



#### In this edition

Professor Stephen Hawking... Dr Justin Yerbury featured on Australian Story... Congratulations Hunter... Does MND run in a family or have a genetic connection?... MND Week 2018 event locations... Order your 2018-19 Entertainment Book... and more.

## A Message from the CEO

Over the past month MND has been front and centre in the national and international media. The death of Professor Stephen Hawking stunned most and had many people talking about his life and MND. We include a link to a video tribute produced by the University of Cambridge on page 2 of the edition of *e-news*.

Closer to home, Dr Justin Yerbury, an eminent MND researcher based at the University of Wollongong, featured on ABC's Australian Story in late March (see page 2). Justin's determination and commitment to MND research and his own diagnosis with the disease has created a huge amount of awareness of MND nationally. Justin and his family showed extraordinary generosity in allowing journalists, cameras and the general viewing public into their lives and we are grateful to them for this.

With MND Week approaching keep the conversations about MND going by talking to your neighbours, friends and work colleagues about this disease.

Graham Opie



## Stephen Hawking dies aged 76

Physicist Stephen Hawking was born on 8
January 1942 and diagnosed with motor neurone disease (amyotrophic lateral sclerosis) in 1963 at 21 years of age. Described as one of the most brilliant theoretical physicists since Albert Einstein, Stephen Hawking died aged 76 on 14
March 2018. Hawking had a rare, early-onset



slowly progressive form of MND. You can watch the University of Cambridge video tribute by clicking the link <u>here</u> or the image above right.

## ABC TV Australian Story featuring Dr Justin Yerbury

A powerful episode of Australian Story was broadcast Monday 26 March on ABC TV featuring Dr Justin Yerbury from Illawarra Health and Medical Research Institute. Justin is an inspiration to us all and you can see the episode online at ABC iview.



## MND Australia Research Update March 2018

This research update is produced by the MND Research Institute of Australia - the research arm of MND Australia. Read the March 2018 Update here.

## Introducing new staff...

# Lauren Lovegrove | Coordinator of Support - Western Sydney and Blue Mountains

Hello. I have over ten years experience working in the community service sector, more recently focusing on case management and working with participants of the National Disability Insurance Scheme. I am looking forward to getting to know the team here at MND NSW and also our members and their families.





#### MND Week 2018

support our wonderful volunteers selling merchandise and collecting donations during MND Week 2018.

## Railway stations 7am-10.30am Cornflower Day Friday 11 May

- Central
- Circular Quay
- Parramatta
- Penrith
- Sutherland
- Wollongong

#### **Shopping Centres**

- Brookvale Warringah Mall, 12 May
- Charlestown Charlestown Square, 11-12 May
- Chester Hill Chester Square, 3 or 10 May
- Epping TBA
- Hurstville Westfield TBA
- Kotara Westfield, 5 May
- Leura Woolworths, 7 June
- Lismore East Lismore Shopping Centre, 9-11 May
- Narellan Narellan Town Centre, 12 May
- Port Macquarie Settlement City, 11-12 May
- Pyrmont Pyrmont Bridge shopping centre side TBA
- Queanbeyan Riverside Plaza, 5 May
- Tuggerah Westfield, 11 May
- Tumut Ice bucket challenge, 12 May
- Tumut Street stall, 11-12 May
- Wagga Wagga Wagga Marketplace, 9-11 May
- Woy Woy Deepwater Plaza, 7-8 May





## Support Service Update

I am writing this after watching the episode of Australian Story featuring Dr Justin Yerbury. He is such an inspiration in how he is living his life with MND. Justin's commitment to continue to research this disease as his physical abilities change is extraordinary. It was fascinating to learn that Justin and his family had met Stephen Hawking



several years ago and to hear Professor Hawking's introduction to the program.

Sadly, Stephen Hawking died this month. Stephen Hawking used his time living with MND to explore the universe but he also helped raise awareness of MND. His experience of MND was so very different to what most people with MND experience as he lived for over 50 years after diagnosis, starkly highlighting how the effects of MND - initial symptoms, rate and pattern of progression and survival time - vary significantly from person to person.

When we see people in the media with MND it can be a good thing but it can also be very confronting to others living with MND, their family and friends. Many questions can come up about the way people live their life with MND, how family and friends are involved and what decisions are made about interventions such as respiratory assistance and gastrostomy (PEG and RIG) for liquid feed and fluids. Each individual will have different priorities and preferences about how they live their life with MND and the decisions they make along the way.

