The Role of the Patient & Public (PPV) Partner for the North West, North Wales and Isle of Man Congenital Heart Disease Network (NW CHD Network)

Main purpose of the role:

The role of the PPV representative is to represent the views and experiences of patients & parents. The patient and public voice is vital in helping to improve the care that is provided across the North West, North Wales and Isle of Man Congenital Heart Disease Network. We welcome people from a diverse background to help the NWCHD Network reach all members of our community with information about congenital heart disease.

The Role of the PPV Representative:

- Ensure that the patient/parent voice is heard and listened to.
- To be a ‘critical friend’ in order to challenge services that need to improve.
- To represent the views and experiences of patients and parents to help influence change.
- Your own lived experience is important, but it is also important to represent everyone’s views.
- Attend and contribute to PPV meetings in person, or via teleconference.
- You will have the opportunity to attend the CHD Board Meetings to represent the patient and public voice views and opinions.
- You may be asked to set aside time for reading so that you know what to expect of the meeting/group you are involved with.
- To provide feedback as to how services across the NWCHD Network are working.
- Encourage the NW CHD Network to regularly review patient, parent and family experiences of NWCHD services.
- If you are an active member of a charity or support group, we may ask you to see what their membership’s opinion is on a particular subject. This may help to get a wider view of patients and parents views.
- You will be required to maintain confidentiality and ensure information is only shared outside organisations on the agreement of the NWCHD Network Board.
- We may ask you to review patient information leaflets, documents about services including information to be published on our website.

Skills and abilities:

Whilst the experience listed below if helpful it is not essential. We want everyone to feel welcome. Living with congenital heart disease makes you an expert in this subject. Training and support can be provided for people if required.

- Experience of speaking in large groups.
- Ability to understand and evaluate a range of information
- Previous experience of representing PPV in healthcare forums.

- Experience of working in partnership with healthcare organisations or programmes.
- Ability to display sound judgement and objectivity.
- Have an awareness of, and commitment to, equality and diversity.
- Understand the need for confidentiality.
- A commitment to the ‘seven principles of public life’ known as the ‘Nolan Principles’: selflessness, integrity, objectivity, accountability, openness, honesty, leadership.
- Ability to represent the views of other patients and parents who have had a CHD journey.
- Be able to communicate your thoughts and ideas.
- We welcome people who use other forms of communication such as sign language, Makaton or braille etc.
- Be respectful of everyone else’s views and ideas at all times.
- Have an interest in helping to improve the quality of care that is provided.
- Be willing to seek support and advice for yourself whenever you feel it is needed.
- Put aside previous personal and organisational relationships, and not to lobby or advocate for a particular interest or group including yourself.
- Act in a way and treat everyone with whom you come into contact equally, with respect and without discrimination.
- You will act in all times in accordance with the values of Alder Hey Children’s Hospital who host the NW CHD Network. They are:

excellence	We pride ourselves on the quality of our care, going the extra mile to make Alder hey a safe and special place for children and their families.
innovation	We are committed to continually improving for the benefit of our patients.
openness	We are open and honest and engage everyone we meet with a smile.
respect	We show that we value every individual for who they are and their contribution.
together	We work across the Alder Hey community in teams that are built on friendship, dedication, care and reassurance.

Experience:

- Personal experience of a CHD journey.
- You may be a current user of the service (we recommend not getting involved within 12 months of a significant event such as bereavement).

- You may be a past user of NHS services related to congenital heart disease (this could be as a patient, parent or carer) or as a representative of a patient support group (national or regional).
- Previous experience of working in a PPV role is helpful but is not necessary as training and support will be given.

Time commitment:

We recognise that not everyone will be able to commit to everything. Whatever time you can commit to will be valued and will be helpful:

- The PPV meetings are held monthly and they will last one hour.
- Attendance at NW CHD Board Meeting which meets every 3 months. This will be done in rotation to ensure everyone has a chance to represent patients and families views. The Board meetings will last for 2 hours.
- If you wish to get involved in smaller groups looking at a specific area this may mean attending meetings in addition to the above which will vary in time and how regularly they meet.
- Commitment to the role for a minimum of one year and a maximum of 4 years.
- We may also ask for your input via email or post.
- Due to the current COVID-19 pandemic most meetings will be held virtually via Microsoft (MS) Teams. This may change as the situation with the pandemic improves to allow more face to face meetings in the future.
- You have the right to step down at any time, knowing that it will not affect any future care or treatment.
- You can refuse to do anything that you feel uncomfortable with or find too stressful.

Next steps:

If you are interested in this role contact Linda Griffiths (Lead Nurse for The NWCHD Network) email: linda.griffiths@alderhey.nhs.uk

Thank you for considering this important role and making sure that the patient and parent remains at the heart of our services