Partnership Board, established in 2019, has been functioning in the North-West. Recently, on reviewing the current governance arrangements and the terms of reference for the ACHD Partnership Board and the CHD Network Board, it has been recognised that, over time, the remit of the two groups has become interlinked and in many areas there is duplication and repetition. It made much more sense to bring the two Boards together into a single Board to improve efficiency and effectiveness of the governance of the operation and delivery of the CHD service across the North-West.

This proposal was put to the two Boards, supported by NHSE Commissioning, and was unanimously approved. Therefore, a new Board has been established with membership including lead clinicians representing the sites involved as well as senior decision makers, collectively providing clear direction and leadership for the NWCHD ODN and their function within the North-West of England, North Wales and the Isle of Man. We have just had our second meeting which was most productive and successful.

I wish to warmly welcome all our new members and thank the members who have left us. In particular, I would like to thank Dr Gordon Gladman for his tremendous hard work in directing the CHD Board over the years and the support he gave me. At our last meeting all the members of the Board entirely agreed with my sentiments and they wish to convey thanks to Gordon and wish him all the best in his retirement. Similarly, I and the Board members thank Helen Sanderson for her sterling work for the CHD Network and wish her all the best for the future.

**Nayyar Naqvi OBE**



**Dr Nayyar Naqvi, Emeritus  
Consultant Cardiologist &  
current Chair of the NWCHD  
ODN Board**



# MEET THE NETWORK TEAM



**Nicola Marpole**  
Network Manager



**Linda Griffiths**  
Lead Nurse



**Michelle McLaren**  
Lead Nurse for Education,  
Training & Research

*Michelle joined the team in August and also works part-time as a Paediatric Cardiac Nurse Specialist at Alder Hey.*



**Gail Maguire**  
Project Manager

*Gail joined the team in April from North West Ambulance NHS Foundation Trust*



**Elizabeth Devonport**  
Data Analyst

*Liz joined the team in September. Previously a Clinical Research Manager at Aintree Hospital & Liverpool University for 8 years, researching outcomes of chronic disease specifically COPD, other respiratory disease, Renal & Gastro.*



**Jill Moran**  
Network Support Officer



## FAREWELL TO HELEN SANDERSON



**Helen Sanderson**

*I have been fortunate to be the network manager for almost 10 years. I have seen so many amazing changes, improvements, and impressive staff over the last decade. I would like to take this opportunity to say 'thank you' to you all, for all the support and dedication you have given to the network, to CHD services and most importantly to the patients, their families, and carers.*







## NW PECSIG GROUP

(Paediatricians with expertise in  
cardiology special interest group)



**Dr Sameer Misra**



**Dr Liz Shackley**

2023 welcomed two new Chairs to the NW PECSIG Group, Dr Sameer Misra, Director of Medical Education Consultant Paediatrician and Lead for Cardiology, Bolton NHS FT and Dr Elizabeth Shackley, Consultant Paediatrician, Stockport NHS FT.

We are delighted to join the Board and look forward to working together to improve heart health for babies and children and young people. PECSIG is society of UK medical professionals with expertise in caring for Children with heart disease. We are Consultant or Specialist Paediatricians, regulated by the General Medical Council and members of the Royal College of Paediatrics and Child Health. We have additional specialist experience in Children with heart disease and work closely with our specialist centres at Alder Hey and Royal Manchester Children's hospital.

Our vision is for families with congenital heart disease to have the right care at the right time and the right place with robust information sharing and transition arrangements between hospitals and healthcare professionals. We would also like to develop the education and training activities of the board.



## TO OUR NETWORK MANAGER NICOLA MARPOLE

The ODN is currently in a very exciting position, with the recent addition of three new members the team is moving ahead at full steam. The networks project manager is overseeing the development of the all-age regional database, the monthly data submissions will be receiving a much needed overhaul in the coming months by the data analyst and the new lead nurse for education, training and research has picked up the reigns from Linda Griffiths, who is now concentrating on quality improvement, and is continuing to grow and deliver the networks development programme.

Together with the ongoing work of the quality improvement lead nurse, who has successfully delivered a network wide clinical governance programme, adult and paediatric patient experience surveys and two very successful staff and patient experience days, as well as the continued development of the network website, production of the annual report and newsletter and coordination of network events by the network support officer, the network has had a very busy and productive year!

Moving into 2024 the ODN workplan is just as jam packed with ongoing and new projects, all aimed at bringing providers together to ensure that everyone has access to high quality, evidenced-based care, and that everyone is dedicated to reducing inequality and improving patient experience and outcomes. I am very happy to be returning to the role of network manager and I'm looking forward to working with the two new clinical directors to support the network in achieving its goals in the new year.

I'd also like to take this opportunity to say a huge thank you to Helen Sanderson, who has done a fantastic job over the last ten years growing, nurturing and developing the network into what it is today. Thank you Helen, on behalf of the network team I'd like to wish you all the very best for the future, you will be missed!



