MT-RNR1 Gene Variants – information for relatives

This leaflet provides information about what to do if one of your relatives has been identified as being a carrier of a variant in the *MT-RNR1* gene.

Why am I receiving this leaflet?

One of your relatives has been identified as being 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* gene variants may develop permanent hearing loss when treated with aminoglycoside antibiotics.

What does this mean for me and my family?

MT-RNR1 variants are passed down from mother to child. Variants in this gene are not inherited from the father. If someone carries this variant, their siblings (brothers and sisters), mother and relatives on their mother's side of the family may be at risk of carrying the variant.

People with a family history of *MT-RNR1* variants on their mother's side have an increased risk of permanent hearing loss if they are treated with aminoglycoside antibiotics.

What do I need to do?

We recommend that you ask your GP to document in your medical record that you have a maternal history of an *MT-RNR1* gene variant and that you should avoid aminoglycoside antibiotics.

People with a family history of *MT-RNR1* gene variants on their mother's side are advised to inform their doctor or pharmacist before they take an aminoglycoside antibiotic.

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.

gesh is a collaboration between St George's University Hospitals NHS Foundation Trust and Epsom and St Helier University Hospitals NHS Trust.

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.

Do I need any tests or treatment?

In most instances, maternal relatives of a carrier of a variant in the *MT-RNR1* gene do not need to be referred for genetic testing.

Some medical conditions increase the likelihood of developing infections that are treated with aminoglycoside antibiotics. Examples include some respiratory diseases including cystic fibrosis and bronchiectasis, and conditions that affect the urinary or reproductive systems. You may be offered genetic testing by your doctor or specialist if you have a medical condition that requires long term treatment with aminoglycoside antibiotics or if you need repeated courses of these antibiotics.

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.

Please contact PALS in advance to check if there are any changes to opening times.

The Walk-in and Advisory telephone services are closed on Wednesdays.

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

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.

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