

Welcome to our first

## North East and North Cumbria Paediatric Palliative Care Collaborative Newsletter



North East & Yorkshire  
Palliative and End of Life Care Strategic Clinical Network

Firstly, may I thank you all for your patience, I am very aware that there has been a lull in the activity of the network and communication from myself and Suzanne Garbarino SCN children's palliative and end of life clinical leads. We have been busy being introduced to the wider SCN Palliative and End of Life teams for adults and children, across the North East, Cumbria, Yorkshire and the Humber.

We have been requested to change our name to '**Collaborative**' rather than 'network' and this is the term we will use moving forward.

It has taken a considerable amount of time for us to understand the complexities of the SCN role and how we fit within the wider All Age Palliative and End of Life (PEoL) SCN and we are still learning!

### Things that have been happening and that may be helpful to know!

- ◆ Suzanne and I attended the final **Yorkshire and Humber Paediatric Palliative Care conference** in September 2022. The Yorkshire and Humber Network is no longer being funded by the ICBs and work has been incorporated into the All Age Network for North East, North Cumbria and Yorkshire and Humber.
- ◆ The **inaugural SCN Palliative and End of Life Care (All Age) conference** was held on 12 October 2022. I have to say that it highlighted how underserved children and young people are within palliative care services. It is our responsibility to highlight this inequality and push for better data collection, clinical standards, investment in services and staffing and education opportunities. We have a long way to go but I hope that we can influence the all age network and the ICBs to truly include children and young people as we move forward.
- ◆ We will be writing a formal PEoL **strategy document** for the NE and NC, setting out our goals, targets and aspirations for the future and identifying key priorities for our region. We hope that you will support the development of such a strategy.

- ◆ We have been successful in securing the following **CYP ICB match funded bids** for our region:
  - 002 Education role, CHIPS
  - 023 Personalised care NECS
  - 028 Transition worker, Jigsaw Hospice
  - 033 Extended hrs, St Oswalds Hospice

We continue to discuss how our collaborative for our specific region may look moving forward and would appreciate your input on the following points:

1. **Education sessions** – Feedback has been that face to face education days were valued in the past. If this is still the case how frequently would we want these to be? E.g. every 6 months. What topics are important to those in our region?  
**E mail: h.aspey@nhs.net**
2. **Feedback from you on the value of the regional CHIPS service**  
The CHIPS service has been in existence now for 2 years. The team have been collecting data during this time in all work streams. Referrals into the service continue to increase. It would be incredibly helpful to have feedback from you formally on the impact that the regional service has made over the last 2 years and where the gaps remain in the service and how it can improve moving forwards. We would like to push commissioners to invest further in the regional team to make it a sustainable resource for the whole region but we need **YOUR feedback** to help strengthen the case for further investment and will discuss how to collect this at our next meeting in March.
3. **What is the role of the collaborative in identifying palliative care need within our region and supporting further bids for funding?** Currently funding for the regional service CHIPS continues to sit within specialist commissioning, however moving forward the ICB will have responsibility for commissioning paediatric palliative care services. I attach the handbook that has been written for ICBs to guide them in their roles/

responsibilities. But you will see that there is a responsibility for them aiming to commission 24/7 services. This will be a difficult task and undoubtedly will need the support and guidance of wider networks to identify how we within our region can meet this standard in the future.

#### PEoLC Statutory Guidance for ICBs

4. **Core Group** – our regions geographical area is huge and the way that services are set up within our region differs greatly from one area to the next. With that in mind we hope to set up a core group within the network of key professionals representing their geographical patch in the hope that no area is overlooked. The role of a core group member would be to be a key link for their area to disseminate information about the network and education opportunities to the wider paediatric workforce and to link with the clinical leads to input into discussions about service development for the region. The clinical commitment would be an additional 30 minute meeting at the end of the quarterly ½ day clinical case discussion/network meetings that we are hoping to reinstate. **If you feel able to take on this role please contact Helen or Suzanne and we are more than happy to discuss further**

#### **New Appointment**

**From 1 Nov 2022 Dr Archana Soman is the new children's PEOl workforce lead for the region. She is a paediatric palliative care consultant at Leeds Teaching Hospitals NHS Trust.**

**E mail: [archanasoman@nhs.net](mailto:archanasoman@nhs.net)**

#### **24/7 Advice Lines for clinicians, parents and children**

**North East and Cumbria Commissioning Support Unit (NECS)**

**The SCN have funded an independent review of children's PEOl advice lines across the region. This will be conducted by NECS between Dec and March 2023. For more information please email the SCN all age network manager on**

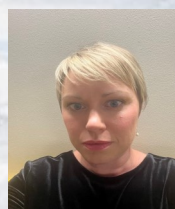
**e mail [Marie.hancock2@nhs.net](mailto:Marie.hancock2@nhs.net)**

#### **DATES FOR YOUR DIARY**

We have been discussing how we can Share educational opportunities with our Y+H colleagues, including joining clinical education sessions virtually. The following dates have been agreed and invitations (Teams) will follow but **please put them into your diary!**

- **12-2pm Mon 13<sup>th</sup> March 2023** - Educational Meeting (approx 3-4 topics, with outside / expert speakers) [Chair: TBC]
- **12-2pm Tues 6<sup>th</sup> June 2023** - Clinical Learning Meetings (Case Based Discussions / Sharing of Helpful Policies / Projects / Incidents) [Chair: TBC]
- **12-2pm Weds 19<sup>th</sup> Sept 2023** - Educational Meeting (approx 3-4 topics, with outside / expert speakers) [Chairs: Suzanne/Helen]
- **12-2pm Thurs 18<sup>th</sup> Jan 2024** - Clinical Learning Meetings (Case Based Discussions / Sharing of Helpful Policies / Projects / Incidents) [Chairs: Suzanne/Helen]

**Next North East and North Cumbria Paediatric Palliative Care Collaborative Meeting –  
Wednesday 18<sup>th</sup> January 2023 1-3pm  
via MS Teams  
Agenda ( Points 1-4 )**



**Dr Helen Aspey**  
**SCN Clinical Lead for CYP**  
**The Newcastle Upon Tyne Hospitals NHS**  
**FT**



**Suzanne Garbarino-Danson**  
**SCN Clinical Lead for CYP**  
**Eden Valley Hospice**