



Scottish Paediatric  
& Adult Haemoglobinopathy  
Managed Clinical Network

# Newsletter

February 2018 Issue

Welcome to the **FIRST** edition of the network's newsletter. This will provide an update on the key areas of work over the last few months and other related items. Please forward this on to any of your colleagues who might be interested as a way for us to communicate with as many of the medical professionals involved in the care of this patient group across Scotland.



**First  
Edition**

## What is SPAH?

SPAH is the acronym for Scottish Paediatric & Adult Haemoglobinopathy Network which was designated as a MCN in April 2011. The Network was established to ensure appropriate links to the Linked National Antenatal and New-born Screening Programme for Haemoglobinopathies which was implemented in October 2010.

The nationally funded Transcranial Doppler and Ferriscan services for children with Sickle Cell and Thalassaemia are also fully integrated with the Network. Due to the complex nature of Sickle Cell Disease & Thalassaemia early involvement of the specialist Haematology team is crucial to ensuring good patient outcomes.

### Thank you but not goodbye.....

Many thanks to Dr Beverley Robertson, Consultant Haematologist in Aberdeen Royal Infirmary for her excellent work as the network Clinical Lead over the last 4 years. Beverley has agreed to keep the new Clinical Lead, Dr Susan Baird, Consultant Paediatric Haematologist, Royal Hospital for Sick Children, Edinburgh right over the next few months as she works out what's what. Beverley will continue to remain as an active member of the Network.

Please get in touch if you have any comments or suggestions or would like to be more involved. Email: [nss.spah@nhs.net](mailto:nss.spah@nhs.net)

# Network Review 2017



The SPAH network has just undergone a 3-5 year review and has been recommended to continue in its current format.

The network was commended for its excellent education work both for haematology professionals in Scotland and other parts of the UK and for patients and families. Extending this to clinical and non-clinical professionals outwith haematology was recommended.

The network was commended for providing useful guidelines for the management of adults and children with sickle cell, particularly in the acute setting. More work on guidance for the management of chronic complications and in thalassaemia would be beneficial.

The network has been seen to communicate well with patients and families

through the organised Patient/Family events which have been running since 2011. Additional ways to communicate have been tried through a recent postal survey questionnaire to identify user views around what is important to them and what can be done to improve their clinical experience. Unfortunately engagement was poor and other options will be considered to gather opinion.

Audit has proven to be a tricky area - we have good data on newborn screening through the programmes returned to the newborn screening laboratory but it has been difficult to audit the network's other Key Performance Indicators (KPI) partly due to difficulties with the Clinical Audit System (CAS) both in terms of users entering data and difficulty retrieving useful and accurate data from the system. More on this later.....

## Steering Group

The network has an overarching Steering Group (full list on next page). The purpose of the Steering Group is to direct and support the development of the network and the services it encompasses. It has the remit to approve work streams which will deliver on the networks' designation objectives.

The Steering Group meets three times per year. The first meeting of 2018 was recently held on Friday 26th January. Highlights from that meeting were the number of paediatric and adult guidelines recently reviewed by members of the group (list adjacent). Other priorities the Network will be focussing on in the coming months are Quality Improvement projects and audits.

### Reviewed Guidelines:

#### Paediatric

- Acute Anaemia
- Priapism
- Stroke and other CNS manifestations
- Exchange transfusion
- Hydroxycarbamide
- Painful Sickle Crisis

#### Adult

- Perioperative Management of Sickle Cell disease
- Acute Chest Syndrome
- Priapism
- Red Cell Exchange Transfusion
- Acute Painful Crisis
- Hydroxycarbamide

# Into the future: our plans for 2018-19 are:



## Audit:

We really need a useful audit system that clinicians feel is manageable to populate with key data and that provides us with useful information as well as showing that the network supports provision of high standards of care for patients in Scotland.

After discussion with the IT team, the IT/Audit subgroup agreed that we should carry on with the CAS system but with some key changes. We will aim for entry of a limited data set that allows us to audit the main KPIs and could output useful information to users e.g. up to date patient lists, who is due pneumovax, when are annual MRIs due.

