

Thumbs UP

MNDALS
Association of South Africa

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

February/
March 2015



Kevin Jordan of Johannesburg with his wife Carla see 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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Aviva Pelham (M. Mus.)

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Logo Print (Maitland) for the printing of our magazine



A REMINDER !

Annual Membership fee R200 –

Banking Details:

Motor Neurone Disease Association of SA (or MNDA of SA)
Account No 27 062 913 0 at Standard Bank, Rondebosch 025009
(Please insert your “name”/membership as reference)

So now we are well into 2015 and possibly some (or most) of those New Year’s resolutions have been tried, tested, and forgotten! Even with the best of intentions, it happens to all of us.

A quick recap on last year:

We report that we had a disappointing run with our Christmas Card sales for the season and we probably could blame the recent postal strike for the public not being enthusiastic enough to take a chance that their cards would or would not be delivered! This was a general trend as the Charity Card Kiosks were not well supported. But let’s hope we have better luck in 2015.

INTERNATIONAL ALLIANCE MEETING:

As reported in our September/October 2014 issue, Dr Franco Henning attended the International Alliance of ALS/MND Association’s 22nd Annual Meeting, the Allied Professionals Forum and in the International Symposium on ALS/MND in Brussels in December. Dr Henning said he was once again impressed by the large amount of clinicians and researchers attending the meetings and symposium, and especially by the international commitment to the management of Motor Neurone Disease. He advised that committed researchers worldwide are collaborating to ultimately develop an effective treatment for MND/ALS.

Dr Henning reported further: “What impressed me at the Alliance meeting were the accounts of the impact that the Ice Bucket Challenge had around the world. What started as a simple challenge between friends snowballed into one of the greatest global awareness events ever seen. This taught me that the impact of an idea is impossible to predict, and that we should simply go out on a limb more often. This is an attitude that our organization could definitely benefit from in the future. Furthermore, I was encouraged by the general attitude of “we’re in this together” among the attendees. We often feel isolated here on the southernmost tip of Africa, and it is great to know that this is in fact not the case if we are part of the Alliance! Thank you very much to the Alliance for making this possible for us.”

FUNDRAISING AND AWARENESS



In 2013, MND patient Kevin Jordan of Johannesburg, together with his wife Carla (front cover), under the banner of “You and Me versus MND” raised R100.000 for the MND Association.

In 2014 they set themselves an even tougher target of

R200,000 ! - well, with lots of hard work and with the help of many generous people they achieved this goal – no mean feat! Events organised included : **Go-Karting days** at Kyalami Karting Circuit, Rivonia Barnyard (ABBA) with 150 people joining for a fun filled evening on Awareness Day 21 June, **Ladies Day** (with 160 ladies!), **a Veterans Football Tournament** arranged by Edenvale Football Club, and a **Charity Bond for the Momentum 94.7 Cycle Challenge** in November.



TO KEVIN & CARLA, THEIR FAMILY AND FRIENDS, EVERYONE WHO PARTICIPATED AND THOSE WHO GAVE THEIR TIME (AND MONEY!) TO SUPPORT THIS FUNDRAISING DRIVE, A HUGE THANK YOU FOR YOUR GENEROUS CONTRIBUTIONS AND HELPING TO MAKE THIS AMAZING DONATION POSSIBLE. THANK YOU !!

Carla says: "Our first event for 2015 will be taking place in April and details will be posted on our facebook page 'You and me versus MND' shortly and she encourages people to 'like' their page, and join them at future events in the support and awareness of MND in South Africa!