# PATIENT AND PUBLIC VOICE GROUP (PPV)

**Janet Rathburn**  
Chair of  
PPV Group

The PPV group continues to work with and support the network. Our regular monthly meetings provide us with the opportunity to get to grips with any issues raised and are also a useful source of information.

We have met virtually with our new lead nurse for education, training & research and project manager and listened with interest to them describing their new roles.

**Marriott Hotel, Liverpool**  
**9th September 2023**

**First Face to Face meeting since Covid!**



Meeting though TEAMS has been really helpful since our representatives are scattered across the region. It was however, really nice to have a face to face meeting in Liverpool in September with all but two delegates able to attend. It was also a wonderful opportunity to say thank you to Doctor Gordon Gladman, as he approached retirement, to say thank you to him for his many years of dedicated service to children and families in the North West, North Wales and the Isle of Man. We wish him a long and happy retirement.

We are very grateful to the medical professionals who give up their time to give us updates at our meetings. Helen Chadwick our NHS Commissioner gave us a particularly useful presentation at our September meeting.



We have advertised the role of the PPV representative across the network. We are actively encouraging new members to join us. We are in the process of designing roller banners about the PPV group to have on display in clinics.

We have been looking at how charities can work together with our hospitals to better support patients and families. We have two charities represented on the PPV group, The Children's Heart Association and Team 1C. Together they have provided emergency supplies packs, sanitary products and surgical bras on request. Emergency funds and shopping vouchers have also been provided. We are also looking at producing roller banners to display information about local charities providing support to CHD services across the network.

Over the year we have invited various specialists, clinicians and commissioners who have provided regular updates to the PPV group on network issues, progress and service developments.

Our group remains committed to ensuring that all patients receive the best possible treatment in a positive and timely way.

**Janet Rathburn**  
**Chair - PPV Group**





## Patient Information Day Liverpool 9th September 2023

Another memorable event was our Patient Information Day on 14th October again in Liverpool. Huge thanks to Linda Griffiths, Lead Nurse, NW CHD ODN for organising the day which ran very smoothly. With excellent presentations covering a range of issues affecting patients of all ages. Those delegates that attended found it extremely useful and we had several emotional responses. It was also another opportunity to say thank you to Dr Gordon Gladman at his last public, official event, with a presentation was made to him on behalf of patients and families. A useful outcome from the day was four delegates expressing interest at becoming PPV representatives.



## Young Person's Outdoor Event 10th September 2023

Thank you to the Somerville Heart Foundation for sponsoring the fantastic outdoors event for our young CHD patients and their families. It was an excellent opportunity to meet people their own age and to chat with our CHD Link Nurses 'one to one'. Also a big 'Thank you' to the staff and instructors at Outdoor Elements near Bolton for organising the brilliant activities. We will definitely be back!



*Great day out!*

sponsored by

**Somerville  
Heart  
Foundation**



*Some very talented archers!*



*Practicing our balancing skills*

# NETWORK EVENTS

In collaboration with Tiny Tickers the Network are proud to support 10 songographer training days



We were pleased to have an excellent turn out for our first North West fetal cardiology 'hands on' sonographer update day held at Liverpool Women's Hospital on 11th November 2023.

We had a great day of interactive learning attended by Sonographers from all over the North West.



## Hands-on Sonographers Training for Fetal Cardiac Anomaly

sponsored by



GE Healthcare

Liverpool Women's Hospital

11th November 2023



*"Excellent day with lots of relevant information provided. Found the hands on very useful. Enjoyed the presentations. Well organised. Thank you!"*

*"Very informative and excellent recap on the fetal heart."*

*"Great day, each section ran smoothly and was very informative."*

*"Worth the session and time taken out."*



## ACHD (Adult Congenital Heart Disease) Study Day for Cardiac Nurses & AHPs Marriott Hotel, Liverpool 30th June 2023

Excellent day of education and networking, the programme included:

Introduction to  
simple &  
complex defects

Endocarditis  
cyanosis,  
arrhythmias heart  
failure

Patient stories,  
practical  
applications

A Paediatric CHD Study Day for nurses & AHPs is planned for **25th April April 2024**, further information to be released shortly. If you have any questions, please contact [michelle.mclaren@alderhey.nhs.uk](mailto:michelle.mclaren@alderhey.nhs.uk)

**SAVE  
THE DATE**





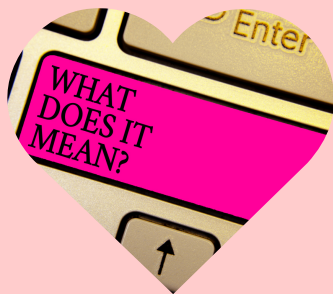
## All-age Database Project



MINDWAVE

The Network has been working hard during 2023 to ensure that our aim of having an all-age database for our region becomes reality. This project has been partly funded by NHSE (NHS England) and the Network.