However our first hurdle is to have **accurate registration** of all patients with sickle cell and thalassemia in Scotland. This has become more complicated with the New Data Protection Regulations (NDPR) and the need for patients to have agreed to opt-in to the database (rather than the current opt-out policy) by May 2019 or be taken off the database (a national decision). Once the new opt-in patient information leaflets have been approved, we will need everyone's engagement to do this. **Please** help by getting patients and parents to read the information and complete the opt-in leaflet in clinic (I think most people won't reply to the postal requests). Laura will help by sending everyone out a list of their registered patients and a bundle of info leaflets.

## Trainee education event:

SPAH has agreed to host an education event every 2 years. This year's *FREE* event is: **"SpR / Trainee Haemoglobinopathy event"**

Date: Friday 9th March, 2018

Time: 09:30—16:30

Venue: Edinburgh Training & Conference Venue.

### [Programme](#)

For further details and to book your place email: [nss.spah@nhs.net](mailto:nss.spah@nhs.net)

## Website:

As many of you will know the website has recently been updated and after some teething problems with broken links, it is looking good (thanks to Laura). It will always be a work in progress so please check regularly for updates. [www.spah.scot.nhs.uk](http://www.spah.scot.nhs.uk)

## Guidelines:

We are pleased to report that many of the paediatric and adult guidelines have very recently been reviewed and are now available from the website. The development of new guidelines is very much part of the workplan for 2018/19. The aim is to alert colleagues when new guidelines, leaflets or information are added. We also plan to add links to existing educational resources e.g. NICE training.

## Communication and education:

As a collaborative approach with other Managed Clinical Networks, the plan is to deliver a national education session for Midwives and health visitors in 2018. More info should be available in our next newsletter.

We will also be looking at how best to get information out to A&E staff both locally and nationally. If anyone has ideas around this please email us?

## MDTs:

The next date will be confirmed shortly. Please check the website soon. As ever, any problems, learning cases are welcome and any events relating to clinical risk. It would be good to encourage as many trainees as possible to join and present. Video conferencing is always available. If you would like your name added to the circulation list for these meetings please email us?

## Meet the Team!



(Pictured from left)  
Mhairi Gallacher, Programme Manager,  
Laura Craig, Programme Support and  
Dr Susan Baird, Consultant Paediatric  
Haematologist.



The network has a great team of committed individuals who are regular contributors to the ongoing work of SPAH. As we are all too aware of the competing clinical demand and commitments, the network continues to make real progress in achieving the aims and objectives of the network and the year's workplan.

### Contact us:

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## Steering Group Membership

- Dr Ruth Allen, Consultant Paediatric Radiologist, NHS GG&C
- Dr Susan Baird, Consultant Paediatric Haematologist, NHS Lothian
- Ruth Bissell, Haematology Nurse Specialist, NHS GG&C
- Dr Vicki Brace, Consultant Obstetrician, NHS GG&C
- Dr Elizabeth Chalmers, Consultant Paediatric Haematologist, NHS GG&C
- Laura Craig, Programme Support, NHS NSS
- Hazel Douglas, Specialist Midwife, NHS Lothian
- Louise Forrest, Clinical Nurse Specialist, NHS Grampian
- Mhairi Gallacher, Programme Manager, NHS NSS
- Dr Buddhi Gunaratne, Consultant Paediatrician, NHS Tayside
- Lyn Hutchison, Senior Programme Manager, NHS NSS
- Angela Iley, Genetic Counsellor, NHS GG&C
- Dr Louisa McIlwaine, Consultant Haematologist, NHS GGC
- Dr Nicole Priddee, Consultant Haematologist, NHS Lothian
- Dr Beverley Robertson, Consultant Haematologist, NHS Grampian
- Karyn Robertson, Senior Programme Manager, NHS NSS
- Sarah Smith, Principal Clinical Scientist, NHS GG&C
- Tara Tchehrazi, Clinical Scientist, NHS GG&C
- Margaretha van Mourik, Consultant Genetic Counsellor, NHS GG&C

There are also 2 parent representatives on the group.

