

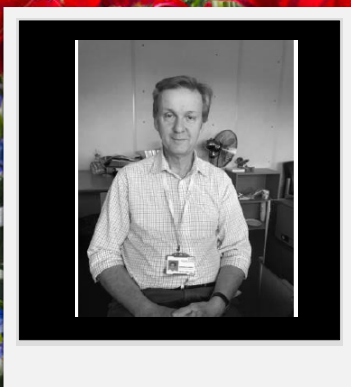
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**SUMMER 2021**  
**ISSUE 2**





## Clinical Director's Introduction

### Welcome to our summer 2021 edition of the North West Congenital Heart Disease Network newsletter!



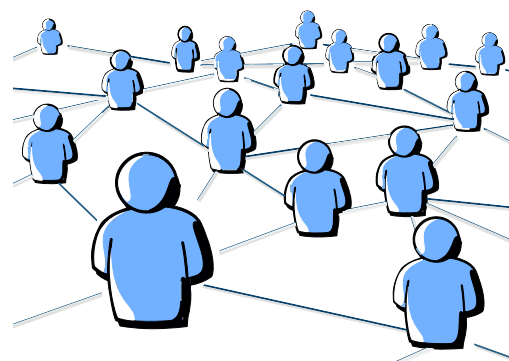
For those unfamiliar with our group, we are an 'all age' network covering the Northwest, North Wales and the Isle of Man. Hospitals within this region that provide care for those born with congenital heart disease (CHD) come under our network umbrella. The network is part of a national group of congenital heart networks that work together to provide the best care for patients and their families.

The past year to eighteen months has provided unique challenges to patients, families and providers of health care given the massive impact of coronavirus. However, I remain impressed by the commitment of all involved to work together to strive to maintain a safe and effective service.

Hopefully as we emerge from the pandemic, life will become 'more normal', though I'm sure the impact of the virus will continue to be present for the foreseeable future. Thanks to all those involved in continuing to provide on-going care and to the patients/families for their patience and understanding at a difficult time.

Finally, thanks also to those involved in putting together this newsletter, I hope you find it interesting to read.

We are a network that covers the Northwest, North Wales and the Isle of Man. Hospitals within this region that provide care for those with congenital heart disease come under our network umbrella. The network is also part of a national group of congenital heart networks that work together to provide the best care.

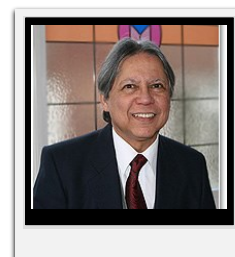


**Gordon Gladman**

Meet the  
Team



Gordon Gladman, Clinical Director



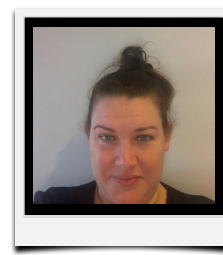
Nayyar Naqvi, Network Board Chair



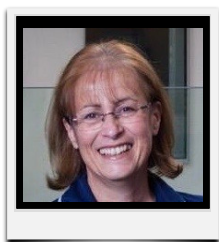
Dr Caroline B Jones  
Consultant Paediatric Cardiologist



Dr Damien Cullington  
Consultant Adult Cardiologist



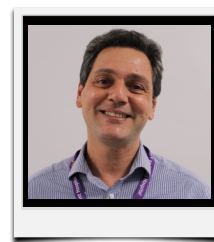
Helen Sanderson  
Network Manager



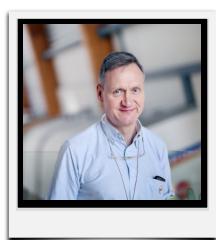
Linda Griffiths  
Lead Nurse



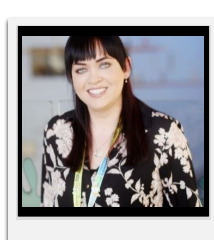
Sarah Ellison  
Primary Care CHD Project Lead



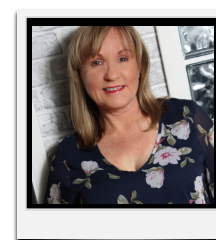
Vas Papaioannou  
Network Governance Lead



Rob Johnson  
Network Governance Lead



Jemma Blake  
Data Manager



Jill Moran  
Network Support Officer



Kenny Ward  
Project Manager



Dan Short  
Project Manager



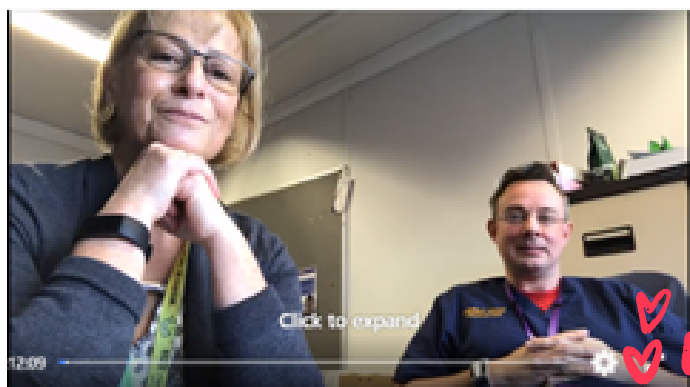
## COVID-19 CHD Support



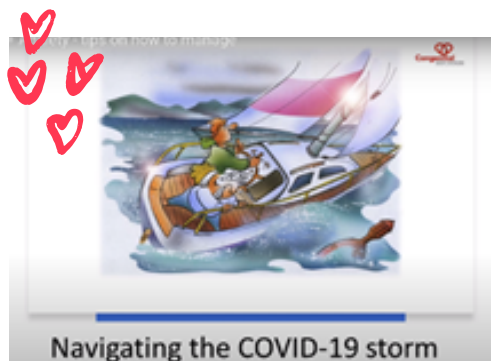
**Working together  
to stay safe**

This past year has been exceptional for individuals, for staff working in the NHS and for patients and families affected by congenital heart disease. Services have had to think differently as to how best to deliver care safely and to tackle the backlogs that have arisen as a result.

