Summary Report - An Audit of the Scottish Pathways for Possible Malignant Hyperthermia

February 2022 – Presentation of findings to link anaesthetists across Scotland

In June 2018, The Scottish Muscle Network approved two pathways for the investigation of possible Malignant Hyperthermia (MH). These pathways cover:
(1) **Affected Case Pathway** - the onward referral of individuals thought to have been **affected** by an episode of MH, and
(2) **Family History Pathway** - the onward referral for individuals with a potential MH **family history**.
The pathways can be found at https://www.smn.scot.nhs.uk/malignant-hyperthermia/.

The period audited was 1st January 2015 -1st January 2020 and all 4 Clinical Genetics Centres in Scotland (Glasgow, Edinburgh, Dundee, and Aberdeen) contributed their data by extensive searches through local patient and molecular databases. Analysis of the combined data showed that referrals to Clinical Genetics in relation to MH increased in 2019, particularly in the smaller centres, following the implementation of the pathways. With the COVID-19 pandemic affecting referral processes during 2020, it is at present unclear whether this will be a continuing trend in the longer term. Overall, it appears that there remains scope to increase the awareness of the pathways and we include recommendations as to how this could be achieved in this report.

A total of 76 patients were referred to the Clinical Genetics service in relation to MH over the period audited. This comprised of 15 individuals with a history of a potential episode of MH and 61 individuals with a potential family history of MH. 27% of patients referred to Clinical Genetics for a potential MH episode were subsequently proven to be MH susceptible (genetically +/- in vitro contracture testing). Furthermore, 42.6% of patients referred for a family history of MH were subsequently given a risk profile – either susceptible (9.8%) or not at risk (32.8%). Both risk profiles groupings are highly relevant for these individuals' management should they require anaesthesia in the future. There was good adherence to the practice of updating the GP/referrer to patients with proven MH susceptibility. The issuing of an electronic alert and an alert card have been suggested as a pathway update.

This audit was presented to the link anaesthetists on 23rd February 2022. A useful discussion thereafter took place (unrecorded) and can be summarised as follows:

- ***Genetic testing & onward referral to Leeds*** – Following an episode of MH, the anaesthetist should discuss the case with the Leeds MH Unit. If Leeds agree the episode was MH and further testing is merited, then the patient should be referred to local MH Clinical Geneticist for genetic testing. Depending on genetic results, the MH Geneticist will then decide if IVCT is required and apply for funding from the National Services Division (NSD) to obtain authorisation for the referral to Leeds. **IVCT referral to MH Unit in Leeds is therefore made by Clinical Genetics in Scotland rather than by Anaesthetics.**

- ***Need for consultation with Leeds***
    - Anaesthetic colleagues should discuss cases of possible/probable MH with the Leeds MH Team for their clinical expertise. Clinical Genetics cannot advise on this.

- Unanimous agreement that Anaesthetists in Scotland are happy to discuss an MH diagnosis once made with patients without there being a need for a patient to travel to Leeds or have a have a video consultation with MH Unit for information.

