The British Society
for Genetic Medicine

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British Society for Genetic Medicine (BSGM)
PO Box 43, 95 Mortimer Street, London. W1W 7GB

Neville Sinclair,

HM Coroner's Officer

25 Bagley's Lane,

Fulham

SW6 2QA

05.05.2026

Dear Mr Sinclair,

Regulation 28, Prevention of Future Deaths response from BSGM regarding Adam Ankers

Following an inquest into the death of Adam Ankers who died from a cardiac arrest on 9th March 2026, the coroner issued a Regulation 28 report to prevent future deaths. Adam Ankers had an inherited cardiac condition (ARVC) which had not been identified at the time of his death. The British Society of Genetic Medicine was asked to respond to Point E: That cascade communication of genetic or hereditary diseases is imperfect and does not reach more than half of those in families that need to know about it.

British Society of Genetic Medicine - BSGM

BSGM is a registered charity (No: 1058821) that provides a forum for a wide spectrum of clinical, laboratory and researchers involved in genetics and genomics both in clinical service and research.

BSGM's objectives include

a) the promotion, encouragement and advancement of the study and practice of clinical genetics and genomics.

b) the advancement of education, research and innovation in clinical genetics and genomics

c) the promotion of public awareness of genetics and genomics as they relate to health and disease

d) the support of the professions contributing to applications of genetics and genomics in the health care systems of the United Kingdom

e) the making available of informed opinion on issues of public interest in relation to genetics and genomics

While many members of BSGM sit in positions of leadership within clinical genetics services and work within cardiac genetic services, it has no remit to implement service change but rather to influence how services are delivered.

The Joint Committee on Genomics in Medicine (JCGM) is a joint committee of BSGM, Royal College of Physicians, Royal College of Pathologists. In 2019, JCGM released the 3rd edition of the guidance document 'Consent and confidentiality in genomic medicine' .This was written by [redacted] [redacted] who has given evidence in this inquest, and [redacted]. Many of the principles in practice within specialist clinical genetics and genomic practice are supported by the principles of this document. Genetic testing is now more embedded in clinical practice outside of the specialist genetics workforce. There are many educational activities underway to equip non genetics specialists to deliver their specific element of genetic medicine, for example by giving patients information about their genetic risk and by requesting genetic testing, giving the result and explaining the implications to the wider family. The principles of the 'Consent and confidentiality in genomic medicine' document underpin much of this education.

Despite this, we acknowledge that the sharing and dissemination of genetic information within families may not be easy and is influenced by the complexities of family structures and dynamics as well as systemic constraints. Efforts are made to encourage and facilitate timely sharing of information and cascade testing in families. Barriers to this include limited service capacity, variable infrastructure and jurisdictional or cross border regulatory frameworks that restrict if, how and when clinical teams can contact or offer testing to at risk relatives directly.

We note from the Regulation 28 Report that the proband (index case) in this family was Adam's paternal grandmother's cousin who had been diagnosed with ARVC. Genetic testing identified a variant which enabled genetic testing for other family members. A letter with important information was written by a genetic counsellor for dissemination to the family. This information was received by Adam's grandmother but no testing had been undertaken in this branch of the family, including Adam. The information was passed onto a cardiologist by his grandmother who attempted to make an appointment to address this, but no appointment was made in error. This was not followed up either by the family or the cardiologist.

BSGM's role in this situation is to raise awareness of the need to share important information about genetic diagnosis and the results of genomic tests. BSGM will also contribute to documents such as 'Consent and confidentiality in genomic medicine' and to help in its dissemination. BSGM through its members can also help to influence service development in both specialist genetic services and also in more mainstreamed genetic medicine. Work is currently ongoing by NHS England to review the service specification for the Clinical Genomics Services and the working group involved in this work includes many BSGM or its contributory groups (Clinical Genetics Society and Association of Genetic Nurses and Counsellors) officers.

It is of note that there is work ongoing nationally, funded by British Heart Foundation (BHF), to embed genetic testing recommendations into Coronial pathways following sudden unexplained death. A more sustainable funding model for this important work would be extremely valuable for families with ARVC where a sudden death occurs.

I have enclosed a copy of the 'Consent and confidentiality in genomic medicine' document for your information.

Please do not hesitate to get in touch if you would like further information.

Yours sincerely,

[redacted]

Chair
On behalf of the British Society for Genetic Medicine

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Consent and confidentiality in genomic medicine