Bellville Support Group

Joey Bayley, Peggy Saxon & Tracy Cuff, Consultants for Cape Town and surrounding areas, organised a "High Tea" in Bellville, on Saturday 6 December, to raise funds for MNSA. Although it was arranged at rather short notice and also at a difficult time of the year to get people to attend, it was a lovely morning with about 60 people supporting this worthy cause. The guest speaker, Bruce Walsh, who was severely injured in the Planet Hollywood bombing, gave a very inspiring talk and you could hear a pin drop! His ordeal and recovery is truly amazing and he now leads a full and productive life, even though he lost both his legs. Some of our MND patients were present as well and as always, we love spending time with them and enjoy their positive outlook on life – they too are very special and inspiring people. The hall looked very festive with white table cloths and poinsettias as table centres. The refreshments were enjoyed by all and hopefully they can do this again in future. On this occasion R5,200 was raised! Thank you to everyone involved and thank you to the guests for "buying" their Saturday morning tea and cake from MNSA!



Momentum 94.7 Cycle Challenge



Tea Party in Bellville



Tea Party in Bellville

Our 1st Fundraiser for 2015

Santa's Story was very well supported and we have to thank Roxy Levy and Peggy Saxon for selling all 256 tickets! We would also like to thank Janet Graham for donating wine for pre-show drinks and Tracey Cahill of Theatre on the Bay for being so helpful and accommodating. But there is a BUT – 4 hours before the show was due to start we got notification that a Stage 2 loadshedding was scheduled for the Camps Bay area and due to the Theatre not yet having a generator which would be “powerful” enough to keep all aspects of the theatre operational, the show might be cancelled! Imagine the panic : what now? We started contacting some of the ticket holders who were further away from town and they were naturally disappointed. BUT we did not reckon on the force of Peggy Saxon (one of our Consultants in the Cape Town area), who announced that there was no way the show could be cancelled and she managed in a short space of time, to organize a generator strong enough to “take the load”. The power went off at 8.10 pm and was restored at 10.10 pm – Aviva Pelham (the star of the show) delivered a magnificent and moving performance which left the audience quite emotional. The show ended with her 96 year old mother Santa, on whom the story is based, joining her in song. Theatre on the Bay have been very accommodating and have offered tickets for another evening to those who did not attend due to the “power panic” and others made an outright donation of the cost of their tickets.

*Life is not the way it's supposed to be
It's the way it is
The way we cope with it is what makes the difference*

NEWS

Dave Nichol & Glynys St Clair were married in Pretoria on 9 October 1954 and spent their honeymoon in Lourenco Marques (now Maputo), Mozambique. Glynys was then secretary to a Mine Manager in Welkom and Dave was a recently qualified Land Surveyor. They celebrated their Diamond Anniversary last year with family and friends at a luncheon at a restaurant in Sardinia Bay. They have 3 children: 2 sons and a daughter and 7 grandchildren.

The highlight of their anniversary was receiving a card from Queen Elizabeth with congratulations and best wishes on such a special occasion.



Dave Nichol & Glynys St Clair

AWARENESS

(From Winter 2015 issue of "Thumb Print" (Magazine of MND Association, UK))

MND is once again in the global spotlight thanks to an Oscar and Bafta-nominated box office hit film which explores the relationship between Professor Stephen Hawking (the Patron of MNDA UK) and his first wife Jane. Prof Hawking was diagnosed with MND at the age of 21 while studying at Cambridge. Now aged 73, he is recognized as one of the world's greatest minds. 'The Theory of Everything', released on New Year's Day, is a biographical romantic drama based on 'Travelling to Infinity: My Life with Stephen', written by Jane Wilde. It focuses on the challenges of being a carer and partner to someone with a progressive condition. The film's star Eddie Redmayne is nominated for a multitude of awards and has scooped a Golden Globe for his role as the renowned astrophysicist and Felicity Jones' portrayal of Jane has also been widely acclaimed.

A lot of problems stem from the fact that so few people have heard of MND, so this film is also raising the profile. Prof Ammar Al Chalabi, Director of the Kind's MND Care and Research Centre, was among those who attended the film's premiere. He said treatment and diagnosis are very different today from that depicted in the film. "The acting was superb. If Eddie Redmayne had come to my clinic like that I would have thought 'this is MND'".