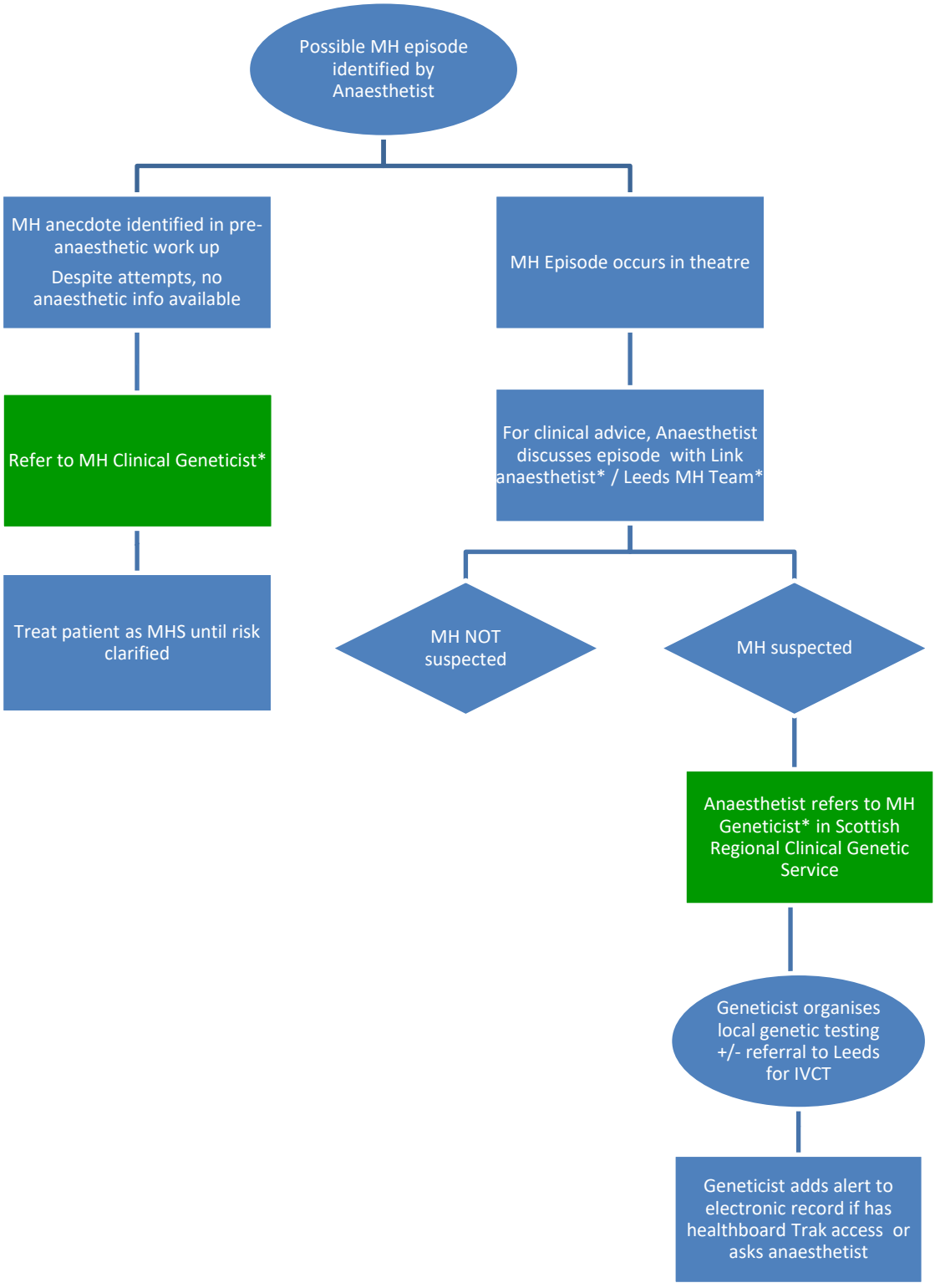
- ***Patient Registries*** – Discussion that patients with rare disease often like to be part of a patient registry to obtain up-to-date information regarding their condition. Geneticists will include signposting relevant registries as part of the Genetics consultation, including:
  - The RYR1 Foundation Registry which is US based: https://www.ryr1.org/registry
  - SMN leaflet on non-NHS muscle registries: https://www.smn.scot.nhs.uk/wp-content/uploads/2020/01/Non-NHS-Registry-Leaflet-v1.pdf

- ***Electronic alerts*** – An MH alert should be placed on Trakcare by Anaesthetist for patients who have experienced an episode of MH. Geneticists can place alerts on for family members if in health board area that they have access to Trakcare for. General consensus that link Anaesthetists would be agreeable to placing alerts for patients in their local health board area at the request of Geneticist if Geneticists are unable to access peripheral Trakcare, e.g., NHS Ayrshire and Arran, NHS Fife.