Paediatric cardiac surgery and interventional procedures have continued throughout the pandemic and the North West is in an enviable position of seeing their waiting lists fall during this time. Adult services were affected more significantly due to the pressures on adult intensive care during the peaks of the coronavirus outbreaks over the past year. They have always been able to provide emergency care throughout and have now increased the number of days that operations are being performed in order to manage the waiting list effectively. The pandemic has seen teams work closely together to provide mutual aid to each other to provide the best care for patients across our region. Staff have been working at weekends and evenings and as a Network we are immensely grateful for everyone's hard work and focus during this difficult time.



**Linda Griffiths, Lead Nurse (NWCHDN) &  
Dr Damien Cullington (LHCH) talking to  
NWACH patient support group**



**Navigating the COVID-19 storm  
Managing anxiety by Dr Emma Twigg,  
Consultant Clinical Psychologist**

There has been an inevitable backlog of patients waiting to be seen in clinic as in all other services in the NHS during this time. Where it has been safe to do so clinics have been held virtually or via a telephone consultation avoiding the need to cancel appointments. Patients who are waiting to be seen in clinic have been reviewed by a Consultant Cardiologist who has decided whether it is ok to delay an appointment for a given period. The Cardiac Nurse Specialists have been available throughout to deal with any clinical queries that patients and families may have, and the secretaries have worked throughout to help with queries about appointments.



**Visit our COVID-19 webpage  
for advice & further useful  
resources**



The **Operational Delivery Network (ODN)** has and continues to focus on attaining a robust, highly functioning and effective governance structure. Aiming to ensure that the Network runs efficiently and effectively, while remaining open and accountable to the patients, and Network members. The Network board is at the heart of the governance structure, ensuring quality is at the core of the CHD Network. Quality, and by that we mean patient safety, effectiveness of care and patient experience is at the heart of all NHS work.

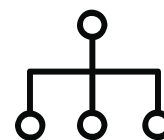


The Network board drives quality by governing effectively and in doing so building public and stakeholder confidence in the CHD service. Ensuring the Network is doing the right things, in the right way, for the right people in a timely, inclusive, open, honest and accountable manner.

The proposed governance structure continues to be debated to ensure that the board and the Network can provide strategic direction but also deliver its comprehensive work plan in the middle of a global pandemic. The resources of the NHS have been continually stretched over the last 15 months as individuals, services and organisations have worked tirelessly to support their communities, patients and colleagues.

## NW CHDN Governance Structure

By streamlining the Network governance structure, the function of the Network continues at the highest possible level, whilst simultaneously maintaining patient care as a priority.



## Maturity Matrix

The Network underwent an annual self-assessment on its maturity in May 2021. A small group including the Network Clinical director, manager and lead nurse was joined by PPV reps, commissioner and host senior manager. The purpose was to evaluate the network's progress against a set of nationally determined indices. The group analysed the network's progress and determined two high level priority areas for the Network over the next 12 months.

### Purpose & Direction

Current Level = 2/3

Target level = 3 (end March 2022)

#### Target level description

The network has an agreed charter, clearly stating purpose, scope, and ways of working. Most members have a good understanding of the purpose of the network and could articulate it to others. There is an agreed plan for developing the network for the next year.

- > Network to produce operation Framework
- > Network to produce regular newsletters (3 times a year)
- > Network to communicate structure and scope to all network members, by sharing appropriate documents via email, website and utilising twitter
- > Network to develop a communication and engagement strategy

Review Date: November 2021

### Governance & Structure

Current Level = 3-2

Target Level = 4 (End March 2022)

#### Target Level Description

Network membership is well rounded, with actions in place to fill any gaps. Relationships with other networks are clear. They work to share and learn beyond the boundaries and with external stakeholders wherever appropriate. Governance is fully effective and is valued. Healthy membership turnover - few 'passengers'.

#### Actions

- > Network to streamline governance, with a well-defined structure, membership and the ability for decisions to be actioned without going to further boards or groups.
- > Network groups to be able to affect change
- > Governance structure well defined in Network operational policy/ framework
- > The Network will hold members to account for attendance and their responsibilities.
- > Network engagement outside of network detailed in operational framework

Review Date: November 2021

## National Standards & Audit

The [CHD National Standards](#) published by NHS England in 2016, are intended to ensure that people with congenital heart disease receive care of consistently high quality that is sustainable for the future. They provide a specialist a framework for people and their families affected with congenital heart disease to receive effective assessment, treatment and person-centred care. The standards encompass the whole pathway for CHD patients including fetal, paediatric and adult services, and includes specifications for level 1, level 2 and level 3 centres.

The establishment of CHD networks to cover different geographic boundaries across the country was also a key component of the CHD standards.

The Self-Assessment of CHD Standards is a process led by CHD networks with the centres within its boundaries. The purpose of the self-assessment process is to understand how centres are delivering the standards. It offers the opportunity for CHD providers to highlight areas that are working well, escalate any gaps or concerns, and request any support from the Network.

The Network is currently working with the South West & South Wales CHD ODN to develop a National Standards Audit Strategy and process to assess the Welsh centres against the National Standards. The aim of the project would be to then extend the self-assessments out to all other providers within our Network area.

## All Age Database Project



We are currently creating a project and change solution to introduce a centralised all age database for the CHD network. We have two stakeholder groups set up, a leadership group and an operational group to complete work packages including currently analysing base line requirements and their impact. This is technology and a new culture that does not currently exist so when completed will have a huge positive impact on how some of our healthcare data is recorded and then reported on."



## Network Data & KPIs

The Network is currently providing a number of Key Performance Indicators or KPI's. These KPI's along with the current and proposed data being collected by the Network will be key in;

- Measuring and monitoring the impact of COVID-19 on CHD services
- Provide key information for winter planning
- Provide national update requests
- Allow the Network to measure regional performance against priorities
- Enable the CHD network board to identify trends and make targeted improvements

## Associated Groups



**Database Stakeholder Leadership Group**



**Database Project Operational Group**

Kenny Ward, Project Manager, NW CHD Network



"Very often GP surgeries are a first point of contact for many patients with congenital heart disease (CHD). The doctors and surgery staff are in a great position to support patients and help spot problems early and signpost to the most appropriate services.