Health professionals including your neurologist, respiratory and palliative care specialists and their teams can provide you with facts about interventions that may assist you in your decision-making. Talking to your family and friends and being in touch with others with MND can also be helpful. Our members often comment on how easy it is to chat to others about MND at a support group, an information day such as our *Living Well with MND* events or our *Care for Carers* 

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workshops. At these events you can see how others are living with MND and the choices they have made along the way, and share information and experiences with others who live with MND every day.

I would like to warmly invite you to our annual Day of Hope and Remembrance, to be held during MND Week on Saturday 5 May at Sydney Olympic Park. At this event we acknowledge all those involved with MND including people living with MND, their families, care providers and researchers. Our guest speaker this year is Janet Nash, Executive Officer Research, MND Australia. Janet has been involved in MND services and research for many years, initially with MND NSW in 1995 developing support services for people living with MND before moving to the MND Research Institute of Australia (MNDRIA) in 2005. MNDRIA amalgamated with MND Australia in 2010 and Janet has worked tirelessly to promote MND research and she will be sharing some of her experiences and hopes for MND. I hope you can join us.

Gina Svolos - Manager

## Retro Trivia and Cultural Night

A big thank you to Parul Amin, Vidjanti Amarsee, Suvin Prasad and Sujata Nathoo for supporting MND NSW with an Indian cultural and trivia night. This fantastic evening was held on 10 March and included trivia, dance items and a raffle with lots of prizes. Everyone who attended had a great night with a fantastic \$4,552 raised. Thank you

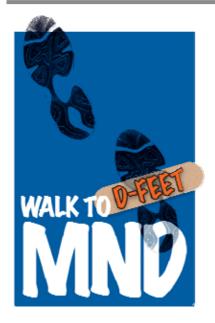


also to MND NSW Ambassador Ben Gooley who attended the evening.

#### For sale - Wheelchair modified car

2001 Chrysler Voyager Limited Edition. 127,000Km, regular yearly service, lovely to drive, leather seats. Seats 4 plus a person in a wheelchair. Non-hydraulic ramp, very easy to use. 6 months rego. \$5000 ono. Phone 0421 645 049.





## Walk to d'Feet MND Hunter Dixon Park

Merewether

Congratulations Hunter. What a fantastic show of support for the Walk to d'Feet MND on 25 March!

It was a new venue this year, and what a great success it was, with a choice of two different Walk routes for participants to choose from. There were over 700 people, lots of furry friends and a wonderful atmosphere.

Thank you to Angie for the great music, the Lions Club for the yummy sausages, Kickin Back Coffee and of course a very big thanks to all our wonderful volunteers. Not to forget our wonderful sponsors Leah Jay, KOFM and Capture Imaging Photography. With \$45,000 raised so far, the fundraising page for your donation will stay open for another two weeks.

Supported by











## Together, let's take steps to d'Feet MND

Join us at a 2018 Walk to d'Feet MND. The name of this event reflects the hope and inspiration these special days provide for the MND Community. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with motor neurone disease. Why not join in the fun at a 2018 Walk to d'Feet MND?

24 Jun Walk to d'Feet MND Canberra Supported by Peace Park, Parkes, ACT



**Register now** 

**15** Jul Walk to d'Feet MND Penrith Supported by International Regatta Centre, Castlereagh



**Register now** 

26 Aug Walk to d'Feet MND Batemans Bay Supported by Corrigans Beach Reserve, Batehaven



Find out more

**16** Sep Walk to d'Feet MND Port Macquarie Supported by Westport Park, Port Macquarie essentia



Find out more

14 Oct Walk to d'Feet MND Wagga Wagga Supported by Apex Park, Wagga Wagga





Find out more

4 Nov Walk to d'Feet MND Sydney Supported by Blaxland Riverside Park, Olympic Park





Find out more



## New venue for Gold Coast Carers MND Support Group

The <u>Gold Coast Carers MND Support Group</u> meets bi-monthly at Clear Island Waters. Come along to the new venue at Surfers Paradise Golf Club for the next meeting on Wednesday 6 June (no April meeting due to the Commonwealth Games). This is a great opportunity for carers to meet in a relaxed environment, enjoy some morning tea and company. For more information and to RSVP contact Chris Carroll, MND NSW Murwillumbah ph. 02 8877 0966 or MND NSW ph. 02 8877 0999.

