

Thumbs UP

MNDALS

Association of South Africa

NPO 155-413

The Newsletter of the
Motor Neurone Disease /
Amyotrophic Lateral Sclerosis
Association of South Africa

May/June 2017



*"Miss Ribbons 4 Roses" with our MND consultant, Tracey Cuff
(see story inside)*

The Mission Statement of the MND Assoc. of S.A. is
"To provide and promote the best possible support for people living with
Motor Neurone Disease, their families and carers and to raise public awareness."

MNDA of South Africa is a member of the International Alliance

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ACKNOWLEDGEMENTS

John Hall for producing the design and DTP (desk top publishing) work.
Logo Print (Maitland) for the printing of our magazine

A few years back, I presented a report about the MNDA of SA at an International Alliance of MND/ALS Associations meeting in Sydney, Australia. I vividly remember the disbelief I was met with when I mentioned what our annual operating budget was. Numerous delegates came to speak to me afterwards, wanting to know how on earth we get by with such a budget. The simple answer was, and still is: we simply have to. And the truth is, what we have we owe to a large extent to the generosity, energy and compassion of people who put in a tremendous effort to raise funds for the MND. These are often individuals or families who lost loved ones to MND, sometimes many years ago, but are still persisting in their efforts to support the MNDA. If you keep an eye on the newsletters, you'll recognize the names, year after year. The MNDA owes our continued existence to them, and they continue to surprise me.

But I am occasionally also surprised in a less pleasant way. Every now and then, a social media post or email surfaces where someone (usually a family member of a person with MND) complains about the extent of services offered by the MNDA or one or more of the MND clinics. These usually are accompanied by confident suggestions on how to improve the services. For example, a recent post suggested that "those who can't travel need Skype consults as well as occasional visits by all disciplines of medical professionals from time to time". In ideal circumstances, this would work great (although not even 1st world countries are able to offer this), but one cannot help to wonder whether the person ever stopped to think about the practicalities before posting. To address these, I think it is important to explain the healthcare context in SA, as well as where the MNDA fits into this and how it functions. Although we usually assume that this is common knowledge, I suspect this may not be the case if one looks at the above and other similar posts and emails we receive.

Let's start with the MNDA of SA. The main aim of the MNDA is to provide support, both home-based and through support groups, for people with MND and their families. We receive no financial support from the state, and all funding is obtained through fundraising, bequests, donations etc. Membership fees barely cover administrative costs. As many of you have experienced, our consultants work tirelessly and are available at all hours. We also try to supply much needed equipment, like wheelchairs, BiPAPs etc to our members. But we have to do all of these on a very limited budget, and with very few people. This means that we are often not able to offer equipment or services to our members that would be available in other countries, simply because we do not have the capacity. And it often means adopting policies that would benefit more of our members at the expense of not being able to meet some individual needs. This is not our choice, it is forced upon us.

But even if we were able to do more, one has to realize that another major component of MND support is the healthcare system. Most people in SA are dependent on the public healthcare system, and I think it would be helpful to make a few points about this system, especially the limitations. I'll use my own work circumstances as an example, but it is important to realize that workload, resources, personnel etc. vary considerably from centre to centre. I work at an academic hospital in the Western Cape. Our personnel consist of one part-time and three full-time qualified neurologists and a group of neurology trainees. We conduct five outpatient clinics every week, where we have approximately 4500 to 5000 patient visits per year. Of these visits, only about 70 or 80 visits are people with MND/ALS (i.e. about 1.5% of patient visits). As is the case at a few other centres across the country, we see people with MND/ALS at specialized multidisciplinary clinics. At these clinics, we have doctors, different types of therapists, and MNDA consultants. By having all of these services at one clinic, we hope to eliminate the need for multiple visits in order to see different healthcare professionals. However, the availability of these services is wholly dependent on the state healthcare system, as none of these are externally funded. Another very important point to consider is the disease profile in SA. Our healthcare system is overburdened by infectious and cardiovascular disease like stroke. Rarer conditions like MND simply do not feature on the Department of Health's list of priorities. Therefore, to believe that additional funding can be channeled to such clinics is not realistic. Even just running a specialized clinic like this depends on individual doctors initiating and maintaining it, as it is not part of the standard healthcare system. Unfortunately, people making use of private healthcare are not necessarily better off. Because MND is still not on the list of PMBs, people in private healthcare are often worse off, as neither the medical aids nor the state would pay for medication and equipment. A last point to consider is the overall shortage of neurologists in SA. To put it into perspective: in the USA there is one neurologist for about 25 000 people; in SA this ratio is about 1:250 000.

