



NICCS Newsletter Summer 2022

Welcome to the Summer newsletter for the Network for Inherited Cardiac Conditions Scotland (NICCS).

Since our last newsletter, there has been lots going on within the network including educational events for staff, patient engagement and national audits. Read on to find out more details on what the Network has been doing and what is planned for the coming months.

Please visit the NICCS website <https://www.niccs.scot.nhs.uk/> to keep up to date with our activities or email nss.niccs@nhs.scot if we can provide further information on any of the items noted below.

Best Wishes

Dr Caroline Coats and Dr John Dean
NICCS Lead Clinicians

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Annual Performance Review



The NICCS Annual Performance Review took place on 19th June 2022 where the progress of the Network in 2021-22 was discussed and our workplan for 2022-23 endorsed. At this meeting the Network commissioner thanked our lead clinicians for their leadership in achieving network objectives in challenging times and thanked Network members for their commitment and contribution. Further details on what the Network achieved last year and our plans for the year ahead can be found in our 2021-22 Annual Report which is available at: [Reports \(scot.nhs.uk\)](https://scot.nhs.uk/reports)

NICCS Education Events



NICCS Annual Symposium – 9th September 2022

The Networks' Annual Education event is taking place on 9th September 2022 at the Station Hotel, Perth. We hope that most attendees will take the opportunity to attend in person our first face to face event for three years, however, there will be the opportunity to attend virtually, where required and sessions will be recorded and made available to Network members after the event. We have an exciting programme planned with a mix of presentations and case discussions on Cardiomyopathies, Aortopathies and Arrhythmias. There are keynote talks from Esther Youd, Pathologist on Lessons from MBRRACE-UK and from Dr Alex Protontarios on Arrhythmogenic Cardiomyopathy. In addition, there will be interactive workshop sessions on imaging and ECG challenges. There will also have introductions to the Scottish Genomics Network and support available for staff from the NES Bereavement Hub.

To see the programme for this event and register your place please go to: [NICCS EVENTS \(scot.nhs.uk\)](https://scot.nhs.uk/niccs-events)

Monthly Education Sessions – 12:30pm, last Friday of the Month

The network continues to host monthly education sessions for health care professionals with an interest in ICCs. While we would like to encourage people to attend the sessions live if possible, we appreciate that this is not always possible and therefore each session is recorded and available on our dedicated NICCS Education Channel on Teams. To see the programme of sessions planned for the remainder of this year please go to: [News and Events \(scot.nhs.uk\)](https://www.scot.nhs.uk/news-events)

If you would like to be added to the NICCS Education Teams channel to access these sessions or have any suggestions of topics that would be of interest for a future session, please email: nss.niccs@nhs.scot

NICCS National Audits



The National Service Specification for the Network for Inherited Cardiac Conditions Scotland (NICCS) outlines the development of national audits to evaluate current service provision in Scotland to improve quality of care for patients and inform workforce planning. We are now embarking on the second round of the HCM National Audit and Sudden Cardiac Death Audits and would appreciate your support in collating the requested information.

If anyone has any question regarding these audits please get in touch with Gillian Kinstry, NICCS Programme Manager at nss.niccs@nhs.scot in the first instance.

The reports following the first round of audits are available to review on our website at: [Reports \(scot.nhs.uk\)](https://www.scot.nhs.uk/reports)

National MDT Meetings



A new initiative from the network is to host a national clinical MDT. The National MDT will meet via Teams for one hour on a quarterly basis and the Chair of the meetings will rotate around the ICC centres. The purpose of these meetings is to provide scientific and clinical expertise to families and support increasing education about complex inherited cardiac conditions.

More information will be shared in due course for further dissemination and will be available on our website. Please noted the dates for these meetings should you want to get involved:

- 12:00-13:00, Wednesday 14th September 2022
- 12:00-13:00, Wednesday 14th December 2022
- 12:00-13:00, Wednesday 15th March 2023
- 12:00-13:00, Wednesday 14th June 2023

Guidance



The HCM guidance has been updated and following consultation with Network members is now being finalised. The Sudden Cardiac Death pathway is also in its final stages and is currently with the SFIU for comment before being finalised. These guidelines will be shared soon and will be available on our website at: [NICCS Guidance \(scot.nhs.uk\)](https://www.scot.nhs.uk/niccs/guidance)

The Scottish Genetic Laboratory Consortium launched the Genomic Test Directory for Rare and Inherited Diseases in March this year. The Test Directory is available on our website at [SCOTTISH GENETICS CONSORTIUM](https://www.scottishgeneticsconsortium.com)

Research

British Heart Foundation – Cure Heart

The BHF announced the winner of their £30 million Big Beat Challenge Award. Cure Heart is an international team of researchers co-led by Professor Hugh Watkins, University of Oxford, aiming to cure inherited heart diseases using genetic therapies. It is an exciting time for everyone within the cardiomyopathy and heart failure community and most of all we hope will offer better treatments for families living with ICCs.

Read more here:

<https://www.bhf.org.uk/what-we-do/our-research/cure-heart>

<https://www.scotsman.com/health/scientists-set-to-cure-genetic-heart-conditions-that-cause-sudden-death-in-thousands-3785447>

Clinical Trials

New medicines are being investigated for patients with:

- Dilated cardiomyopathy due to Lamin A/C gene variants
- Hypertrophic cardiomyopathy with outflow tract obstruction

Please contact NICCS office (nss.niccs@nhs.scot) to find out more.

Save the Date



AICC Annual Conference – 12th December 2022

The Association for Inherited Cardiac Conditions are holding their annual conference in Scotland this year. The event is taking place on 12th December 2022 in the Golden Jubilee Conference Hotel, Clydebank. Further details will be shared in due course.

NICCS/AICC Training Day – 13th December 2022

A training day for health care professionals is being arranged to take place on 13th December 2022 in the Golden Jubilee Conference Hotel, Clydebank. This training day is being supported by NICCS, alongside pharmaceutical sponsorship, which will allow health care professionals working in Scotland to attend the training session for free. We would encourage as many people to attend as possible and ask that local boards support your attendance through study leave/travel costs. Further details on this day will be shared in due course and be made available on our website at [News and Events \(scot.nhs.uk\)](https://www.scot.nhs.uk/news-and-events)

Future Events – Looking ahead to 2023

- The European Human Genetics Conference 2023 Glasgow, Scotland, UK. June 10-13, 2023
- Association of Cardiovascular Nursing & Allied Professionals (ACNAP) Edinburgh 2023

Feedback



We hope you enjoyed this Newsletter. If you have anything you would like to include in future editions or if you would like to share information on what is happening in your area please get in touch.

We would also welcome your feedback on this newsletter and wider communications from the Network. All feedback is used to improve future communications.

Please email your comments to nss.niccs@nhs.scot