#### Call for Abstracts 9th National MND Australia Conference

Health professionals, MND Associations, primary, palliative, aged and disability care providers are invited to submit an abstract to present at the 9th National MND Australia Conference, MND Care – Informing, Influencing, Innovating Adelaide, Australia on Thursday 30 August to Friday 31 August. Call for abstracts now open. More information and submission guidelines <a href="https://example.com/health/profession-new-more information-new-more infor

## Variety Concert supporting MND

Thank you to Don McMurray who organised his 4th MND Variety Concert in support of MND NSW. The concert included performances from Sophie Aked, Annette Phillis and the Sing Australia Choir. Thank you also to everyone who attended and for the generous donations, with \$2,307 raised.



## Tennis Charity Day

On Sunday 14 January, the Manly Lawn Tennis Club and The CorriLee Foundation hosted the Phil Dent and John Alexander MP Tennis Charity Day for MND NSW remembering the Australian tennis professional Peter Doohan. A tennis pro-am was played in the morning followed by a wonderful lunch presentation for about 80 people. Tennis



playing guests included former pro's John Alexander and Phil Dent, 2-times French Open winner Lesley Bowrey, and 5-times Olympian Alex Watson.



#### Panel discussion from 3rd MND Connect now available on YouTube

The video of the Panel Discussion from the 3rd MND Connect at University of Sydney is now available for free online viewing at YouTube. MND Connect is an annual interactive forum connecting people impacted by MND, with Australia's leading MND researchers. In November 2017 this Forum was held in New South Wales at the University of Sydney.



Panel members from the 3rd MND Connect included:

- Prof Matthew Kiernan, The University of Sydney
- Prof Julian Gold, The Albion Centre
- Carmen Sanchez CNC Calvary MND Service
- Gina Svolos, Manager Support Service, MND NSW

Watch the video of the Panel Discussion on YouTube.

## Pre-order today

2018-19 Entertainment<sup>™</sup> Books are a great way to save money and make a great gift for family and friends. 20% of every membership sold on the Entertainment Book Motor Neurone Disease Association of NSW link below is contributed back to



MND NSW. Help us achieve our goal by sharing the link below with your family and friends. <u>Pre-purchase your 2018-19 book or electronic membership before 6 April to receive Early Bird Offers you can use straight away</u>.

- Sydney and Sydney North \$70
- Sydney Greater West \$65
- Canberra \$60
- Newcastle, Central Coast and The Hunter \$65
- NSW South Coast \$60
- Gold Coast and Northern NSW \$60
- and many other areas across Australia and New Zealand.



	l	<b>Jpcoming</b>	Support	Service	event
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Click to find out more.

- Information Evening for people recently diagnosed with MND

  Gladesville
- Day of Hope and Remembrance
  Homebush
- Care for Carers 15 May, 22 May, 29 May and 5 June Gladesville
- Living Well with MND

  Port Macquarie
- Information Evening for people recently diagnosed with MND
  Gladesville
- Information Evening for people recently diagnosed with MND
- Living Well with MND
  Woden, ACT
- Past carers lunch
  Gladesville
- Living Well with MND
  West Ryde
- Information Evening for people recently diagnosed with MND Gladesville
  - Celebrating National Carers week morning tea Gladesville

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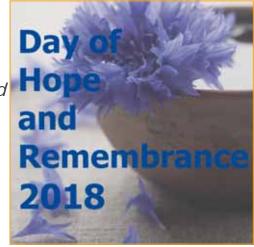
## Upcoming Support Service events (cont'd)





## Day of Hope and Remembrance Saturday 5 May 2018

We hope you, your family and friends will come along to our annual *Day of Hope and Remembrance* on Saturday 5 May 2018 from 1.30pm to 3.30pm at Soka Gakkai International Centre, 3 Parkview Drive, Sydney Olympic Park.



This afternoon of hope and remembrance

is for all those whose lives have been touched by motor neurone disease; including people living with MND, family, friends, supporters, volunteers and those working with MND.

There will be a candle lighting ceremony to represent the hopes and losses of those whose lives have been touched by MND. Let us know if you wish to volunteer to write a dedication or light a candle.

Our guest speaker is Janet Nash, Executive Officer Research with MND Australia, who will speak about the significant developments she's seen in MND research and care during the last two decades.

The MND March of Faces banners will be displayed and afternoon tea and light refreshments will be served.

For catering purposes please RSVP by 2 May by phone 02 8877 0999 or 1800 777 175, or email <a href="mailto:reg@mndnsw.asn.au">reg@mndnsw.asn.au</a>.