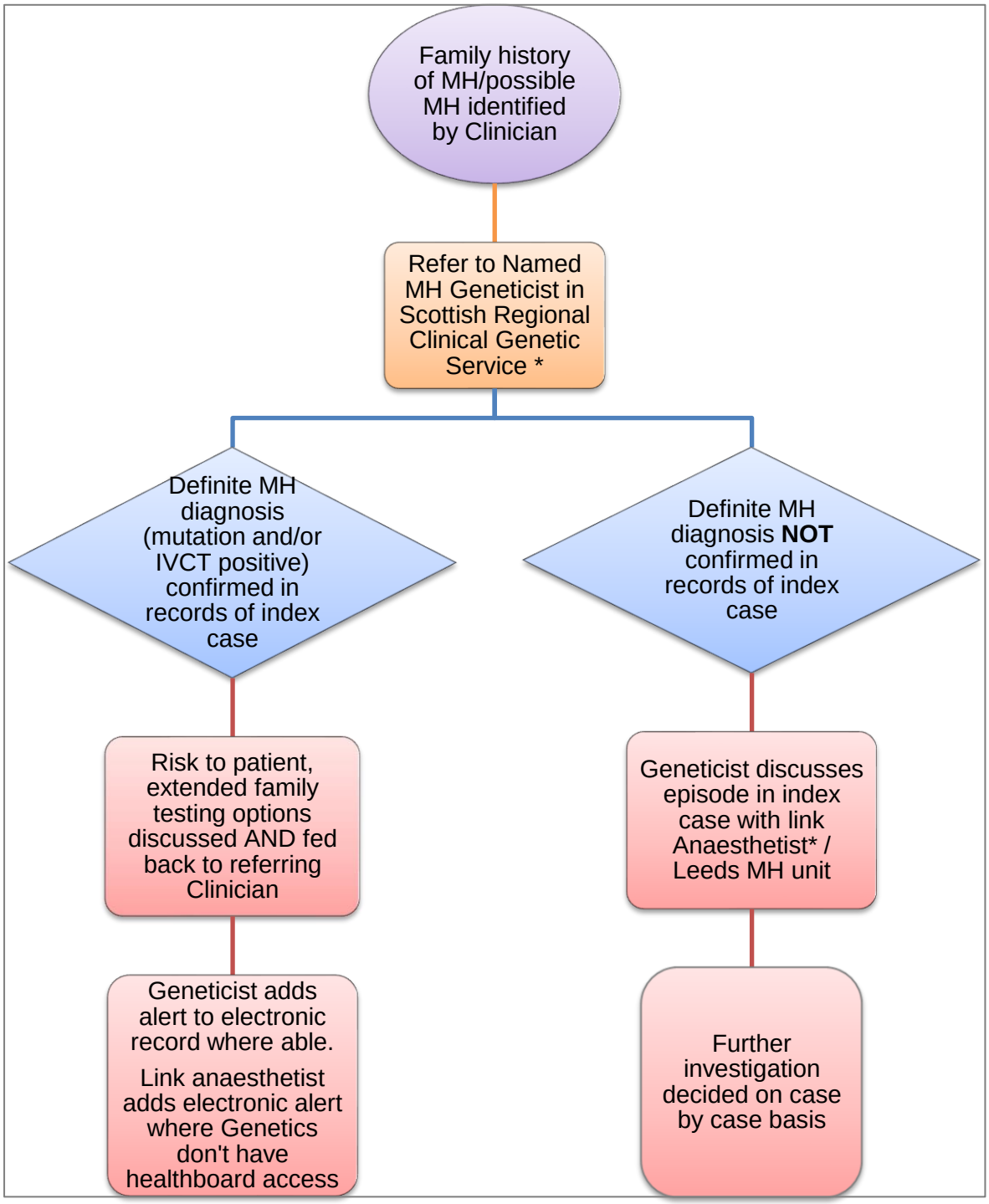
- ***Updates to Pathway:***
  - Adaptations to make clear Geneticist / Anaesthetic Role in 'Affected Case Pathway': In cases where Anaesthetists need clinical advice as to whether an equivocal episode in theatre was MH or not, advised to discuss with local link MH anaesthetist +/- Leeds MH Unit.
  - Where Leeds and local clinical opinion agreed that this was not an episode of MH, current pathway recommends informing MH Geneticist. However, feasibility and usefulness of this is questionable and unanimous agreement that this can be removed from the current pathway.
  - In patients with an anecdotal story of MH, and no locally available documentation to prove MH, Leeds MH Unit may have no further info on patient or where the history of MH is in a relative, Anaesthetics should refer to Genetics to investigate further. Genetics may thereafter also liaise with Leeds MH unit.
  - Electronic alerts as per above.