The message I am trying to bring across is simply this: we as the MNDA, as well as the healthcare sector, are doing our very best to offer you the best support we are able to. If we are not able to meet some individual needs that you may have, please know that it is not because we don't want to or are not trying. We live in difficult financial times, and it is always the most vulnerable people in society that will feel the effect of this the most. But please know that we will not stop trying, and, with your help, we'll continue to make a difference.

Dr Francko Henning

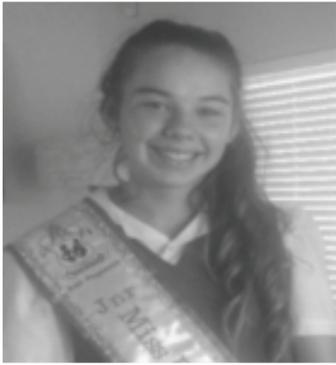


Thank You!

What an amazing and generous gesture - we are so very grateful to Sue Harris for the substantial donation of R205,000 in memory of her husband John who succumbed to MND in April 2011. This is such a boost and inspiration to help us fulfil our mission of providing the best possible support for people living with MND.

We also received a donation in memory of a loved one from the Wiseman family, and for the past 7 years have received an annual donation in memory of a club member, from Masonic Bowling.

Thank you for all donations received, whether monthly or in lieu of birthdays and special occasions, or just simply because and thank you also, to the members who have paid their membership fees for the current year (and that little bit extra in some cases !)



Megan Latsky of the Strand, Western Cape, is, through a high school initiative, an ambassador for 'Ribbons & Roses' a charity organization which collects donations and gives to people in need. She contacted Tracey Cuff, MNDA Consultant for that area and donated a wheelchair for one of our patients. (See front page)

Megan is to be commended for giving her time to get involved with such great work. We wish her well for the future, and success on whichever path she may follow.

NEWS



Harriet Koen, a patient from Vanderbijlpark in Gauteng who attends the MND Clinic at Chris Hani-Baragwanath Hospital, recently received her tablet which was programmed especially for her (voice banking). This will enable her to communicate without any confusion and she is so excited !! We wish Harriet well with her new device and happy chatting !

*A bad attitude is like a flat tyre
It won't get you anywhere until you change it*

~ Unknown ~

21 JUNE IS GLOBAL AWARENESS DAY !!!!

Excerpt from the Spring 2017 issue of "Thumb Print" MND A, UK, Magazine:

"The lasting legacy of a single blood sample"

"Our DNA bank is a vital resource for MND researchers. For 10 years we collected blood samples and personal information from people living with MND, their partners and family members. Samples collected years ago are still being used by researchers, leading to new knowledge about the causes of MND.

When we began collectin the samples there was no way of knowing how rapidly technologies would progress. However, as new knowledge and technologies have emerged, our DNA bank has never been more important. Dr Jean Walters who is living with Progressive Muscular Atrophy (a slower progressing form of MND) was one of the first people to provide a blood sample in 2007. Jean said : 'When you are diagnosed, you are suddenly confronted with a disease that has not treatment or a cure, only hope for what research will uncover in the future. Providing a sample felt like a very positive, proactive thing to do.'

'It is incredibly heartening to think that by providing that little bit of blood, it has helped with the advancements that we are seeing today.'

"Once Jean's blood was collected, it was divided in two. One half went to a "Hub" centre where a pure DNA sample was extracted. The second half was used as an 'insurance' sample in case the supply of DNA ran out. To make sure Jean's blood cells could be used in the future, they were specially treated so that they would grow forever, creating what is known as a 'cell line'. Jean's pure DNA sample was then used for whole genome sequencing. Whole genome sequencing analyses every letter of our DNA – as that is approximately 3 billion letters, it generates a huge amount of information.

This technique might tell us about the generic contribution to MND in those that don't have a family history – the so-called 'susceptibility' genes. As these effects are likely to be very subtle, it is important to have as many samples as possible to be able to spot these susceptible genes.