## Upcoming community fundraising events

Thai-riffic Night

BarLame Thai Restaurant, Dural



6-12 MND Week 2018
Warious across NSW and ACT



Run MND 2018

Sutherland to Cronulla



7th Annual Riddla MND Golf Fundraiser
Twin Creeks Golf and Country Club



- Australian Bee Congress
  RACV Royal Pines Resort, Benowa, Gold Coast
- 7 Bunnings Sausage SizzleOct Eastgardens
- Gundaroo Music Festival 2018
  Gundaroo Park



Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? <a href="http://www.mndnsw.asn.au/get-involved/fundraise.html">http://www.mndnsw.asn.au/get-involved/fundraise.html</a>

A gift to MND in your Will can make all the difference to an individual, their family and carers.

Your generosity can give help in many ways. For more information contact Yvonne Hamilton, Supporter Liaison Officer ph. 02 8877 0927 or <a href="mailto:yvonneh@mndnsw.asn.au">yvonneh@mndnsw.asn.au</a>.



## Care for Carers. Register or find out more today

Do you have a family member or friend supporting your day to day care? Then you may like to encourage them to attend the MND NSW *Care for Carers* program starting Tuesday 16 May.

Care for Carers is a supportive, enjoyable program held in at our centre at Gladesville once a week over four weeks. It aims to increase the practical



knowledge and wellbeing of a family member or friend caring for someone with MND.

Those who have attended say that the practical know-how gained, increased their confidence and ability to adapt to and sustain their caring role. Some rich and lasting friendships have also endured between many those who first met in this program.

Care for Carers is held just once a year and there is no cost to attend, so do make sure your family member/carer registers their interest as soon as possible. Register or find out more today.

## Understanding a little more about MND

About 30 people living with MND, their families and friends from South West Sydney and surrounds attended the Bossley Park *Living Well with MND Day* on Tuesday 20 March. We were very fortunate to have many of the team from the Liverpool Hospital MND Clinic attending - sharing their expertise about living with MND and how the Clinic can assist.



Dr Dennis Cordato, Neurologist, gave a very informative talk about MND to start the day. This included an overview of MND, clinical trials that are currently in progress in NSW, and diseases that mimic MND. He spoke of the new drug edaravone and answered commonly asked questions about medications and whether they make a difference in (Continued on page 14)



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managing symptoms such as fatigue, cramps, spasticity, depression and anxiety, pain and insomnia. He also spoke about the importance of a multidisciplinary approach to care to enable good symptom management.

Catherine Gregory, Senior Speech Pathologist provided some excellent tips on communication strategies. Occupational therapists, Bianca Brady and Leonie Siddens, brought along a range of aids and gadgets for everyone to try. The particular item that entertained the crowd was the helping hand extending arm stick that could be used to prod other participants!

David Wong, Head of Physiotherapy, demonstrated safe use of a transfer belt to assist a person with MND to move from sit to stand. He also spoke about how a carer needs to avoid pulling a person's arms when assisting someone change their position. A big message from David was to remind carers that they needed to look after their own positioning so they were not putting extra strain on their own body.

Hima Vedam, Respiratory Staff Specialist, has been a driving force behind the development of the Liverpool Hospital MND Clinic, concerned that people with MND in the region were not receiving the multidisciplinary care they required. Hima shared simple strategies to help with breathing and explained how non-invasive ventilation works.

Finally Desi Secombe, Palliative Care Specialist, reminded everyone that palliative care really means to help people live well for as long as possible and that this includes symptom control, planning ahead, decision making, advocacy and supporting people during difficult conversations.

During the day many questions were answered and people said they really benefited from talking to others with MND. *Living Well with MND* is on in Port Macquarie on Friday 25 May, Woden in the ACT on Wednesday 15 August and West Ryde on Tuesday 25 September. There is no charge to attend and lunch and refreshments are provided. Register or find out more today.

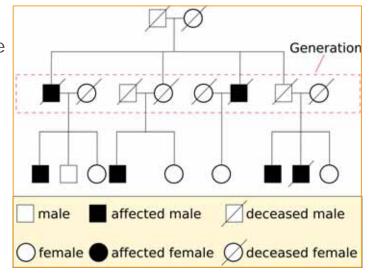


## **Article**

## Does MND run in a family or have a genetic connection?

About 10% of MND is 'familial'; that is, there is or has been more than one affected person in a family. The remaining 90% of people with MND are the only affected person in their family and are said to have 'sporadic' MND.

