

June 2020

Welcome to the NICCS Summer newsletter. This edition will highlight latest news and what is ahead in 2020.

NETWORK NEWS: New Manager and Lead Clinicians

NICCS New Programme Manager - Dawn Currie

Dawn has been a nurse with over 30 years experience across a variety of clinical and non-clinical roles. Her last clinical post was 13 years in the Beatson West of Scotland Cancer Centre as Sarcoma Clinical Nurse Specialist and then Advanced Nurse Practitioner.



larly those that cause sudden death and heart failure in the young. She is a member of the European Society of Cardiology Working group for Myocardial and Pericardial disease and Principal investigator for clinical trials evaluating new treatments in cardiomyopathy.

This is an exciting time for genomics in cardiology. Being able to perform gene testing has a major impact on making an early diagnosis and preventing complications. I want NICCS to provide the highest quality support, advocacy and education for our pa-

Dr John Dean, New NICCS Co-Lead Clinician

Dr John Dean is a Consultant in Clinical Genetics in Aberdeen and emeritus Reader in Medicine at the University of Aberdeen. He has a longstanding interest in inherited cardiac conditions particularly familial arrhythmias (including long QT syndrome), and Marfan syndrome and related disorders.



He studied genetics as an undergraduate in Cambridge and trained in adult medicine and paediatrics in Edinburgh. He was involved in setting up the arrhythmia genetic testing service for Scotland in Aberdeen, based on early research projects on the genetic causes of long QT syndrome and has been a member of the Familial Arrhythmia Network Scotland (now NICCS) since the beginning. He has developed electronic genetic records systems including genetic variant interpretation support for the North of Scotland. *I hope that NICCS can build on the excellent work of Dr Anna Maria Choy in creating and developing the network and improving services for patients with inherited cardiac conditions in Scotland. Developments in genetic and genomic testing, and in health data infrastructure will support improved standards of care. NICCS can be instrumental in maximising access to education materials and clinical tools for staff, and promoting information and support for patients. This will underpin improvements in care for arrhythmia and cardiomyopathy families in Scotland "*

Her project management experience includes managing multi-centre, national clinical trials working with international pharmaceutical companies. Now she works as a Programme Manager in the National Network Managed Service, part of NHS National Services Scotland, initially supporting national diagnostic networks but transferred over to national managed clinical networks in January 2020 as a Programme Manager for NICCS, Cleft Care Scotland (CCS) and Scottish Paediatric Adolescent Rheumatology Network (SPARN).

Welcome
aboard

Dr Caroline Coats, New NICCS Co-Lead Clinician

Dr Caroline Coats is a Consultant Cardiologist at Queen Elizabeth University Hospital Glasgow. She trained in Inherited cardiac conditions at The Heart Hospital, London before moving back to Scotland in 2015. Her particular interest is in inherited forms of heart muscle disease particu-



From FANS to NICCS – a personal journey



Scotland has been first in many things that have had significant impact on the health and well-being of its people and I like to think the network approach in the management of inherited cardiac conditions is one. The idea for a network was germinated by a story in the local paper relating the anguish of a family needing answers following the sudden unexplained death of a daughter and the parents fears and anxieties of not knowing what lay ahead for

their other children.

As a clinician on the other side of the equation, it did not take much to imagine the difficulties that family would face in getting answers in a system that did not naturally lend itself to working across disciplines in primary care and secondary care, health boards and other key agencies.

The concept of a network to draw in and engage key stakeholders to work together to overcome the barriers and inertia in the system, coalesced many people who contributed to the establishment and shaping of the network that was to become FANS, the Familial Arrhythmia Network of Scotland. It was a day to celebrate the culmination of tremendous effort and drive of many when FANS was officially launched in Holyrood on the 3rd February 2010.

The original objective of the network of improving care for families impacted by sudden death and familial arrhythmia syndromes through developing local pathways and services; updating clinical management based on guidelines and evidence; setting standards and audit; professional education and raising awareness; support for families; and advising on ICC at a national level; still remain relevant to the current network, NICCS. Many milestones have been achieved by FANS in terms of these goals.



Steering Group members met Nicola Sturgeon and Cross Party Group MSPs at the Launch.



To date, multidisciplinary working has been embedded in many centres, regional referral pathways for testing and diagnosis have been streamlined, improved access and investments in genetic testing have significantly increased number of tests, ten CPD accredited national symposia for healthcare professionals have been held with record attendances, strong engagement with the third sector supports education and service development; these are the obvious achievements of FANS. What made FANS unique was the drive to build on this success to progress and develop the network to include other ICC in its remit, namely the cardiomyopathies.

FANS was thus well placed to take up the opportunity to work with the Miles Frost Fund and the BHF to develop a Scotland-wide network of local genetic screening clinics and Specialist Nurse Practitioners trained in genetic counselling and cardiomyopathy. Although there remain challenges ahead, this has given Scotland one of the most comprehensive and effective screening services in the world.

Even as FANS becomes rebranded to NICCS, reflecting the wider scope and refreshed structure of the network, the raison d'être remains unchanged. There are still challenges ahead for NICCS, particularly regarding processes related to sudden unexplained death; patient engagement using new platforms to engage with younger patients; using registry data for audit and research that will improve clinical care.

The support for FANS from the beginning and over the years has been exceptional. Much credit and gratitude to the many who had belief in what we were setting out to achieve for these families, to the many who have contributed and continue to do so in many different ways.

There are too many names to individually mention from the past 12 years; the network administration team, the steering group and subgroup members, NSD colleagues and others but especially the patients and their families. When I look back, it has been a joy to have worked with so many along the FANS journey and to see what has been accomplished in Scotland, for Scotland. It truly ranks as one of the highlights of my career and I am very grateful.

Clinical Trials Update

Over the last few years we have seen real progress in the development of new treatments for individuals with Inherited Cardiac Conditions.

Over the last 12 months, the Scottish Medicine Consortium approved two new treatments for individuals affected with **hereditary transthyretin-mediated amyloidosis**.

In May 2020, the US pharmaceutical company MyoKardia announced very promising results from their EXPLORER-HCM clinical trial of the drug Mavacamten, the first drug developed to target the specific molecular defect of obstructive hypertrophic cardiomyopathy (HCM).

In Scotland, there are current opportunities for patients to enter clinical trials evaluating new treatments for:

1) Dilated cardiomyopathy due to Lamin gene variant

2) Hypertrophic cardiomyopathy with associated obstruction

We hope new therapies will continue to become available to our patients. For further information please contact NICCS on nss.niccs@nhs.net

New look - NICCS website

We have made changes to the way our website looks—we would like to adapt it to your needs! As a healthcare professional—what's important & useful? What do you think your patients are looking for? Is there anything missing? Please let us know: nss.niccs@nhs.net

www.niccs.scot.nhs.uk



NICCS Launch—new structure

Due to extraordinary national crisis this year it has been decided to move NICCS Launch Event from 17 June to 1 October 2020. It is anticipated to meet and discuss the new setup, membership of sub groups and workstreams and the 3-5 year workplan for the Network.

It is being considered that the event might potentially be happening virtually - please look out for the communication from the Network in coming months.

In the meantime—please save the date!

Upcoming events

Mark your diaries

27-30 September 2020 - **Heart Rhythm Congress** - due to current restrictions the conference will take place virtually. Visit heartrhythmcongress.org for more details.



26th-27th November 2020 - **British Society of Heart Failure**—23rd Annual Autumn Meeting—virtual (www.bsh.org.uk)

Get involved

Further details can be found on the NICCS website: www.niccs.scot.nhs.uk
Or, contact us at nss.niccs@nhs.net



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