

# Network NEWS

Working together to provide patient pathways for children with cancer

**Issue 9 | October 2024**

## Overview

The NW CC ODN is mandated through NHS England; and hosted through Manchester Foundation Trust (MFT) in partnership with Alder Hey via the Northwest Paediatrics Partnership board. There is joint Clinical Leadership from Professor Bernadette Brennan (Royal Manchester Children's Hospital) and Dr Lisa Howell (Alder Hey Children's Hospital). The ODN is accountable to NHSE specialised commissioning.

The NW CC ODN circulates a newsletter issue quarterly. The newsletter focuses on sharing successes, identifying learning opportunities and signposting you to the wider network resources.

Please contact  
[info.nwccodn@mft.nhs.uk](mailto:info.nwccodn@mft.nhs.uk)  
For further information.

## Social Media

Follow us on our Social Media Platforms @NWCCODN



Welcome to the latest edition of our quarterly newsletter. We're excited to share an overview of the ODN's recent projects. This issue contains updates on the following:

- Care Closer to Home Project (CC2H)
- Cancer Improvement Collaborative
- The North West TYA Network
- Charity News

## Care Closer to Home Innovation and Service Development for Paediatric Oncology Services

We are pleased to announce the NWCCODN have been successful within an innovation bid; in partnership with the 3 Cancer Alliances! This is an exciting opportunity to explore models around making *care closer to home* a reality for children with cancer and their families. The *proof-of-concept project* is due to launch in Q3 of 2024/2025 and will be an 18month project; with 3 phases.

1. Planning Phase
2. Regional Home Care Team
3. Mobile Cancer Care Unit

We will be circulating further information and formal communications soon. There will be a pre-recorded webinar circulated and we will be holding various professional workshops across the region, in addition to patient and family workshops to commence the planning phase and ensure that all colleagues and service users are included in the co-development of this exciting innovation and improvement work.

### Launch of Project

- Pre-recorded Webinar (via email release)
- Engagement Workshops (in-person)

### Professional Engagement Workshops (in-person):

- Wednesday 20th November (@AHCH in AM)
- Friday 29th November (@RMCH in AM)
- Friday 6th December (L&SC in AM)

Information will follow on how to book a place and get involved in the co-design aspects. A virtual mop up of the discussions at the professionals workshops and PPI workshops will be held on Thursday 12th December.

# Cancer Improvement Collaborative

The NWCCODN are involved in the Cancer Experience of Care Improvement Collaborative (CIC) Cohort 6. The overarching theme for this cohort is *Administration of Care*: which refers to *Communication, Access and Navigation, or Coordination of Care*. Nationally ODN's are collaborating to undertake a scoping exercise that will be a deep dive into the common communication issues and opportunities faced by service teams working in CTYA Cancer, to identify areas for improvement that could deliver change at a regional or national levels. This is a relevant and valuable project to be involved in; and links into U16CPES previous feedback. Should you be interested in finding out more about this work, please follow our social media channels, or link in via the generic email address (info.nwccodn@mft.nhs.uk).

## North West TYA Network Update

The North West TYA Network has had a successful start to the year in appointing to the PMO office vacancies and would like to welcome the following members to the team:

**Rachael Hastwell**  
TYA Network Programme  
Manager

**Peace Amaefule-Orie**  
Clinical Pathway Project  
Manager

**Aneta Murkova**  
TYA Administration  
Assistant



Since joining the team have been focused on establishing key relationships across the network and Nationally, to help progress the TYA strategic objectives.

### TYA ODN - Things to celebrate:

- 2 lucky candidates were granted places to present their abstracts at the **Global AYA congress** in December 2024 in Melbourne – congratulations to **Kathryn Davies** from Clatterbridge and **Lyndsey Griffiths** from the Christie.
- Our Network launched **TYA MDT Notification Forms**. The notification of young people with cancer to the TYA MDT helps the early identification of their age specific needs, leading to faster interventions and TYA support from the specialist TYA Team.
- The Network had a national project accepted for the "*Cancer Improvement Collaboration- Administration of Care*" with a specific focus on '**Late Effects Information**'. Some of our project team attended the launch meeting in London on 24<sup>th</sup> September.



From left to Right, Dr Laura Elder – TYA lead nurse C&M, Rachael Hastwell – TYA Network Programme Manager, Dr Sindhu Retnabai – Specialty Doctor for TYA at the Christie

## Milly's Smiles

Milly's Smiles was founded in November 2015 by Lorraine Hargreaves, in memory of her daughter Milly. Milly was diagnosed with Acute Myeloid Leukaemia in November 2014 aged 11. She was treated at the Royal Manchester Children's Hospital for 10 months, until she very sadly passed away weeks before her 12<sup>th</sup> birthday.



Milly's Smiles became a registered charity in March 2016, with their objective to help children and families going through a similar journey that Milly and her family had embarked upon.

Children are often admitted into hospital unexpectedly after being initially diagnosed with a cancer by their local GP or hospital, parents often have nothing with them and are unprepared for a long hospital stay.

Milly's Smiles provide help and support to families at this point. A Milly Bag is given on arrival onto the ward and contains essential and luxury items that families do not realise they need until they need them. The bag is so much more than practical support, it also lets families know that someone is thinking about them and understands their fears and their worries. It is like being given an understanding hug in a bag.

Milly's Smiles currently support 5 Principal Treatment Centres, The Royal Manchester, Children's Hospital, Alder Hey Children's Hospital, Leeds Children's Hospital, The Queen's Medical Centre in Nottingham and most recently The Great North Children's Hospital in Newcastle.

Each Milly Bag costs £140 and a total of 1705 families have been supported which equates to £238,700.

## The Positivitree



"The Positivitree is a wellbeing movement dedicated to empowering parent-carers raising children with a wide range of additional health and care needs. Our organisation was founded after my son Jack relapsed with a rare cancer/autoimmune disease called Langerhans Cell Histiocytosis, so I have first-hand experience of the challenges involved in raising children with additional health or care needs. This lived experience is central to our work, ensuring that our services are relevant, compassionate, and effective.

One of the key strengths of The Positivitree is its foundation in the lived experiences of myself and all of our team members. This connection enables us to design support services that are both practical and deeply empathetic to the needs of our community. Over time, we have grown from a grassroots movement into a trusted support network within the Wirral community, fostering connection, resilience, and empowerment among parent-carers.

Our small, dynamic team is highly responsive to the changing needs of our community, allowing us to adapt quickly to external challenges such as the COVID-19 pandemic and the ongoing cost-of-living crisis. Additionally, we have developed strong partnerships with public sector bodies, local organisations, and the NHS, which enhance our ability to provide comprehensive support to the families we serve."

**Rachel Daley, Founder/CEO**

Follow us on our Social Media Platforms @NWCCODN for regular Network updates or visit our website! <https://www.nwchildrenscancerodn.nhs.uk/>

