

## NICCS Newsletter Winter 2022/23

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

Since our last newsletter, the Network has been busy with our programme of educational events for staff, guideline development and national audits. Read on to find out more details on what we have been doing and what is planned for the year ahead.

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](mailto:nss.niccs@nhs.scot) if you would like to get involved in the Network.



On behalf of the Network for Inherited Cardiac Conditions Scotland we would like to wish you a Merry Christmas and a Happy New Year. We look forward to working with you in 2023!

Best Wishes

*Dr Caroline Coats and Dr John Dean*

NICCS Lead Clinicians

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## Lead Clinician (Genetics) Vacancy



Dr John Dean has advised that he plans to step down from the Network Lead Clinician role when his tenure comes to an end in April 2023. Early in the new year, NICCS will advertise for the Lead Clinician (Genetics) vacancy which will be offered as 1PA per week for an initial 3 year term. If you would like to find out more about the role of Lead Clinician ahead of the formal recruitment process please get in touch by email to [nss.niccs@nhs.scot](mailto:nss.niccs@nhs.scot)

To support continuity of the Network during this transition period, Dr Caroline Coats has agreed to extend her tenure as Lead Clinician (Cardiology) for a further year.

We would like to take this opportunity to thank Dr Dean for all of his work in leading the Network over the last three years and for his contribution to improving care for people/families affected by inherited cardiac conditions in Scotland.

## Education Events



### **NICCS Annual Symposium – 9<sup>th</sup> September 2022**

The Networks' Annual Education event was held on 9<sup>th</sup> September 2022 in Perth. This was the Networks first face to face event for three years with around 35 people attending in person and a further 40 people joined the meeting virtually.

The event had a mix of presentations and case discussions on Cardiomyopathies, Aortopathies and Arrhythmias, with keynote talks from Dr Esther Youd, Pathologist on Lessons from MBRRACE-UK and from Dr Alex Protonotarios on Arrhythmogenic Cardiomyopathy. The event also included workshop sessions on imaging and ECG challenges and an opportunity to find out more about the Scottish Genomics Strategic Network.

Feedback from the meeting was positive with 95% respondents rating the quality of the education provided at the event as excellent or good. Despite the technical difficulties participants were keen to ensure that future events had the opportunity to attend in person and online. It was noted that in the future the number of the presenters attending the meeting virtually should be limited to improve the experience for those attending in person.

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

The network has continued to host its virtual monthly education sessions for health care professionals with an interest in ICCs. Ten sessions have taken place across the year with a wide range of topics covered including psychological impact of ICCs, Variants Interpretation, ICCs and Pregnancy, Peripartum cardiomyopathy and genetic testing in children.

All education sessions were recorded and are available to view on the NICCS Monthly Education Teams Channel which now has over 80 members. We are currently evaluating our 2022 programme and seeking feedback on what topics people would like to see covered in future sessions. The 2023 programme will be shared on the NICCS website as soon as this is available.

If you would like to be added to the NICCS Education Teams channel to access the recordings of previous sessions or have any suggestions of topics for a session, please email: [nss.niccs@nhs.scot](mailto:nss.niccs@nhs.scot)

### **AICC Conference and NICCS/AICC Training Day - 12<sup>th</sup>/13<sup>th</sup> December 2022**

The Network worked in partnership with The Association for Inherited Cardiac Conditions to host their annual conference and a training day in Glasgow this month. Despite the challenges encountered with train strikes and adverse weather over 90 people managed to attend in person each day.

The AICC Conference focused on how the rapid growth in genomics and understanding of disease pathophysiology has led to more precise clinical care. The meeting provided an update on latest guidelines and emerging evidence relevant to practicing clinicians. The AICC conference was streamed live to those unable to travel to Glasgow and around 90 people watched the meeting online.

The Training Day was hosted in partnership with the AICC and NICCS to give medical trainees and allied health professionals the opportunity to access training in ICCs to better equip them to deal with these patients. This event was an in-person event to enable the day to be interactive and enable networking.

Feedback from both events is being collated but informal feedback from attendees on both days was very positive. The Network would like to thank colleagues across Scotland who supported the planning and hosting of this event and making it such a success.