People with familial MND have the disorder because of a



mutation in a gene. A mutation is an error in the genetic code which causes a gene to work abnormally. People with genetic mutations can pass these onto their children. If a person has an MND-related genetic mutation each of their children has a 50/50 chance of inheriting the MND-related genetic mutation.

People who inherit an MND-related genetic mutation have a high, but as yet uncertain, chance of developing MND during their lifetime. However, not all people with an MND-related genetic mutation will develop MND.

The age at which symptoms of MND appear in people with an MND-related genetic mutation varies greatly. It can be as early as the 20s and as late as the 80s. As well, the age of onset can vary considerably within a family, even though the mutation carried by family members is the same. The average age of onset of familial MND is around 45 years.

Mutations in the genes that cause MND are also found in some people who have sporadic MND. The number of people with sporadic MND who also have an MND-related gene mutation is not known.

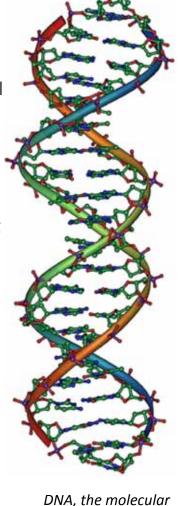


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#### MND-related genetic mutations

- In 1993 the first genetic mutation related to MND was discovered in the superoxide dismutase 1 gene (SOD1). About 20% of familial MND is caused by mutations in the SOD1 gene.
- In 2008 mutations in the TAR DNA binding protein (TDP-43) gene code were found to cause TDP-43 to become toxic, causing MND in a small percentage of MND families. Researchers are yet to find out how and why TDP-43 behaves abnormally to cause MND.
- In 2009 a gene mutation that causes a rare inherited form of MND, FUS (Fused in Sarcoma, a protein) was discovered. Researchers have found that genetic mutations of FUS are a cause of MND for a small number of familial forms of MND and account for between 3% - 5% of MND families.
- In 2011 the discovery of mutations in the <u>C90RF72</u> gene was announced and has since been found in about 40% of all families with familial MND.
- In 2016 <u>NEK1</u> was discovered through a genome
   -wide search for ALS risk genes in more than
   1,000 ALS families.
- In 2018 the <u>KIF5A mutation</u> was announced with patients with this mutation exhibiting a much longer survival period than other mutations. On average, people with the KIF5A mutation live approximately 10 years with ALS post-diagnosis.

KIF5A is one of the several motor protein genes encoded by our DNA.



basis for biological inheritance. Each strand of DNA is a chain of nucleotides, matching each other in the centre to form what look like rungs on a twisted ladder.

Image: Uploader's work on original work by mstroeck https://en.wikipedia.org/wiki/Genetics#/media/File:DNA\_Overview2.png

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 Although there are still some MND families in which the faulty gene has not yet been identified, the SOD1 gene and other MND-related gene mutations discovered in recent years now account for about 65% of all people with familial MND.

#### Current research

Researchers continue in their quest to find the mutations in other genes that cause familial MND in the 35% of familial MND families in which the genetic cause has yet to be identified.

Researchers are carrying out further studies to:

- understand how the known genetic faults cause MND
- work out how many of those with a faulty gene will actually go on to develop MND later in life
- identify mutations in other genes which may cause familial MND
- discover ways of preventing and treating familial and sporadic MND.

## Relevance of the discovery of gene mutations that cause MND

It is now possible to test for the presence of mutations in the SOD1, TDP43, FUS and C9ORF72 genes in a person diagnosed with familial MND. Other family members can also be tested to determine if they have the same mutation that caused MND in their relative. For example, adult children or brothers and sisters of an affected person can be tested.

Unborn children can be tested to determine if they have inherited the mutation known in the family.

Pre-implantation genetic diagnosis (PGD), an advanced screening technique, can be used in conjunction with IVF to determine whether an embryo has inherited the familial MND gene.

Some people who have an MND gene mutation may never develop symptoms. For those with an MND gene mutation who go on to develop symptoms, it is not possible to predict the age when symptoms will first appear.

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Research will increase our understanding of the mechanism by which these mutations cause MND, and may lead to treatments which can prevent or delay the onset of MND in someone with an MND-related genetic mutation. It is possible that research into MND caused by genetic mutations will also contribute to our understanding of the causes of other types of MND.

Some issues associated with testing for MND gene mutations Some reasons people have given for wanting to know if they have an MND-related genetic mutation:

- I am the sort of person who wants to know as much as possible about myself and my future and find it hard to live with uncertainty.
- To enable me to plan my life.
- To help with decisions about marriage and having a family.
- To provide information of importance to my children.
- If I do not have the gene, the information may help when I apply for jobs, life insurance, superannuation or when taking on longterm financial commitments.
- If I have a genetic mutation and it becomes possible to prevent
   MND, I can make use of the preventative measures.