The Primary Care CHD project is working with local surgery staff to help support the creation registers of patients, both children and adults with CHD. Many other long term conditions are identified in surgeries by registers and creating one for CHD is relatively easy to do using read-codes P5, P6 & P7. The benefit of this is that it enables identification of all the patients with CHD. As the numbers are still relatively small those that may have become "lost to follow up" care over the years can be identified and signposted to the most appropriate services. It also allows for understanding of current prevalence and supports future forecasts for service provision."

**Sarah Ellison, Primary Care CHD Project Lead, NW CHD Network**

### Next Steps

Our next steps are to collate results from the survey and act on the findings. Present this work to local and national forums and patient groups. Further develop local pathways to support creation of CHD registers for patients, both children and adults. Create a Primary care section to our website with all the pathways included.



## What's happening in Primary Care

### Primary Care Survey 2021

We have just completed a North West Primary care survey to identify current understanding and awareness of our local CHD services especially adult provision. The survey also aims to discover any training or education requirements. Most importantly we have engaged with our North West Primary Care colleagues to help inform and support the future provision of CHD services in our area.

## Network Documents

**New document available on our website:**

- **Paediatric Cardiology Outpatient Referral Guideline**

[Go to website](#)

**Visit our [Resources](#) Page**

**Linsha George**  
**ACHD Nurse Specialist**  
**Liverpool Heart & Chest Hospital NHS Foundation Trust**

**New  
Members  
of Staff**



Linsha graduated as a Nurse and Midwife in 2010 (MG university, Kerala) and completed her master's in Medical Surgical Nursing (accredited Level 7 Masters equivalent) specialised in Cardiothoracic and Vascular Nursing in 2015 (JIPMER, Puducherry) from India.

Working in medical ICU, surgical wards, neonatal ICU, post-caesarean ward and Cardiac Critical care unit from different hospitals in India, Linsha has gained much clinical experience. Joining Liverpool Heart and Chest hospital (LHCH) in 2017 as a Cath Lab Nurse where she developed her specialist cardiac nursing skills. From 2019 to 2021, Linsha worked as a research nurse at LHCH leading and supporting several commercial and portfolio studies, and is excited about her current role as ACHD specialist nurse which is very challenging with lots of learning opportunities. Linsha said "I am thrilled to be part of the wonderful team of ACHD nurses who always go above and beyond and deliver excellent patient care."

Linsha lives with her husband; the rest of her family being back in India. Her hobbies include listening to music, reading and watching movies.

**Little Hearts  
at Home App**

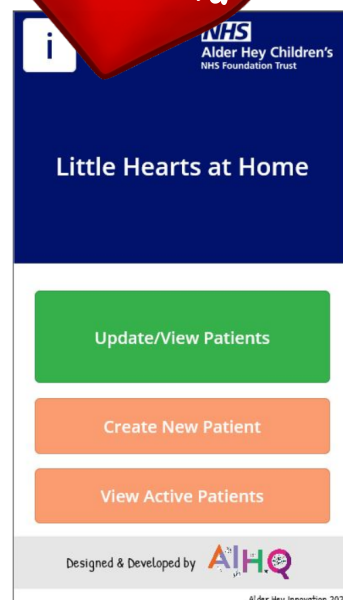
**Alder Hey Heart Centre in collaboration  
with the Alder Hey Innovation Team,  
are set to launch the first Home Monitoring Power  
App for CHD Single Ventricle Patients called  
'Little Hearts' at Home.**

Home monitoring technology, allows a Community Nurse to use a mobile device to perform routine tests and upload / send test results to the Level 1 paediatric specialised Congenital Heart Centre, (Alder Hey Children's NHS Foundation Trust) in real-time without the necessity of visiting a Medical Centre. Live data will be closely monitored via Power BI Dashboards by the Senior Cardiac Nurse Specialist Team.

All single ventricle patients will be individually assessed for home monitoring with their own unique thresholds. Patients who exceed their threshold will be automatically flagged via traffic light system to professionals who can consult appropriate care.

- Allows sending patient data to professionals in real time
- Allows Level 1 centre close monitoring of very complex specialised patients with a traffic light system
- Improves patients lifestyle and overall outcome
- Could reduce emergent situations and hospital re-admissions
- Increases patient accountability
- Improves patient centre care and experience
- Improves patient outcomes

**Coming Soon!**  
**August 2nd**



**Dr Phuoc Duong- Consultant Paediatric Cardiologist**  
**Helen Walker- Cardiac Nurse Specialist Lead**  
**Jemma Blake - Data Manager**



## Happy Retirement

Network Manager, Denise Szpunar retired from the Network in April 2021.

Denise was instrumental in developing the Network, she worked hard for the last 7 years to get us to where we are today, and we are very fortunate to have had her as part of our network family. We wish Denise the very best and will miss her very much.



Network  
News

## Good Luck & Thank You!



**Happy Retirement Dr Peart  
the "Miracle Man"**

Tributes, Good Luck and Thank You messages are being received from many patients, families and colleagues for Consultant Paediatric Interventional Cardiologist, Dr Ian Peart's imminent retirement. Dr Peart has been described by one family as the "Miracle Man" for eternity!

An official retirement date hasn't been set yet as Dr Peart, being the kind hearted person he is, has kindly agreed to stay on for a few months longer to help out. On behalf of all your colleagues & friends within the Network, we wish you 'Good Luck'!

## Bake Off Entry

Well done to our Network Support Officer, Jill Moran for her fabulous entry to the Alder Hey 'Bake Off' competition. Jill didn't win but received some fabulous comments on our Twitter feed.



