

June 2019

Welcome to the summer newsletter. This edition will summarise the work that SPAH has undertaken or been involved in during early to mid 2019.

## Rare Disease Day

It was a privilege for the Network to be invited to present at the Rare Disease Day on 5th March in the Scottish Parliament. This was a great opportunity for Dr Susan Baird, Lead Clinician, to promote the ongoing work of SPAH and to highlight the work done to improve the lives of those living with Sickle Cell disease. Pictured below; Christine and Olalekan provided the parent and patient perspectives of living with or having a child with Sickle Cell disease.



Pictured L-R: Dr Susan Baird, Olalekan Oyedepo and Christine Membi - The Hope Project.  
Acknowledgement to Claire Tennant Photography

## Annual Report

## Communication Strategy

The 2018/19 Annual Report is now available from the SPAH website:

<https://www.spah.scot.nhs.uk/publications/>

A Communication Strategy has been developed following feedback from stakeholders at the patient/family event and the wider membership. This can also be found on the following link of the SPAH website:

<https://www.spah.scot.nhs.uk/publications/>



GDPR

**UPDATE**

The General Data Protection Regulations (GDPR) deadline has now passed. We are pleased to report the number of patient's who consented for their data to be stored on CAS has achieved a massive 59%. **A big thank you** to colleagues who worked so hard in helping us to achieve this.

**Please** don't stop encouraging consent! We will provide a further update in our next newsletter.

## New Key Performance Indicator

From 1st April, 2019 collection has begun on a new KPI:

***KPI 7 - 100% of patients with Thalassaemia or Sickle Cell disease should be offered an annual review.***

An update on achieving this KPI will be reported in the next issue of the newsletter.

## Data collection

Since our last newsletter in December, 2018 the number of patients with Sickle Cell disease, Thalassaemia Major and Thalassaemia Intermedia currently registered on the Clinical Audit System (CAS) has increased by 4.5% to **229**. The table below illustrates patient numbers and the geographical spread.

Treatment Centre (group)	Conditions		
	SICKLE CELL DISEASE	THALASSAEMIA INTERMEDIA	THALASSAEMIA MAJOR
FORTH VALLEY	<5		
GG&C	103	11	11
GRAMPIAN	31	6	<5
LOTHIAN	36	<5	7
TAYSIDE	12	<5	5
Grand Total	184	21	24

## Quick Guide to CAS

**Remember!** The Quick Guide is now available on the SPAH website:

<https://www.spah.scot.nhs.uk/clinical-audit-system-cas/> This will remind you how to enter data and how to confirm when a patient has consented to their data being held on the Clinical Audit System.



## Sub group updates

## Paediatric & Adult Protocols/Guidelines sub group

This group is making great progress on reviewing existing guidelines and developing new ones. Please visit on a regular basis to keep updated!  
<http://www.spah.scot.nhs.uk/professionals/>

### Recently reviewed

#### Paediatric Guidelines

- Acute Chest Syndrome
- Hydroxycarbamide

#### Adult Guidelines

- Sickle Cell Outpatient Management
- Thalassaemia Outpatient Management

#### Pathways

- Diagnosed beyond Newborn Screening
- New case identified by Newborn Screening
- Surgery & Anaesthesia

### Currently under review

#### Paediatric Guidelines

- Sickle Cell chronic transfusion
- Paediatric & Adult Physiotherapy
- Inpatient Specialist Management of acutely unwell children with haemoglobinopathies

#### Adult Guidelines

- Iron Chelation
- Management of Hyperhaemolysis
- Acute Anaemia

#### Pathways

- Ferriscan referral
- Thalassaemia Intermedia

### For development

#### Paediatric Guidelines

- TCD protocol

#### Adult Guidelines

- Leg ulcers
- Renal
- Thalassaemia Endocrine
- Surgery

#### Pathways

- MRI
- Transfer

### IT / Audit sub group

Consenting patients onto CAS had somewhat taken precedence at our last meeting in February. Audit of the 7 KPIs will now be a top priority and that will be taken forward at our next meeting on 11th September.

### MDT Meetings

One MDT meeting has taken place so far this year. Future dates are being planned, so please visit the website where the new dates will be advertised. These meetings are educational events as well as a decision making forums. Please encourage as many trainees as possible to join and present. Video conferencing is always available.

### Nurses sub group

The annual meeting took place in March. A number of patient information leaflets were due for review which are all underway. A small number of new leaflets will be developed in 2020/21 which will include: Family Planning and Eye Checks. Part of this meeting allows for a peer to peer education session which the members are finding very useful.

Two members of this group; Rosie Hynd and Terri Lee Hughes are moving onto pastures new. We are grateful for their involvement to date and wish them both well for the future!

### Steering group

The most recent meeting took place in March and the next one is scheduled for 30th August. This meeting will also be the Annual Performance Review by National Services Division (NSD).

If you have anything you would like to add to the agenda for discussion at future Steering Group meetings please contact the network office.



## British Society for Haematology

The Sickle Cell Society had been invited to have a stand at the British Society for Haematology event in SEC, Glasgow on 1<sup>st</sup> and 2<sup>nd</sup> April. The Society kindly invited the network to support their stand.

Pictured below: Mhairi Gallacher and a representative from the Sickle Cell Society.



## Transition questionnaire

If you have a patient you have moved from children's to adult services in the last 5 years, please encourage them to complete our questionnaire. The aim is to understand whether our planned improvements will change the transition experience.

If you need a further copy of the questionnaire please email: [nss.spah@nhs.net](mailto:nss.spah@nhs.net)

## Website address

If you haven't already done so, please try to remember and add the network's website address to the bottom of your clinic letters to help improve traffic to the site?

[www.spah.scot.nhs.uk](http://www.spah.scot.nhs.uk)



## Scottish Ambulance Service (SAS):

A meeting with the Transformation Lead has taken place which was a mutually beneficial meeting. An action plan has been developed which includes, for example:

- Develop a patient leaflet "what to do when calling an ambulance"
- Short podcast/video about acute sickle cell complications to be made available on internet/intranet
- Develop a hazard alert notification form

Liaising with SAS will continue and a further update on progress will be shared in our next newsletter.

COMING SOON



## Laboratory Education Event

Planning is afoot to host this event in Glasgow around early November.

## SpR Education Event

A further event will take place in Spring 2020 in Glasgow.

**Keep an eye on the website for confirmation of both events!**