

Summer 2020

Welcome to the summer newsletter. This edition will summarise the work that SPAH has undertaken or been involved in during early-mid 2020.

Coronavirus (Covid-19)



We will all now be well adjusted to the “new norm” in our working lives. The pandemic has put a “fast forward” on the number of different options available to us in supporting the continuation of working remotely and virtually. Near Me and Teams are probably the two most used platforms in the NHS, and whilst we all had to learn very quickly how to use these, we are pleased to report that these are working well for SPAH.

What impact has this had for SPAH?

There is no doubt that Covid-19 has put limitations on a number of objectives on our workplan, but these have only been impacted in the short term. Planned meetings and events, for example, over the period from March to May were postponed, although that was only until we all became “super users” of our new technology, and now we are re-scheduling these events later in the year and using Teams to do this.

There may be some positives to take from this crisis - for example, considering ongoing delivery of some clinics appointments virtually where appropriate. This new format may well be welcomed by those living in remote and rural locations, and for those who struggle to travel to hospital, particularly for multiple appointments, as it would vastly reduce travel and time.



Annual
Report

The 2019/20 Annual Report is available from the SPAH website:
<https://www.spah.scot.nhs.uk/publications/>



An education event aimed primarily for SpR's has been planned for September. These will be delivered via Microsoft Teams over two afternoon sessions on:

Wednesday 16th September and
Wednesday 23rd September.

More details will be available soon and on the website.

To register your interest, please email:
nss.spah@nhs.net



General Data Protection Regulation (GDPR)

UPDATE

The latest position is that we are no longer required to obtain a patient/parent's written consent to keep information on the Clinical Audit System (CAS). This new position means that should a patient/parent not wish their/their child's information be held, they must request the removal of that in writing.

DATA

The last Newsletter in June 2019 reported there was a total of 229 patients on CAS, and we can confirm that has risen significantly by 27% to 291. The table below illustrates the numbers of patients, condition and treatment centre.

Patients and Conditions by Treatment Centre			
	SICKLE CELL DISEASE	THALASSAEMIA MAJOR	THALASSAEMIA INTERMEDIA
ABERDEEN - ADULTS	16	<5	<5
ABERDEEN - CHILDREN	25		<5
DUNDEE - ADULTS	13	<5	<5
DUNDEE - CHILDREN	<5	<5	<5
EDINBURGH - ADULTS	25	5	<5
EDINBURGH - CHILDREN	14	6	<5
FORTH VALLEY	<5		
GLASGOW - GRI	58	<5	<5
GLASGOW - QEUH	<5		<5
GLASGOW RHC	74	12	10

Sub group updates

IT/Audit Group

Issues with Business Objects reporting through the Clinical Audit System (CAS) as well as other constraints resulted in data being unavailable for many months. We are pleased to report these issues are now resolved and data reporting can continue. As a result of the issues, the group had not met since late 2019, although a meeting is being scheduled for sometime in September/October.

As reported in the last newsletter, the Network would begin collecting data on a new Key Performance Indicator (KPI):

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

The reporting of that KPI was put on hold until April 2020.

MDT Meetings

The frequency of MDT meetings has changed recently. The group now meet monthly for a one hour meeting, although if there are no cases to discuss the meeting is postponed to the following month. So far, two meetings have been held in May and June where a total of 6 cases were discussed together with updates on Covid-19

We are also pleased to have been invited to join the West London Haemoglobinopathy Co-ordinating Centre MDT meetings for sickle cell, thalassaemia and rare anaemias. This provides a great educational opportunity and regular access to specialist advice for some of our more challenging cases. The team have also been a useful source of information and updates about the recommended care for this patient group during the COVID19 pandemic. We were delighted to have had Dr Josu de la Fuente, Specialist in Transplant for haemoglobinopathies, visit Glasgow RHC in February, where we had the opportunity to discuss a number of planned transplant procedures



Sub group updates
..cont'd

Joint Guidelines Group

Coronavirus has certainly impacted on the review of a number of SPAH guidelines and pathways, although we are now in a position to take those forward and plan to have those completed by the end of the year.

A small number has been reviewed:

Paediatric & Adult Guidelines

- Sickle Cell chronic transfusion (paed)
- Surgery & Anaesthesia (paed)
- Paediatric & Adult Physiotherapy (joint)
- Iron Chelation (adult)

Pathways

- Adult Ferriscan referral

There are also 6 guidelines (both paediatric and adult) and one Pathway in development.

Please check the website in the coming months for updates.

Nurses Group

The annual meeting of the group which is normally held in March was cancelled. Teams is the way forward for this group, and a meeting is being scheduled for the end of October to review outstanding patient information leaflets and discuss the development of new ones. A Teams channel has also been set up where we can share and review leaflets/documents.

We would like to welcome 2 new members to the group who are both paediatric nurses:

Lucy Paterson, NHS Lothian

Jenny Milne, NHS Tayside

Steering Group

The most recent meeting took place on 12th June and the next one is scheduled for 9th September. 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.

Laboratory Education Event

In November 2019, a Laboratory Education Event was held in Queen Elizabeth University Hospital, Glasgow with 35 delegates in attendance. Below is a copy of the programme detailing the excellent internal and external speakers who presented. Feedback was very positive with comments including:

- *Good to hear of various techniques/protocols in use across sites*
- *Good mix of case studies, information and discussion.*
- *This has added to my knowledge in interpretation of variants*

Experiences from a routine screening laboratory	Jennifer Eglinton, Oxford University Hospital
Overview of Newborn Screening for Sickle Cell disease	Sarah Smith, Director of Newborn Screening, NHS GG&C
UK NEQAS Haematology: Performance Matters	Barbara De la Salle, Director, UK NEQAS
Haemoglobin Variant identification by Tandem Mass Spectrometry	Jason Eyre, Lead Biomedical Scientist, Sheffield Teaching Hospital
Laboratory comparisons	Glasgow, Grampian & Lothian
"Ask the experts" – Q&A session	All speakers

New Information Leaflet

A new adult information leaflet:

Sickle Cell Disease information for GPs: Adult Patient Management in Primary Care

Is now available from the website and a paediatric version is in development.

Scottish Ambulance Service (SAS)

We have completed work with SAS to raise awareness of the needs of persons with Sickle Cell disease in the out of hospital emergency setting. We have developed an alert to be uploaded, with consent, to the patient Key Information Summary via the GP, which will provide clear information for attending SAS staff. Please discuss with your patient whether they are willing for this to be shared and an email outlining the process will be circulated.

A helping hand...

For 7 weeks, through May and June, Laura offered her support one day a week to assist colleagues at the Scottish National Blood Transfusion Service in Glasgow in the pre-triage of donors.

Here she is in her SNBTS T-shirt and PPE kit!!