## Going Above & Beyond

Congratulations to Gill McBurney, Fetal Cardiac Nurse Specialist, who was acknowledge recently on 'Tiny Tickers' Twitter for the amazing volunteer work she does for the charity. Well done Gill! If you would like to learn more about volunteering for 'Tiny Tickers' [click here](#) to find out more.

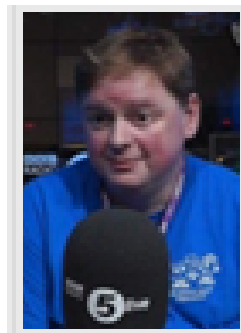


@tinytickers - Jun 5  
... is another of our valued volunteers ...  
... ring with us last year, proof-reading our materials ...  
... ss. It is thanks to Gill that we've been able to deliver ...  
... webinars to health professionals ...  
... nteersweek



**Patient & Public  
Voice Group  
(PPV)**

## This is probably not what you were expecting in a Patient and Public Voice Group



**Paul Willgoss**  
PPV Member

### What is a Patient and Public Voice (PPV) Group?

written by Paul Willgoss, PPV Group Member

We are a group of individuals bound together by a passionate commitment to improve the service we rely on for all children, teenagers and adults with congenital heart defects in the North West, North Wales and the Isle of Man.

The concept of parent and increasingly patient involvement in the development of congenital heart services in the UK has been pushed for many decades by passionate committed people. They were hoping that the mix of lived experience and passion would help drive systemic improvement. They were correct and the North West Network PPV Group adds a couple of extra elements. We are bound together by that passion, that commitment and the shared experience of the highs and deepest lows of the congenital heart world.

#### Experience

The first of the extras we bring is experience; approaching 300 years of combined lived experience. Experience of contributing to the NHS and experience of working with families and adults. Experience of being the listening ear and the shoulder for tears to fall on. Experience of helping to write the congenital heart disease NHS England standards (2016) that define our care. Experience of working with commissioners and challenging the services we rely on to be the best they can be.

#### Professional Skills

The second of the extras is our professional skill sets; collectively we are skilled with numbers, words, communications, IT, working with communities, running businesses and charities.

We don't leave those skills at the door when we are working as part of the PPV Group. Some of our members have written articles for journals, are government scientists, nurses, pharmacists and yes even a man of the cloth.

We are bound together and whilst we may disagree with each other we always respect each other's opinion. We are experienced and committed to challenge the Network and providers and will not stop doing so until the congenital heart service in our region is providing a world class service for all ages.



## Are you interested in joining the PPV Group?

The Network Patient and Public Voice (PPV) Group has been meeting regularly since May 2020. The meetings are held via Microsoft Teams so you can attend from the comfort of your own home. The PPV Group play a very important part in our Network and ensure that the patient is at the centre of the services we deliver. They are working in partnership with the Network to help improve services. The most important skill that you bring is the lived experience of a lifetime of congenital heart disease. Everyone is welcome and everyone has something to bring to the table. We especially want to welcome people with a mixed ethnic background.

Please see the advert on page 10 for more information about what is involved in becoming a PPV Member. If you are interesting in joining, contact our Lead Nurse Linda Griffiths via email [northwestchdnetwork@alderhey.nhs.uk](mailto:northwestchdnetwork@alderhey.nhs.uk) for more information.



## Patient & Public Voice Group (PPV)

## Meet some members of the PPV Group



**Are you interested in helping us to  
improve services for people with  
congenital heart disease?**

*Consider joining the North West, North Wales and Isle of  
Man Congenital Heart Disease Network as a Patient and  
Public Voice Representative*

### Who Should apply?

Parents who have a child with congenital  
heart disease  
Adult patients living with congenital heart  
disease  
Patients/parents/carers of someone living  
with a learning disability  
We are looking for people from a  
diverse background to join us

### What can you expect?

Regular meetings  
Support  
Training  
Join a working group  
Make new friends  
Attend Board meetings to represent  
patient/parent views

### If you want to know more?

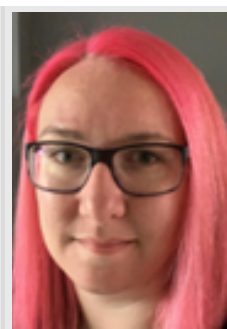
Email: [northwestchdnetwork@alderhey.nhs.uk](mailto:northwestchdnetwork@alderhey.nhs.uk)  
Website:  
[www.northwestchdnetwork.nhs.uk](http://www.northwestchdnetwork.nhs.uk)  
CHD Helplines:  
Adult: 0151 254 3333

### Influence change

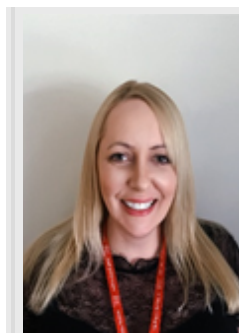
Have you got any ideas of  
what might improve the  
care we  
provide?  
Consider joining us!



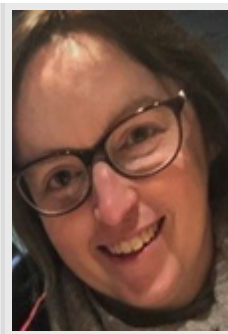
**Janet Rathburn  
Chair**



**Debbie Rigby  
PPV Member**



**Claire Cathcart  
PPV Member**



**Lowri Smith  
PPV Member**



[Click here](#) to view on our website



The group  
currently meets  
every two weeks  
via MS Teams

## Meet our CHD Link Nurses

## Paediatric Cardiac Link Nurses, Ward 85, Royal Manchester Children's Hospital



The Network has been busy developing Paediatric and ACHD Link Nurse Forums this year. Nurses from across the North West, North Wales and the Isle of Man have been invited to participate and we now have over 30 paediatric nurses from specialist CHD Centres, district general hospitals and primary care who are meeting regularly every 6-8 weeks. The ACHD Link Nurse Forum has just started in June as well. Both Forums are growing rapidly, and we are looking forward to them becoming truly representative of our large all age network. The link nurse will be given an opportunity to learn and develop new knowledge and skills with the aid of CHD link nurse competencies and a programme of mentorship. As we develop the knowledge and skills of a much wider workforce, patients should expect to see an improvement in the expert care that is delivered closer to home. With everyone working together towards common pathways and ways of working.