The Project MinE initiative aims to collect and analyse as many DNA samples as possible from people with MND. MND genetic researchers from around the world are pooling their expertise to interpret the results of the genetic analysis. We have committed to sending approximately 2,000 samples to Project MinE and we are already 75% of the way there.

One way a blood sample can be used to understand what is happening in people with MND is by turning it into a motor neurone. In the last five years, a new way to grow human motor neurones has been developed. This technique reprogrammes human cells into motor neurones by creating 'induced pluripotent stem cells' (iPSCs) as a step in the middle. Thr programming can start from either blood cells or skin cells. Blood cells from the DNA bank are being used for these studies.

We are currently funding Professor Chris Shaw at King's College London, to generate iPSCs. Once Professor Shaw and his colleagues have created a goo drange of iPSCs from different people with MND, these will help researchers in understanding the causes of MND.

Director of Research Development, Dr Brian Dickie, marks 20 years at the Association, and looks back on his time at the Association:

"I will never forget my first day. I walked in and the staff were using computers with tiny six inch green screens. Our research team was just one and a half people (including me) and we were funding three research projects worth around £100,000. Now our research grants number more than 80 and is topping £14.6million.

The advance of the Internet has helped encourage collaboration and the sharing of information and new findings across continents. Researchers cannot afford to operate in silos and this is particularly true for rare diseases. The impact of international collaboration has been particularly successful in the search for genetic causes of MND, giving rise to initiatives such as Project MinE. While cyberspace is a fantastic tool and facilitator, there is also much to be said for face to face contact outside of the laboratory. What I call coffee queue collaboration remains one of the key reasons the world's best researchers across so many fields attend our annual International Symposium.

The Association still has its roots in the branch system that evolved soon after the foundation of the charity in 1979. Despite our growing scale and influence as a charity and as a research funder, I like to think we haven't lost our sense of community and people often refer to our MND family. It's humbling and inspiring to visit our branches and groups and see the amazing support that we provide to families affected by this devastating disease.

We have come a long way in the past 20 years in our understanding of MND. The challenge now is to turn that understanding into effective treatments. This is a challenge I am increasingly optimistic we can meet!"

Making the link between genetic and environmental factors:

We think the reason most people get MND is due to a combination of lifestyle, environment and genetic factors. To help understand the environmental and lifestyle factors we asked people who had provided a DNA sample to complete a questionnaire covering many things, ranging from the houses they'd lived in, smoking history, jobs, hobbies, to their medical history.

Comparing the answers from people with MND with healthy controls will give us clues regarding what factors may contribute to why someone develops MND. This way researches will be able to make links between genetic and environmental causes of MND. We have shared this data with Professor Ammar Al-Chalabi at King's College London to help understand why people develop MND.

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*Success is not final, failure is not fatal  
It is the courage to continue that counts  
~ Winston Churchill ~*

## GREAT NEWS !!

### ALS Therapy Development !

***On-going research bears fruit – ALS TDI statement regarding FDA marketing approval of Radicava (Edaravone) as a treatment for ALS.***

[www.als.net/news/fda-approves-radicava-edaravone-as-treatment-for-als/](http://www.als.net/news/fda-approves-radicava-edaravone-as-treatment-for-als/)  
(Robert Goldstein – “I have been working at ALS.net since 2004. I write about the latest science in ALS

*and aim to provide a layman's overview of topics important to patients, caregivers, clinicians and researchers alike. I am a Staff Writer and Editor for our Research News and Commentary Section of ALS.net.”*

“The Food and Drug Administration announced today (5 May 2017) it has granted approval to MT Pharma America to begin marketing edaravone as a treatment for amyotrophic lateral sclerosis (ALS). The approval of edaravone marks the first new treatment to be approved for ALS in the United States since Rilutek® (Riluzole) was approved in 1995.

“This announcement (<https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm557102.htm>) is an important one. The approval gives people with ALS and their doctors a new treatment option to explore together. ALS is a complex disorder and it will require multiple different approaches to bring relief to all those diagnosed with ALS. With several additional potential treatments in clinical trials today, this is a uniquely hopeful time for the ALS community”, said Steve Perrin, PH.D, CEO & CSO of the ALS Therapy Development Institute (ALS TDI).

People with ALS can refer to the MT Pharma America website ([www.mt-pharma-america.com](http://www.mt-pharma-america.com) (<http://www.mt-pharma-america.com/>)) for more information about edaravone.

