





December 2020

Welcome to the NICCS Winter newsletter. This edition will summarise the work that NICCS has undertaken or been involved in during 2020

NETWORK RELAUNCH Event: 1 October 2020



Meeting etiquette

1. Please switch off your video & mute your audio when entering the meeting  
2. Full programme of this meeting can be found in the 'Files' at the top of channel page
3. Should you wish to ask a question, please use the [chat function](#) or the [Raise Your Hand button](#), and then wait for the Chair to call upon you before unmuting your microphone  
4. If you lose connection, please re-join by using the original link

NICCS Relaunch Meeting PROGRAMME

- 10:00 – Welcome & housekeeping
- 10:05 – Network Update
- 10:20 – Lead Clinician Update
- 10:30 – Implementing the National Specification in Every Health Board
- 10:40 – Looking ahead
- 10:50 – Q & A
- 11:00 – 11:15 BREAK

On the 1 October we have organised a national event to relaunch the Networks new name and structure now encompassing Inherited Cardiomyopathies engaging with health care professionals involved in the care of ICC patients.

There were around 60 delegates on the day, the presentations included talks on Implementing National Specification for ICC Services in Scotland, Covid impact on services, key priorities, challenges—followed by 2 separate workgroups discussions Inherited Arrhythmias and Inherited Cardiomyopathies.

Both sessions were appreciated by colleagues attending and number of actions were noted:

- Establish AHP sub group (to include genetic counsellors and specialist nurses) to focus on the education programme & the role in the care of ICC patients
- Update NICCS Long QT Protocol to include patient pathway, testing children for LQT
- Establish Pathology sub group (to focus on SCD/SUD pathway, communication following post-mortem, uniformity of pathology reporting & genetic sampling)
- Develop referral pathways for primary care
- The role of the ICC service in coordinating care and surveillance – understanding the clinical presentation in family members
- NICCS engagement with each HB in Scotland to discuss implementation of National Specification for ICC Services in Scotland & referral pathway
- Engagement with patient group to take specific pieces of work forward/consultation



Copies of the presentations will soon be available on the NICCS Website. If you wish to be get involved in any streams of work mentioned above –get in touch: nss.niccs@nhs.scot

NICCS end of the year Lead Clinician message

This year has been dominated by the global pandemic. Covid-19 has changed the way we live and work in ways we might never have imagined. Despite the uncertainty and challenging circumstances, NICCS has continued to work together to build progress for all those affected by inherited cardiac conditions.

In April we took up our roles as joint lead clinicians and have met regularly with the aim of implementing the National Service Specification across the whole of Scotland. In October the network was officially re-launched under its new name, NICCS (Network for Inherited Cardiac Conditions Scotland) reflecting its wider remit for both inherited arrhythmias and cardiomyopathies. Thank you to all of you who joined



At the heart of our network is our patients and their families. We are grateful to all those who have joined our new patient engagement group and also to the patient charities. These organisations have been supporting families more than ever, in what has been a tough year both financially and logistically.

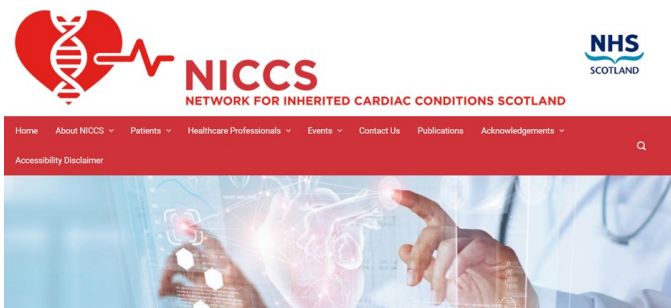
Your support, commitment and camaraderie is very valued and we look forward to the New Year with optimism that things will improve for us all. Stay well and we wish you and your families all the very best.

Dr Caroline Coats

Dr John Dean

NICCS Lead Clinicians

NICCS Website - new look



We have updated our website with the new colour scheme and logo & continue to improve it. If you feel there is anything missing—please give us a shout on nss.niccs@nhs.scot

Save the dates

22-31.03.2021 Virtual Interactive Cardiology Conference—organised by Royal College of Physicians and Surgeons in Glasgow. If you wish to attend please follow this link: [Virtual Conference](#)

Get involved

Further details can be found on the NICCS website: www.niccs.scot.nhs.uk



Or, contact us at
nss.niccs@nhs.scot
NICCS is on Facebook at:

www.facebook.com/NICCSScotland