## Patient Experience Survey



The network conducted a patient experience survey between October 2021 and August 2022 to gather feedback patients/carers/families affected by ICCs. The Network was keen to explore what was important to people affected by ICCs, to find out what works well at the moment and areas for improvement so that services could be tailored to better meet the needs of people affected by these conditions.

There were 31 responses to the survey with 20 people reporting that they had an inherited cardiac condition and eleven responses from relatives of someone affected by an inherited cardiac condition. Some of the key areas of feedback included:

*Respondents reported overwhelmingly that access to information was the most important thing to help them live with their condition. Information about their condition and treatment options was highlighted most often, however, information on lifestyle options and support available for people with an inherited cardiac condition was also noted by many respondents.*

*In response to what worked well with their/their relative's experience of living with an inherited cardiac condition the main area highlighted was around the clinical support they received with comments highlighting*

*support from clinical staff at diagnosis, advice on treatment options and follow-up care.*

*Respondents were asked what could have gone better with their/their relative's experience of living with an inherited cardiac condition. A wide range of responses were noted but the key area was the need for more information about the condition including implications of having the condition, treatment options and risk to family members.*

The feedback was collated into a report and shared with the NICCS Steering Group, Nurse/AHP Subgroup and Patient Engagement Group to inform future activities of the Network. Please email [nss.niccs@nhs.scot](mailto:nss.niccs@nhs.scot) if you would like to see a copy of the collated feedback. Thank you to everyone who took the time to give feedback and to the staff for their support in sharing this with people attending inherited cardiac care services.

## National MDT Meetings



The network has now hosted two national clinical MDT meetings and feedback from those who have attended has been very positive. The purpose of these meetings is to provide scientific and clinical expertise to families and support increasing education about complex inherited cardiac conditions. The Network has developed guidance for the format of the National MDT to support people who would like to submit a case for discussion. The meetings take place quarterly via dedicated/secure Teams channel with the next meetings taking place on:

- Wednesday 15<sup>th</sup> March 2023, 12:00-13:00
- Wednesday 14<sup>th</sup> June 2023, 12:00-13:00

Please email [nss.niccs@nhs.scot](mailto:nss.niccs@nhs.scot) if you would like to submit a case for discussion or get involved in one of these meetings.

## 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.

This year we embarked on the second round of the HCM National Audit and Sudden Cardiac Death Audits, and we would like to thank you for your support in collating the information requested. The data is currently being analysed and we hope to be able to share the findings with you in the Spring.

## Guidance



The Sudden Cardiac Death Pathway was endorsed at the Steering Group in November and will be published soon.

The HCM guidance has been updated and following consultation with Network members is now being finalised – the new guidance will be published early in the New Year.

These guidelines will be shared as soon as possible and will be available on our website at: [NICCS Guidance \(scot.nhs.uk\)](http://NICCS Guidance (scot.nhs.uk))

## Clinical Trials



Recent scientific advances have opened up new avenues for treating inherited cardiomyopathies. New medicines, called myosin inhibitors, are being investigated for patients with hypertrophic cardiomyopathy. In Glasgow, we have recently opened enrolment into SEQUOIA-HCM, a clinical trial of Aficamten for obstructive hypertrophic cardiomyopathy. Clinical trials are important because they allow the safety and effectiveness of new treatments to be properly tested.

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

## Future Events – Looking ahead to 2023



### **NICCS Patient/Family Event – 25<sup>th</sup> March 2023**

The Network is hosting a patient/family event on **Saturday 25<sup>th</sup> March 2023** in the **Edinburgh Training and Conference Centre, 16 St. Mary's Street, Edinburgh EH1 1SU**.

The programme for this event is being finalised but we plan to share information and offer practical support to families affected by a genetic heart condition. Topics will include mental wellbeing, support for young people and families, and living with the condition. Further information on this event will be shared with you soon and details will be available at: [www.niccs.scot.nhs.uk](http://www.niccs.scot.nhs.uk). We would be grateful for your support in promoting this event to people affected by inherited cardiac conditions.

### **NICCS Annual Symposium – 8<sup>th</sup> September 2023**



The 2023 NICCS Symposium will take place on **Friday 8<sup>th</sup> September 2023** in **COSLA, Edinburgh**. This event will again offer virtual attendance, but we would encourage you to attend in person if possible. The programme for the event will be shared in due course but for now please save the date in your diary.

## 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](mailto:nss.niccs@nhs.scot)