Some forms of ALS are genetic linked to dozens of different genes associated with the disease. However, most ALS cases are still considered sporadic, having developed without a known genetic link. For these reasons and others, ALS remains a challenging heterogeneous disease, with many different forms of highly variable progression rates between each individual person diagnosed.

Edaravone was developed by Mitsubishi Tanabe Pharma Corporation in Japan, originally as a treatment used in the recovery from stroke. Later, the company worked through several clinical trials in Japan to explore its potential as a treatment for ALS given its properties as a free radical scavenger. Japan's pharmaceutical regulatory agency approved edaravone to be marketed as a treatment for ALS in 2015. In Japan edaravone is marketed as Radicut, whereas in the United States it will be marketed by MT Pharma America as Radicava following the FDA approved issued today (5 May 2017).

The ALS Therapy Development Institute will hold a public webinar in the coming days to discuss edaravone with the ALS community. Advance registration required at <http://www.als.net/als-webinars/>.

- Background on Radicava (<http://www.als.net/news/date-set-for-decision-on-radicut-as-als-treatment-in-united-states/>)
- Comments on Radicava presentation at Dublin International ALS/MND Research Symposium in 2016 (<http://www.als.net/news/global-als-research-progress-a-report-form-2016-international-symposium-in-dublin/>)

*Edaravone / Radicava is not yet commercially available in South Africa. It is possible to import the medication, but in order to do this, an application has to be made to the Medicines Control Council by the treating doctor. This has to be done for each patient individually. This is unfortunately a very expensive process. The drug is administered via IV infusion, which is usually done at the hospital, daily for 10 days every month. The cost of the medication is approximately R8500 per month, excluding the cost of administration in a hospital or day clinic.*

**Bee natural .....**

The Ancient Egyptian queen, Cleopatra, definitely knew a thing or two when it came to eternal beauty, and still has us green with envy decades later! So when it was discovered that her key beauty ingredient was the gloriously sweet, golden liquid we love for so many reasons, there is no doubt that honey is the absolute bee's knees! and who does not want to be and look younger?

**Anti-aging :** Rich in antioxidants, 15ml honey a day will keep free radicals at bay.

Add honey to your healthy diet to delay aging. You could also smear some honey on your face to get rid of wrinkles and other signs of aging

**Sleep problems :** Take 15-30ml honey before bed

**Razor bumps :** Apply some raw honey immediately after shaving and rinse off after 10-15 minutes. You'll be bump free

(Ref : March 2017 Get It Joburg West)

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*I asked God to give me everything so that I can enjoy life
 Instead He gave me life so that I can enjoy everything*

(Sent to 'Thumbs Up' by Mrs Peerbhay of Estcourt, with a message of blessings to all)

**Condolences to the family and friends of :**

Barbara Leachman (15/2), Farieda Joseph (19/2), Magdalene Snyman (20/2), Vivian Zaayman, Annetjie Fourie (24/2), Christo Kotze (4/3), Jenny Price (6/3), Johannes de Wit (8/3), Eric Cronje (9/3), Lisa McNichol (10/3), Mogamat Franciscus (11/3), Samuel Adams (3/4), Stephan du Toit, Junaid Isaacs (11/4), Elizabeth Williams (12/4), Bernice Schilling (16/4), Reginald Parker (20/4), Jan de Hart (24/4), Jasmine Moodley (25/4), Dominic Sass (12/5), Theodore Wilson (16/5), Emile van Lill (18/5)

BE PART OF OUR MND COMMUNITY

WE ARE ALWAYS LOOKING FOR SNIPPETS OF NEWS, PHOTO'S OF EVENTS AND/OR GATHERINGS, AN INTERESTING STORY OR TWO (FUNNY and EVEN NOT SO FUNNY!) TO SHARE WITH OUR MEMBERS AND READERS, SO PLEASE LET US HEAR FROM YOU !

PERHAPS YOU CAN LET US KNOW WHAT YOU DO FOR
GLOBAL AWARENESS DAY -
21 JUNE



**We welcome your ideas – THUMBS UP is your voice –
 So if you would like to Contribute to the next issue – Please write to us !**

HELPING THROUGH YOUR WILL

Your Will can be a convenient vehicle for making a charitable gift of a lasting value. Please consider MND Association as a living memorial for a loved one.

Many people support the work of the MND Association of South Africa through bequests from their Estates.

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