

MND Genies

Motor Neurone Disease NSW

Hello and welcome to MND Genies.

MND Genies is an online support network for people who have tested positive for a familial MND gene mutation. We do not provide medical, ethical or other advice, instead we exist to accomplish two things:

1. Better access to genetic counselling and support for people wanting to find out if they carry a known gene mutation. We are aiming to achieve this through our advocacy work at both a state and federal level.
1. The establishment of an informal support network for people who carry a known familial MND gene.

We know that genetic testing is a very personal decision. We respect everyone's right to hold their own views and feelings as a result of this process. It can be frightening at times, it can also be challenging, but what we hope for most through this group is to show that there is life after a positive genetic test for familial MND.

We hope being part of this group will help you feel connected to others who understand. Together with us you can make a difference and we can work towards achieving a world without MND.

To get you started we have enclosed some business cards, information about the MND Genies and some of our merchandise. Feel free to share the cards and to contact us if you would like to purchase additional items of merchandise. We especially want to hear from you if you want to join us in our advocacy work.

Once again, welcome, we are so pleased to have you join us.

Kaitlin, Jessica and Rebecca
Founders MND Genies



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Who are MND Genies:

MND Genies is a group for people who have a motor neurone disease related genetic mutation, but do not have MND. The aim of MND Genies is to provide a space where people can connect and share their experiences.

Where we began:

When the 3 Founders met by chance, they immediately saw the benefit of meeting others with the same experiences and knowledge, and the potential opportunities this would bring. The idea of the MND Genies was born.

We contacted MND NSW and put forward our ideas. MND NSW understood the need for a familial MND support group and helped the group to become established. Since then the MND Genies have been involved in reaching out to the wider community and government to raise awareness of MND and genetic testing. We have featured on Channel 10's 'The Project' and visited Parliament House as part of our advocacy work and we have much more planned for the future! You can find out more about some of our advocacy work by searching for MND Genies online.

[MND Genies: Advocating and raising awareness of familial MND](#)

How can you help:

Firstly, make sure you connect to us on Twitter and Instagram and share our posts to help spread awareness. Send photos to us of you wearing your merchandise, so that we can add these photos to the group sites too! If you're happy for us to share your photos, then please complete and return the photo consent form to mndgenies@mndnsw.asn.au

We would love you to join with us in one of the many Walk to d'Feet MND events throughout the year across the country. These events are run by the state MND Associations and the more of us who walk together in our MND Genies gear the bigger our impact will be!

We also plan to organise some fundraising events through the year, and we are always looking for people to help with this. Buying, or encouraging others to buy, our merchandise also helps!

Lastly, help us speak out about living positively with a positive genetic test. When we do, we may help make the experience a little easier for others.



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PHOTOGRAPH CONSENT

This form is to be completed where photographs, film footage, audio material and electronic images are used in material using the MND New South Wales (MND NSW) name or logo or collected/taken in the name of MND NSW, in services or activities organised by MND NSW or for MND NSW services and activities.

Material would always seek to display the individual and MND NSW in the most positive and appropriate manner.

There are two levels of approval:

LEVEL 1— For use by MND NSW when educating and raising awareness about motor neurone disease directly with health and community care professionals, such as at the Special Interest Group (SIG) workshop.

LEVEL 2— For use by MND NSW for motor neurone disease promotional, awareness-raising, fundraising or educational purposes that concern or benefit people with MND. This includes print, radio and web use.

The person involved needs to indicate their consent and sign the form below.

LEVEL 1— I DO / DO NOT (please circle) authorise the use of photographs, film footage, audio material, electronic images of me by MND NSW when educating and raising awareness about MND to health and community care professionals.

LEVEL 2— I DO / DO NOT (please circle) authorise the use of photographs, film footage, audio material, electronic images of me by MND NSW for promotional, awareness-raising, fundraising or educational purposes that concern or benefit people with MND. This includes print, radio and web use.

Name:

Signed:

Date:



Thank you. This form can be renewed at any time if requested by you or MND NSW