### What's our Role?



Ward 85 is a children's ward that treats patients with cardiac conditions. As the link nurses we act as a bridge between specialist practitioners and ward level staff. As part of the role, we attend study days and dedicated link nurse meetings to gain knowledge into new policies, treatments, and transfer guidance as we transfer many children to Alder Hey and other specialist centres for surgery.

In order to educate staff further, we do ward based teaching. A dedicated cardiac week was recently held, in which the specialist nurses attended the ward to do specific teaching on normal and abnormal heart structures, common conditions and medications and various treatment and surgeries that are performed. We have created posters to display in our oral medication room outlining which cardiac drugs can and cannot be given together.

Furthermore, as link nurses we each had a dedicated day with the cardiac specialist nurses where we have gained insight into their role and then liaised with them to gather expectations of nurses looking after cardiac patients. This has included information such as making sure daily weights are recorded ready for ward round and the importance of strict and accurate fluid balances.

**Are you interested in the role of the CHD Link Nurse? Then please contact our Lead Nurse Linda Griffiths via email to discuss the role at [linda.griffiths@alderhey.nhs.uk](mailto:linda.griffiths@alderhey.nhs.uk) and to request to join either the paediatric or ACHD Link Nurse Forum**



**Christina Needham**



**Chelsea Topping**



**Nicole Almond**



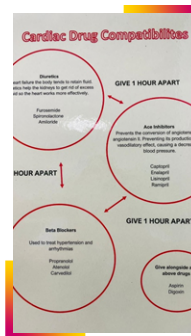


## CHD Link Nurses: Increasing Awareness

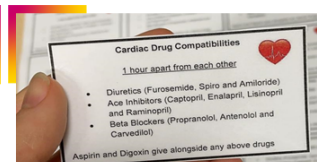
Below is some of the work we have been doing to increase the knowledge of Cardiac Drugs:-

- Drugs room poster
- Pocket size information cards
- Cardiac book
- Posters highlight 'Cardiac Week'

## Increasing Knowledge of Cardiac Drugs



Drugs room poster



Pocket sized card outlining cardiac drugs

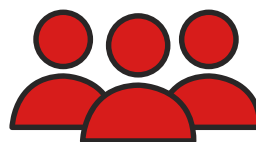


We have created a "Cardiac Book" to explain the main congenital heart defects we come across



Posters created for 'Cardiac Week'

## National CHD Meeting 14th June 2021



## Recent Network Events

North West, North Wales and Isle of Man  
Congenital Heart Disease Operational Delivery Network



### National CHD Network Meeting

Monday 14th June 2021

10:00—13:30 Via MS Teams

|             |  |
|-------------|--|
| Chair:      | Professor Bernard Clarke: Group Associate Medical Director/Consultant Cardiologist, Manchester University NHS Foundation Trust   |
| 10:00—10:10 | <b>Welcome</b><br>Professor Bernard Clarke   |
| 10:10—10:40 | <b>ICS Framework &amp; Potential Impact on CHD ODNs</b><br>Michael Wilson, Programme Director, Specialised Commissioning, NHS England (10:40—11:00 Q&A)  |
| 11:00—11:20 | <b>NCARDRS &amp; Antenatal Detection</b><br>Nicola Miller, Head of Registration PHE (11:20—11:30 Q&A)  |
| 11:30—11:50 | <b>ACHD in Primary Care</b><br>Sarah Ellison, Primary Care CHD Project Lead, NW CHD Network (11:50—12:00 Q&A)  |
| 12:00       | <b>BREAK</b>   |
| 12:15—12:35 | <b>Feedback from National Audit of Nurse Education</b><br>Linda Griffiths, Lead Nurse, NW CHD Network (12:35—12:45 Q&A)  |
| 12:45—13:15 | <b>Open Discussion about the need for a national dataset/dashboard for CHD Networks</b><br>facilitated by Dr Andrew Tometzki, Paediatric Cardiologist and Clinical Director South West and South Wales CHD Network<br>What is the consensus<br>What should it include<br>How often should the data be collected<br>If agreed – what are the next steps to making that happen?<br>Data support for networks |
| 13:15—13:30 | <b>Close / AOB</b>   |

We were delighted to be able to host the National CHD Network meeting on 14th June, chaired by Professor Bernard Clarke, Consultant Cardiologist, Manchester University Hospitals NHS Foundation Trust.

This had to be held virtually due to the coronavirus pandemic but this didn't hinder the packed agenda and the ability for everyone to engage in meaningful discussions.

Michael Wilson gave an update on the new ICS (Integrated Care Systems) and the potential impact on how this might affect the future of how Networks will function. We also discussed the important data being collected by NCARDRS around antenatal detection rates and Sarah Ellison delivered a talk on the work she is doing around "lost to Follow up" and in particular the important role that primary care has in looking after patients with CHD. Our Lead Nurse presented the result of the UK wide audit into nurse education and then finally there was a discussion about having a national approach to data collection. It was lovely to catch up with all our colleagues from around the UK and to Network virtually – although we are looking forward to being able to meet up in person too.

The Network is involved in supporting and driving education. Working alongside expert clinicians, Liverpool John Moores University and the Liverpool Centre for Cardiovascular Sciences, we have been able to provide a module that offers healthcare professionals the opportunity to enhance their skills and knowledge in relation to adult congenital heart disease and the care of patients with a congenital cardiac anomaly.

The course has been developed in collaboration with local clinicians and international experts in the field of adult congenital cardiology and cardiac surgery. This Module is now well established and is attracting candidates from around the UK each year. It is consistently evaluated very highly.

