

Your guide to supporting **dilated cardiomyopathy** research

Introducing a new, investigational genetic testing program identifying **dilated cardiomyopathy patients with variants in the BAG3 gene.**



In this document you'll find:

- **Why** this study is happening
- **What** participation involves
- **How** your health information will be used and kept private, safe and secure

Where can I direct questions?

We're here to help in any way we can. Call us, email us, or start a live chat via the Sano Genetics website.

contact@sanogenetics.com | sanogenetics.com



Why is this study happening?

Dilated cardiomyopathy (DCM) can be caused by both genetic and non-genetic factors, and studying these factors helps doctors understand how the disease develops and who is at risk.

This study focuses on the genetic factors.

Using an investigational device, at-home genetic testing, we are finding people with DCM who have changes in a gene called BAG3.

Changes in the BAG3 gene are strongly linked to DCM, with about 80% of individuals over 40 who carry a pathogenic variant in this gene developing the disease.

People found to have this change as part of this study will be given the option to participate in a clinical trial. You will find out more about this trial if your test results indicate you have a change in the BAG3 gene.



Why was I invited?

You were invited because you have been diagnosed with DCM.



What are the benefits?

If you are eligible, you will benefit from:

- ✓ cost-free, at-home genetic testing
- ✓ cost-free genetic counseling
- ✓ understanding more about your specific case of DCM
- ✓ helping researchers identify potentially life-saving treatments for DCM
- ✓ gaining access to personalized clinical trial opportunities

! While genetic testing can help you better understand your condition and your family's risk, it can be challenging to receive your results. Before pursuing genetic testing, it's important to consider the implications carefully.

Conducted by

 **ALEXION**
AstraZeneca Rare Disease

 **Sano**

Reviewed and approved by

 **wcg**TM

What's involved?



You will need to sign a consent form



You will need to complete a short online questionnaire to confirm your eligibility for genetic testing



You will need to provide a saliva sample via an at-home genetic test kit that will be posted to you or provided to you by your healthcare provider



You will need to post your sample back to the lab

If you have a change in the BAG3 gene, you will:

- ✓ need to meet online with a genetic counselor to learn about your results
- ✓ be asked to provide a blood sample. **This is completely optional**

If you already have a genetic report showing you have a change in the BAG3 gene, you will be asked to upload your report.

It takes no more than 15 minutes to find out if you are eligible. The total time commitment for this study is roughly one hour. However, if you are found to be eligible for the clinical trial, this will require a further time commitment.



the testing in this study is for research use purposes only.

They will not appear on your official healthcare records or be used to make decisions about your clinical care.



Enrolled



MESSAGES

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Sano Genetics

There's a new study opportunity that may be right for you

How does genetic testing and counseling work in this study?

- ✓ If you are eligible, you will receive a free genetic testing kit from Sano Genetics.
- ✓ This will be posted to your home or you'll have access to a test through your healthcare provider.
- ✓ You will follow the instructions provided with your kit to collect a saliva sample and send it back to the lab, completely free of charge.
- ✓ Once your sample reaches the lab, your DNA will be analyzed.

How will I receive my results?

- ✓ Once your results are ready, we will notify you by email.
- ✓ If a genetic change is found, you will have the opportunity to review your results during a virtual, 1:1 meeting with a genetic counselor.
- ✓ A genetic counselor is a gene expert who will help you understand your results and address any questions you may have. This session is at absolutely no cost to you.
- ✓ Your results will also be accessible on your Sano Profile to download at any time.

How is my information used and protected?

- All study information is stored on secure and encrypted servers
- This genetic test is for research purposes only and, as a result, will not appear on your official healthcare records.
- Your anonymised information will be combined with other study participants' data and may be shared with Alexion Pharmaceuticals and/or sites participating in this trial.

How will my data be used?

The answers that you provide and your genetic testing results will be used to assess your eligibility for a clinical trial.

Your de-identified information (where any personally identifiable information has been removed and replaced with a unique code) may be combined with that of other people participating in the study and summarised in a report about the outcome of the research.

How will my sample be handled?

Your DNA sample will be sent to our third-party DNA testing lab. The lab will extract DNA from your sample and analyse it to see if you carry a change in the BAG3 gene.

Only de-identified information will be sent to our genetic testing lab partner.

Sano ensures compliance with all applicable data protection laws, including but not limited to: the GDPR in the EU, the Data Protection Act in the UK and the HIPAA in the US.



You can review our full data and privacy policy here:
sanogenetics.com/privacy

Compliance is an effective way to validate trustworthiness. Sano is pleased to provide independent verification that our security and privacy practices comply with the most widely accepted standards such as ISO 27001 and Cybersecurity Essentials.



How will my personal information be protected?

The information and genetic sample you provide us with will be stored on secure and encrypted HIPAA and UK-GDPR compliant servers owned by Sano Genetics and located in the UK.

Following trusted standards helps show that Sano takes security and privacy seriously. We're proud to have independent proof that our systems meet well-known safety standards like ISO 27001 and Cyber Essentials.