MT-RNR1 Genetic Test Result – variant identified in the *MT-RNR1* gene

This leaflet provides information for patients who have been identified as a carrier of a variant in the *MT-RNR1* gene.

What are *MT-RNR1* gene variants?

MT-RNR1 gene variants are a change in the DNA sequence of the *MT-RNR1* gene found in the mitochondrial DNA within our cells. Carriers of certain *MT-RNR1* variants may develop permanent hearing loss when treated with aminoglycoside antibiotics.

What does carrying a variant in the *MT-RNR1* gene mean for me?

A variant in the *MT-RNR1* gene means that you have an increased risk of permanent hearing loss if you are treated with aminoglycoside antibiotics.

Which medicines do I need to avoid?

Aminoglycoside antibiotics are used to treat certain infections, these types of antibiotics are often given by injection or as a nebuliser in a hospital. Some ear drops, eye drops, creams and ointments may also contain aminoglycoside antibiotics. The risk of hearing loss is highest with injections and nebulisers. The risk with other forms of aminoglycoside antibiotics is less clear but cannot be ruled out.

A list of aminoglycoside antibiotics used in the UK is:

- Gentamicin
- Amikacin
- Tobramycin
- Streptomycin
- Neomycin
- Framycetin
- Netilmicin

Some examples of aminoglycosides that may be used outside of the UK include kanamycin, arbekacin, astromicin, bekanamycin, dibekacin, isepamicin, netilmicin, paromomycin, ribostamycin, sisomicin, streptoduocin.

Be aware that medicines have two names, a brand name and a generic name which is the internationally recognised, scientific name for the active ingredient in a medicine. It is recommended to check the ingredients of medicines. Ask your doctor or pharmacist if you are unsure.

Your doctor may be able to prescribe you a different medication that won't affect your hearing in the same way. If this isn't possible, you should decide with your doctor whether the benefits of taking aminoglycosides outweigh the possibility of permanent hearing loss.

What does this mean for my family?

Around 1 in 500 people in the UK have a variant in their *MT-RNR1* gene. *MT-RNR1* variants are passed down from mother to child. Variants in this gene are not inherited from the father. You may have inherited this variant from your mother which means that your siblings (brothers and sisters), mother and relatives on your mother's side of the family are also at risk of carrying this variant.

What do I need to do?

We recommend that you ask your GP to document in your medical record that you carry a variant in the *MT-RNR1* gene and that you should avoid aminoglycoside antibiotics.

You should inform your doctor or pharmacist that you carry a variant in the *MT-RNR1* gene before taking an aminoglycoside antibiotic.

We recommend that you share this information with your relatives on your mother's side of the family. We have an information leaflet for relatives. The staff member in charge of your care can help you to decide with which family members to share this information.

Do I need any further tests or treatment?

If you experience hearing loss or changes to your hearing, we recommend that you speak to your GP who can refer you to local services for assessment if required.

Where can I go for more information?

The Royal National Institute for Deaf People (RNID) website provides information and support on ear health and types and causes of deafness including ototoxic drugs and hearing loss. The web address is www.rnid.org.uk .

Contact us

If you have any questions or concerns about the information in this leaflet or about genetic testing for *MT-RNR1* gene variants, please contact the Clinical Genetics Service on 020 8725 0572 (Monday to Friday, 9am to 5pm) or email genetic.secretaries@stgeorges.nhs.uk

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Was this information helpful? Yes / No

Please let us know, contact patient.information@stgeorges.nhs.uk and include the leaflet title.
Thank you.

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:
Monday, Tuesday and Thursday between 10am and 4pm
Friday between 10am and 2pm.

The Walk-in and Advisory telephone services are closed on Wednesdays.
Please contact PALS in advance to check if there are any changes to opening times.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS UK

The NHS provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.
Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.
Tel: 111

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

Reference: GEN_VID_01 **Published:** August 2025 **Review date:** August 2027