**Educational Opportunities**

## Local Study Days

During the pandemic we have had to adapt our Network Study Days and have been able to provide online opportunities. In January we held our first ever online event via Microsoft Teams. This went very well with no major IT issues and was evaluated very well. So, we are hoping to provide several more over the coming months.



## ACHD Masters Module

### Level 7 (postgraduate), 20 credits

Adult Congenital Heart Disease: Care of the patient through their lifespan. Next cohort due to start **8th November 2021**. See link below for details

[Adult Congenital Heart Disease: Care of the patient through their lifespan | CPD | Liverpool John Moores University \(ljmu.ac.uk\)](#)

Information is also available via the Liverpool John Moores on line [CPD for healthcare professionals brochure](#).

For further information please contact:

Faculty Admissions Team  
Faculty of Health  
Liverpool John Moores University  
79 Tithebarn Street  
Liverpool L2 2ER

T: 0151 231 5829  
E: [Health@ljmu.ac.uk](mailto:Health@ljmu.ac.uk)

Or you can email Dr Robyn Lotto (Course Facilitator):  
[R.R.Lotto@ljmu.ac.uk](mailto:R.R.Lotto@ljmu.ac.uk)

## Paediatric CHD Masters Module Level 7 (postgraduate), 20 credits

We are very pleased to announce that work is in progress to also provide a Paediatric CHD Module also accredited at Liverpool John Moore's University – keep a look out for more information in the coming months. This is likely to commence in February 2022.

## Online Events

### Inaugural Study Morning - 2nd July 2021

Our ACHD Team are holding their first ever inaugural annual study morning on 2nd July 2021. This study day is aimed at our anaesthetic and ICU colleagues and acute care physicians working in A+E. For all enquiries, and book a place, please email [David.mayhew@lhch.nhs.uk](mailto:David.mayhew@lhch.nhs.uk) using 'ACHD Study Morning' as the subject.

### An Introduction to ACHD

**22nd July / 16th September / 11th November 2021  
9.30-10.30**

Our Lead Nurse is providing regular online teaching called "an Introduction to ACHD". This is aimed at adult clinicians who encounter ACHD patients in their clinical areas but do not feel as if they are experts. It's a good overview and introduction. It is meant to be a bit of a paddle rather than a deep dive and gets evaluated very highly. If you are interested in attending this online event, email [linda.griffiths@alderhey.nhs.uk](mailto:linda.griffiths@alderhey.nhs.uk) for more details.

### Study Day Sessions

**Paediatric Link Nurse Study** - September date TBC  
**Psychological Well-being Study Day** - October date TBC

**ACHD Link Nurse Study** - November date TBC

## ACHD Clinic Wythenshawe



**Northwest Heart Centre at Wythenshawe**

The Wythenshawe cardiac department is a large tertiary unit well known for its cardiac imaging, treatment of heart valve disease and advanced heart failure including ECMO and cardiac transplantation. There are 26 cardiologists offering complex cardiac work but having been an adult congenital heart disease (ACHD) centre in the past, for the last decade there has not been a dedicated clinic to manage such patients. That has all changed with the launch of the new ACHD clinic in January 2021 under the joint supervision of Dr Anita Macnab, Head of Echocardiography and Dr Reza Ashrafi, ACHD consultant from Liverpool Heart & Chest hospital. The clinics are held in the North West Heart Centre building.



**Dr Macnab with Wendy and Mark**

ACHD clinics have been running on the first Wednesday of each month but as referrals are mounting, the plan is to increase the frequency. They are joined by specialist nurses Kate and Laura from the MRI and supported by our advanced sonographers Wendy, Mark and Sarah.

Patients can expect to come in the morning to get an ECG and echo then meet the doctors and specialist nurses before returning home with a management plan.

The dedicated cardiac MRI and CT department are available for any complex cardiac imaging requirements. The cardiac catheter lab team are on hand for any invasive cardiac diagnostics. The close collaboration between Wythenshawe and Liverpool also means that patients who need onward referral for surgical can have a seamless pathway to the surgical centre, which is Liverpool.





We've been around for a very long time, and never had such a quiet year. We've had to take a break from our favourite events and concentrate on other areas. No panto, no zoo trips or Christmas Pizza with the Elves, no museum sleepovers, barbeques or ice cream farm picnics. It's been hard as the main reason that the CHA is so successful is bringing families together for shared support whilst enriching family lives. Friendships are easy to make when you're all having fun together and those friendships are then vital when you or your child are going through some tough times that no one else around understands.

**CHA - What we normally get up to....**



**Pizza with Elves**



**Inflatanation jumpathon**

We are a primarily a support group and quite unique in that we offer support along the whole journey to anyone with a congenital heart problem living in the area covered by this NW network – whatever their condition or age. Other groups focus on supporting a hospital or ward and tend to run events that are fundraisers. CHA does look to raise funds for our hospitals, and over the last 5 years we have spent over £58,000 on supporting families, almost £60,000 on trips, events, big things and little things! We buy around a dozen CoaguChek machines each year at £400 each given directly to our 3 NW cardiac units to enable families to home check INR results. We've bought pushchairs, car seats, train tickets, toys and emergency support packs. And for each family who receive a new diagnosis at either of our children's units they are given a copy of Heart Children bought by CHA. We order a few hundred books per year. Whatever the units ask for we look to provide – except those items that the NHS should be paying for! The nursing team can ask for top ups whenever they need for petty cash to give to families for taxi fares or a coffee or meal etc.

Our events are either free, or subsidised by around 50% and range from picnics on the beach and visits to steam railways to occasional wonderful weekends to Disneyland Paris, Flamingoland or PGL adventure holidays. We include all members of the family to ensure siblings enjoy the same fun as our heart children and this extends to grand parents and grand children too.

At the beginning of the pandemic we had many requests from across the country to join our group as our reputation for giving sensible advice had spread and that's because we have such close links with our clinical teams. We have our main NW Facebook page but have another group CHA UK Friends for those living in other areas of the country. It's not been the same just holding virtual get togethers and we can't wait to restart safely. Restrictions permitting we're looking at going to Blackpool Zoo and PGL in September, and holding TWO Pizza with Elves parties at Manchester Airport in December to accommodate even more families safely, and in between a Christmas meal for any adult CHD people who wish to attend.