Some reasons people have given for not wanting to know if they have an MND-related genetic mutation:

- I can accept living with uncertainty and will be able to plan my life without knowledge of my genetic status.
- I would not change my plans regarding marriage and having a family, whatever the test result.
- I do not think I would cope with knowing that I have the gene and will have an increased risk of developing MND.
- If I have a genetic mutation, the information may limit my life opportunities for example, in relation to career choices, life insurance, superannuation and financial matters.

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- Relationships with my family, friends and workmates may change if I am shown to have the gene.
- I am always free to change my mind and can take the test in the future if, for example, a treatment becomes available that can prevent MND.

# Frequently Asked Questions How is the test performed?

Testing is offered as part of a formal program providing the information, counselling and support a person might need when trying to decide whether to have the test and after the result has been provided. The test is usually done on genetic material (DNA) obtained from a blood sample. Testing must be voluntary. While each person will consider the views and feelings of family and friends, the final decision must be taken by the individual concerned. It would be inappropriate for someone to take the test because of pressure to do so. There is no Medicare rebate for testing for the presence of gene mutations that cause MND. Some genetic services may provide subsidised or free testing for several MND-related genes.

#### Can children be tested?

Children under 18 years of age should not be tested. Anyone having this test must be able to give informed consent. They need to understand and accept the testing process and the implications of the test result. This is a test which can give an indication of a person's future health and the results can have tremendous effects on various aspects of life. The right of parents to have information about their child does not outweigh the child's right to make a personal choice about whether or not to be tested.

#### Can DNA be stored?

DNA can be stored frozen, so blood from people with the disorder can be collected now and used in the future to help other family members when further genetic mutations are discovered.

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# Can I give a blood specimen for research, but without getting the result?

Yes. Researchers are keen to receive blood samples from people with a family history of MND, particularly if testing for the known mutations has proved to be negative in that family. If you would like to support research in this way, please contact your local MND Association for more information.

#### Will the test result be kept confidential?

The result will not be released to others without the formal consent of the person tested.

#### Who can provide support for those taking the test?

Family, close friends or other trusted people close to the individual can provide emotional support, as can health professionals such as doctors, (clinical geneticists, neurologists, psychiatrists, general practitioners), MND Associations, counsellors (including genetic counsellors) and social workers.

## Who can help with IVF and genetic testing?

Genetic counsellors can provide information and support for people who have an MND-related genetic mutation and are planning to start a family, as can health professionals such as doctors, (clinical geneticists, neurologists, psychiatrists, general practitioners) and MND Associations.

Pre-implantation genetic diagnosis (PGD) involves screening IVF generated embryos for genetic conditions prior to embryo transfer with only unaffected embryos transferred to the uterus.

IVF clinics can provide information on PGD and on where this specialist screening is available. They can also provide information on the associated costs and the Medicare rebates available. Genea is one private IVF company that provides a PGD financial assistance program to those able to demonstrate financial need, though there could be others.

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## MND Associations – what role do they play?

- Provide guidance and advice for people with MND, families and health professionals
- Produce and disseminate information
- Fundraise and advocate for MND research
- Advocate for the development of clinical programs which have a written protocol and provide full counselling and support for those taking the test
- Promote the sharing of knowledge and experience as research proceeds and clinical testing programs expand
- Support clinical programs which provide diagnostic testing

#### More information

Genetic counselling clinics operate across Australia. The Centre for Genetics Education Ph. 02 9462 9599 maintains a national list at <a href="http://www.genetics.edu.au">http://www.genetics.edu.au</a>.



For information on IVF and pre-implantation genetic diagnosis (PGD) contact IVF Australia ph. 1800 111 483.

For information on the PGD assistance program contact Genea ph. 1300 361 795 or visit the website at <a href="http://www.genea.com.au">http://www.genea.com.au</a>.

For more information about familial MND contact:

- the neurologist who is treating, or treated, the person in your family with MND
- MND NSW Info Line ph 1800 777 175 or 02 8877 0999.



# **Motor Neurone Disease Association** of New South Wales

Building 4 Gladesville Hospital, Gladesville NSW 2111 (Locked Bag 5005, Gladesville NSW 1675)

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Team Leader Eileen O'Loghlen

...and many valued volunteers