Updated Pathways following meeting on 23.2.22:

1. Affected Cases



2. Family History Cases



Scottish Muscle Network

Scottish Pathway for investigation of possible Malignant Hyperthermia (MH)

LINK ANAESTHETISTS / GENETICISTS

Adult cases

West of Scotland

Chris Johnstone	Crosshouse Hospital	Chris.johnstone@aapct.scot.nhs.uk
Gabi Lindhoff	Golden Jubilee	Gabriele.lindhoff@gjnh.scot.nhs.uk
Rose McRobert	University Hospital Ayr	rose.mcrobert@aapct.scot.nhs.uk
Michael Moneypenny	Forth Valley	michael.moneypenny@nhs.scot
Fiona Pearsall	QEUH & Gartnavel	Fiona.pearsall@ggc.scot.nhs.uk
Colin Pow	Crosshouse Hospital	Colin.pow@aapct.scot.nhs.uk
David Macnair	Dumfries & Galloway	david.macnair@nhs.scot
Rebecca Jadhav	Glasgow Royal Infirmary	Rebecca.jadhav@ggc.scot.nhs.uk

South East

Duncan Henderson	St John's Hospital, Livingston	Duncan.henderson2@nhslothian.scot.nhs.uk
Phillip Roddam	Western General, Edinburgh	philip.roddam@nhslothian.scot.nhs.uk
Charlotte Scott	Royal Infirmary of Edinburgh	charlotte.scott@nhslothian.scot.nhs.uk
Eva Biczo	Borders General Hospital	Eva.biczo@borders.scot.nhs.uk
Christine Kerr	Victoria Hospital, Fife	Christine.kerr2@nhs.scot

East/Tayside

Cameron Weir	Ninewells Hospital	cameron.weir@nhs.scot

North – Adults

Luna Saqr	Aberdeen Royal Infirmary	Luna.saqr@nhs.scot
Emma Whyte	Raigmore Hospital	emma.whyte@nhs.scot

Paediatric cases

West of Scotland

Nicholas Crutchley	Forth Valley	nicholas.crutchley@nhs.scot
Anne Goldie	Royal Hospital for Children, Glasgow	Anne.goldie@ggc.scot.nhs.uk

South East

Suzanne Boyle	Royal Hospital for Children & Young People, Edinburgh	suzanne.boyle@nhslothian.scot.nhs.uk

East/Tayside

Cameron Weir	Ninewells Hospital	Cameron.weir@nhs.scot

North – paediatrics

Kay Davies	Royal Aberdeen Children's Hospital	kay.davies@nhs.scot
Emma Whyte	Raigmore Hospital, Inverness	emma.whyte@nhs.scot

Geneticists

West of Scotland

Cheryl Longman	QEUH, Glasgow	Cheryl.longman@nhs.scot

South East

Elaine Fletcher	Western General, Edinburgh	Elaine.fletcher@nhslothian.scot.nhs.uk

East/Tayside

Catherine McWilliam	Ninewells Hospital, Dundee	catherine.mcwilliam@nhs.scot

North – Genetics

Alison Ross	Aberdeen Royal Infirmary	Alison.ross3@nhs.scot

Leeds MH Unit: www.leedsth.nhs.uk/a-z-of-services/malignant-hyperthermia

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