It is challenging to understand the total number of patients being cared for within the Network due to each hospital using different patient administration systems (PAS). Some providers have multiple lists within their own PAS system for different elements of the service. Patients can often be on multiple lists, with duplication of appointments in different hospitals and clinics across the Network. This may result in inappropriate use of limited specialist resources creating less capacity to deal with increasing backlogs. This complexity of the system and lack of oversight across the region presents a risk of patients becoming lost to follow-up and care not always being delivered as close to home as possible.



**The aim of the database is to:-**

- understand the exact number of patients with paediatric cardiac conditions and adult congenital heart disease within the North West, North Wales and the Isle of Man
- Be able to see the full range of conditions that these patients have in order to better understand what resources we need so that we can provide the right care, by the right people as close to home as possible.

**We have been working with a company called Mindwave who have a strong track record of working with NHS providers. We are hoping to have phase 1 live next year in 2024.**

### Level 1

#### Specialist Children's Surgical Centre

Alder Hey Children's NHS Foundation Trust

### Level 1

#### Specialist ACHD Surgical Centre

Liverpool Heart & Chest NHS Foundation Trust  
Liverpool University Hospital NHS Foundation Trust

### Level 2

#### Specialist Children's Cardiology Centre

Manchester University NHS Foundation Trust (RMCH)

### Level 2

#### Specialist ACHD Cardiology Centre

Manchester University NHS Foundation Trust (MRI)

### Level 3

#### Local Children's and ACHD Cardiology Centres

Wirral University Teaching Hospital Foundation Trust (Arrowe Park Hospital) / Manchester University NHS Foundation Trust (Wythenshawe Hospital) Warrington, Wigan & Leigh NHS Foundation Trust (Royal Albert Edward Infirmary) / Betsi Cadwaladr University Health Board (Wrexham Maelor, Glan Clwyd & Bangor Ysbyty Gwynedd Hospitals) / Mersey and West Lancashire Teaching Hospitals NHS Trust (Whiston Hospital) / Warrington & Halton Teaching Hospitals NHS Foundation Trust (Warrington Hospital) / Northern Care Alliance NHS Foundation Trust (Rochdale & Royal Oldham Hospitals) / Lancashire Teaching Hospitals NHS Foundation Trust (Royal Preston Hospital) / Stockport NHS Foundation Trust (Stepping Hill Hospital) / Mid Cheshire NHS Foundation Trust (Leighton Hospital) / The University Hospital of Morecambe Bay NHS Foundation Trust (Royal Lancaster Infirmary) / Nobles Hospital, Isle of Man / Countess of Chester NHS Foundation Trust (Countess of Chester Hospital) / East Lancashire Hospitals NHS Trust (Burnley General Teaching Hospital & Royal Blackburn Teaching Hospital) / Bolton NHS Foundation Trust (The Royal Bolton Hospital) / Blackpool Teaching Hospitals NHS Foundation Trust (Blackpool Victoria and Furness General Hospitals) / Hywel Dda University Health Board (Bronglais Hospital)

*Thank you!*

**Thank you to our Project Manager, Gail Maguire and Data Analyst, Liz Devonport for their dedication and hard work in progressing the Network Database to where it is today.**





## OTHER NEWS



### JAKOB'S SPECIAL APPOINTMENT

Our very own, Dr Caroline Jones, featured in a BBC Newsround article recently which was presented by one of her young patients 'Jakob'. [CLICK HERE](#) to watch the video clip.

## WELCOME

### NEW TEAM MEMBERS

#### ALDER HEY

##### CONSULTANTS

Eapen Thomas  
Sophia Khan  
Daniel McLennan  
Tommaso Generali

##### PECSIGs

Rachel Tan  
Vayyeti Narayana

#### LIVERPOOL HEART & CHEST

##### CONSULTANTS

Sarah Elgamal  
Julia Jones

#### ROYAL MANCHESTER CHILDREN'S

##### CONSULTANTS

Paulo Santos  
Nedezhda Dzhelepova

##### PAEDIATRIC CARDIAC SPECIALIST NURSE

Maria Hollingsworth

## NETWORK PATIENT SURVEY



### North West Congenital Heart Disease Patient Survey

**THANK YOU!**

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

**CLICK HERE**

**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

**Scan the QR code  
or  
[Click Here](#)**

# Congratulations!



A **paediatric first**, life enhancing, **clinically validated** remote monitoring platform. **Connecting** congenital heart patients in the community with their clinical teams. **Reducing** time in hospital and anxiety for families, through **data driven personalised care**.

We have successfully deployed the platform in Alder Hey Children's Foundation Trust across the Congenital Heart Disease Network, onboarding over 300 Community Nurses across 29 regional teams that cover Alder Hey patients in the NW England, North Wales and Isle of Man.





Email us at:

**NorthWestCHDNetwork@alderhey.nhs.uk**

**Join the NWACH Support Group  
on Facebook**



**@NwchdN  
now has 822  
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 0151 252 5740/5418