**Here's to some normality soon!**

**ACHD Christmas meal**



**Photos with the cast after our annual trip to the pantomime**



## Cardiovascular Research News

**Mr. Attilio Lotto, MD, MCh, FRCS-CTH**  
Consultant in Congenital Cardiac Surgery  
Alder Hey Children's Hospital  
Liverpool Heart and Chest Hospital



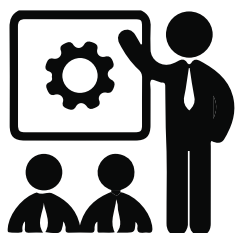
As you might know Alder Hey Children Hospital (AHCH) and Liverpool Heart and Chest Hospital (LHCH) have an active research programme in Congenital Heart Disease (CHD).

The unique North West Clinical Network of Level 1, 2 and 3 centres, caring for all ages, has been an opportunity for to develop a robust Network approved research themes entitled "Life Course Effect of CHD".

Within our strategy, we have developed streams of research with Quantitative and Qualitative projects. Both are looking at different angles of a general theme under the name of Quality of Care in Congenital Cardiac Surgery in the North West.

Quantitative studies are looking at aspects pertaining to cardiovascular science, for example how we can enhance brain protection during cardiac surgery or how we can identify new markers of cardiac disease for an early diagnosis.

Qualitative projects are looking at different aspect of care, overlooked in the past, in relation to the experience our patients and their carers have during their journey through diagnosis, treatment and follow up of their disease. Example is a study which explored perception of risk in parents of children undergoing cardiac surgery. A second study is looking at which obstacles families encounter enrolling children with a single ventricle in exercise activities.



## Report from recent European Congenital Heart Surgeons Association (ECHSA) Annual Meeting

The ECHSA 2021 Annual meeting was held during the weekend 11-12 June. As last year, it was held in a virtual format. It was a very good occasion to meet with friends and colleagues also from the sister USA organisation World Society for Paediatric and Congenital Heart Surgery (WSPCHS).

Alder Hey presence was well noted with 5 high quality presentations of projects conducted in collaboration with Alder Hey, LJMU and LCCS.

The results of a study looking at Cerebral Blood flow velocity during aortic arch repair in neonates were presented. As seen in graphic (Fig 1 page 21), we found that there is no difference in CBFv when the operation and the cerebral perfusion is performed at 20- or 25-degrees C. The importance of the results is that, when needed to drop the perfusion temperature to such low degree, the brain perfusion does not seem to be affected.

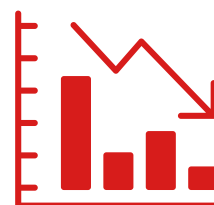
## Cardiovascular Research News Cont/d.....

Lucy Finnigan, our first PhD student, has finished her project and presented the results of CBFv monitoring during ECMO weaning. She showed that in patients with a successful wean from ECMO, the CBFv is higher than in patient who failed the ECMO wean (Fig 2). This should be used in the future to help decision making in borderline patients.

Amr Ashry, one of our senior registrars, reported the results of a retrospective study looking at a different technique of closing VSD which seems to reduce, in particular subgroup of patients, the incidence of right bundle branch block (RBBB). This technique does not increase the operative time and the degree of TV regurgitation.

We also presented our results in dealing with aortic arch hypoplasia with Deep hypothermic Circulatory Arrest in neonates and infants. Our results are in line with the best series published.

The last paper was from Dr. Robyn Lotto (senior Lecturer at LJMU), who presented the results of a systematised review about Quality of Life following congenital heart surgery, showing how patchy is the evidence and how much work need to be done in the field of qualitative research in CHD.



We have long term ambitions and we believe we are paving the way for a sustainable future where research will be embedded in everyday practice, looking at different aspects of service improvement. We are linking with prestigious national and international institutions with fruitful collaborations. Of evidence is the possibility to study large database and the link with the European Congenital Heart Surgery Association (ECHSA) Database will open the doors for large epidemiological studies.

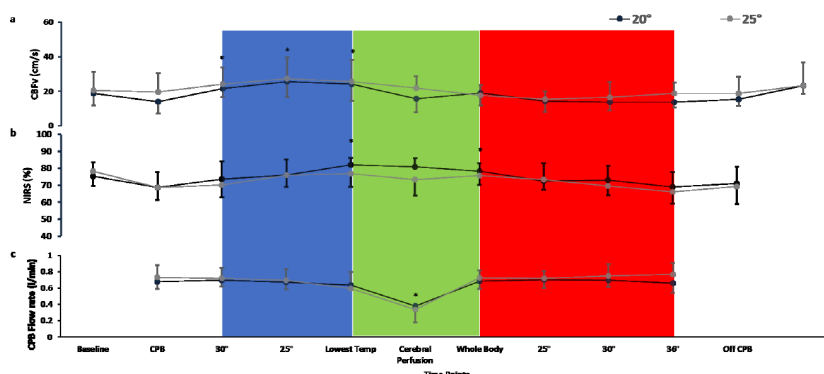


Fig 1 Variation of CBFv during different stages of the operation. No difference was noted between the two temperatures

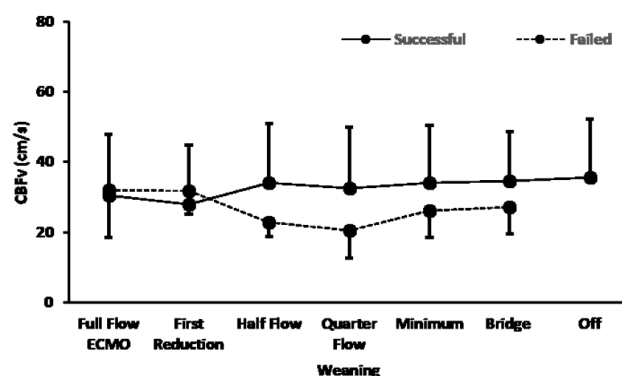


Fig 2. CBFv is higher in patients successfully weaned off ECMO

**CPR! Would  
you know  
what to do?**

In light of what happened to footballer Christian Eriksen at the European Championships recently, would you know what to do if someone had a cardiac arrest? Below are some simple steps to follow from the British Heart Foundation. See the 'Useful Links' for further information.



## Steps to CPR

Less than 1 in 10 people in the UK survive an out-of-hospital cardiac arrest.

A cardiac arrest is the ultimate medical emergency. Follow these steps to help save a life.

## Call Push Rescue



**1**

### Shake and shout

Check if the area is safe, if the person is responsive and shout for help.



**2**

### Call 999, send someone for a defibrillator

Continue CPR and follow the defib's instructions.



**3**

### Check for signs of life

Lay a piece of material over their mouth and nose, if there's risk of infection.



**4**

### Give continuous chest compressions

Repeat until the ambulance crew has taken over.



**5**

### Wash your hands

Thoroughly wash with soap and water or use an alcohol based hand gel.

To learn life saving CPR  
**[bhf.org.uk/cpr](http://bhf.org.uk/cpr)**

## Useful Links

[bhf.org.uk/cpr](http://bhf.org.uk/cpr)  
[life-saver.org.uk](http://life-saver.org.uk)





## Congratulations!


### e-Poster Success!

Linda Griffiths our Lead Nurse for the Network has recently had an e-poster presentation accepted at the ESC-ACNAP meeting #EuroHeartCare on 18th & 19th June 2021. This was a collaborative piece of work with The British Adult Congenital Cardiac Nurse Association (BACCNA) and Liverpool John Moores University looking at nurse training and congenital heart disease. All CHD Networks in the UK were invited to participate from fetal, paediatric and adult services. Less than 17% of nursing staff felt confident in looking after a patient with congenital heart disease, with band 5 nurses working in any setting and all staff working in a non-CHD setting having higher levels of anxiety. A third of staff had undergone no training in the past two years and those that had – had only engaged in self-directed study or accessed a local study day.


And  
Finally!



Alder Hey Children's 

NHS Foundation Trust



### Educational needs of nurses caring for patients with a congenital heart defect: a national survey

Linda Griffiths<sup>1</sup>, Dr Sarah Seaton<sup>2</sup>, Dr Robyn Lotto<sup>3</sup>

Acknowledgements: British Adult Congenital Cardiac Nurse association (BACCNA)

**Background**

- 1 in every 130 babies are born with some form of congenital heart defect
- 90% survive into adulthood
- Need access to appropriate education for nursing staff

**Aims**








- Explore educational needs of nurses who may encounter this group

**Methods**

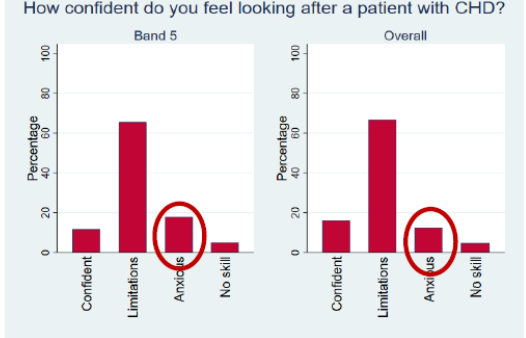
- National online survey undertaken between 4/06/2020 to 06/07/2020

**Results**

- 513 survey responses were received
- Band 5 nurses reported a higher level of anxiety
- Around 1/3<sup>rd</sup> of band 5 staff had received no training in the past 2 years
- Nearly 3/4 were based in non-CHD settings
- Priority topics and modes of delivery identified

**How confident do you feel looking after a patient with CHD?**



| Category    | Band 5 | Overall |
|-------------|--------|---------|
| Confident   | ~15%   | ~15%    |
| Limitations | ~65%   | ~65%    |
| Anxious     | ~20%   | ~20%    |
| No skill    | ~5%    | ~5%     |

**Conclusion**

- Education well developed in specialist centres
- Band 5 nurses find it more difficult to access education
- Those in a non-CHD setting are particularly at risk of being left behind
- Targeted approach to meet the needs of band 5 nurses required particularly those working in a non-CHD setting

The study has highlighted a gap in nurse education for band 5 nurses working in any setting and all nurses working in a non-CHD setting. Linda has now set up a working group locally in the North West to look at local solutions. She continues to lead the educational sub-group of BACCNA and recently presented the results at the National Network Meeting on 14th June. There is a keen interest in developing a national solution to this by exploring the options of developing e-Learning for Health Modules that can be made available free of charge for all health and social care staff.





Email us at:  
[NorthWestCHDNetwork@alderhey.nhs.uk](mailto:NorthWestCHDNetwork@alderhey.nhs.uk)



@NwchdN  
now has 460  
followers



Join the **NWACH Support Group**  
on Facebook



North  
West  
Helpline:  
0151  
254  
3333

N-WACH Support Group

Private group · 750 members

About Discussion

Join Group

[Click here](#) to join the Adults CHD Support Group

### 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 ask for a call back. Make sure you leave your contact telephone number with switchboard.

Contact  
Us

### Congenital Heart Helplines:

If you need any personal advice about you or child's congenital heart problem our Congenital Heart Nurse Specialists are very skilled and experienced and able to help with any queries. Our helplines are available Monday to Friday between 09:00 – 17:00. Please ring and leave a message and the Nurse Specialists will call you back to help with your query.

### Alder Hey Children's Hospital

**For non-urgent enquiries:**

Cardiac Help Line: 0151 252 5291

**For Urgent queries outside of normal working hours:**

Contact Alder Hey Children's Hospital Switch Board on 0151 228 4811 and ask to be put through to Ward 1C for advice.

### 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 out of hours on 0161 701 8500/8501

**Next Issue:  
December 2021**