Excerpt from the Autumn 2014 issue of "Thumb Print" (Magazine of the MND Association, UK):

New Era for DNA Bank : Beyond Genetic Research

The UK MND DNA Bank was set up in 2003 to find out more about the causes of MND, using DNA from donated samples. Now, thanks to exciting new developments in technology, the samples will soon be used in research that would have been deemed science fiction a decade ago.

MND is thought to be caused by a combination of subtle genetic, lifestyle and environmental factors. The UK MND DNA Bank was designed to help identify the genetic factors involved to help identify the genetic factors involved in the disease by studying the DNA (or genetic material) of people with MND.

The DNA Bank consists of over 3,000 samples, which were donated from people with MND, their family members and healthy participants (often from a partner or spouse of someone with MND. These act as 'controls' in research studies).

Together with the accompanying, anonymized information on the participants, these have been used to create an important resource of DNA samples and lymphoblastoid cell lines (white blood cells) for MND researchers to use.

Exciting changes

Originally two blood samples were collected. One was used to extract DNA, which is now stored at the University of Manchester. The second blood sample was sent to Public Health England in Wiltshire, to create an everlasting supply of DNA by storing the white blood cells from the sample.

Today, MND researchers are just as interested in the white blood cells as they are in DNA. This is because, thanks to advances in technology, these white blood cells can be used to create cell models of MND. White blood cells can be converted into 'induced pluripotent stem cells', which in turn can be turned into motor neurons. Creating motor neurons from blood cells was unimaginable when the UK MND DNA Bank was first created. Now these models will be used to further understanding of MND in the lab. The samples would not be given to patients.

Making great strides

People living with MND, and everyone who cares for them, are at the heart of everything being done. We know that investing in research is important to you. This is why it has not been agreed to researchers using the samples in wider MND research studies (rather than just genetic research) to help achieve the vision of a world free of MND.

Dr Belinda Cupid, Head of Research at the Association (UK), leads on the project. She said: "We've made great strides in discovering the genes that contribute to MND. There's more to do, and DNA in the UK MND DNA Bank will continue to be an important resource. However, the next step is to understand why the genetic damage or variations cause motor neurons to die. This means looking at these genes within cells, ideally motor neurons. It is a significant and important step forward that we can use the cells from the DNA Bank for this too".

Dr Colin Fenwick, who has MND, donated a sample to the bank in 2011. He said: "I'm obviously very pleased that the MND Association is widening the type of research that can access samples from the DNA Bank. In the last few years advances in analytical technology have made it possible to search for clues in areas that were little more than science fiction only a decade ago. By opening the DNA Bank to these exciting new areas of research, the Association is increasing the likelihood that a breakthrough will be made sooner rather than later". Colin's wife also gave a sample. She said: "If the DNA Bank can give more information to increase our understanding, and perhaps one day to help in the development of treatment for MND, then I am very proud to contribute. I hope this one small positive thing can come out of Colin having this awful condition".

.... on the local front

A much-needed epidemiological project studying the incidence, course and genetics of MND/ALS in South Africa has

been initiated by our Chairman, Dr Franco Henning. This collaboration between local universities and international researchers will be a first for MND/ALS in our country. We are very happy that, due to the wonderful response to the Ice Bucket Challenge, MND of SA will be able to contribute to this much-needed and long-awaited project.

VENTILATION – A matter of Choice

(From the Winter 2015 edition of Thumb Print (MND of UK))

With MND, the use of ventilation many need to be considered, where a machine helps support breathing. Deciding whether or not to use this support can be difficult. Three people living with MND, made different choices.

Ventilation cannot stop MND progressing: if breathing muscles begin to weaken, this will continue to get worse. Nevertheless, although the benefits may vary, assisted ventilation can improve quality of life and help reduce anxiety and fatigue.

An assessment is needed to find out if ventilation is suitable. The GP should be asked for a referral to a respiratory team where staff can help an individual make an informed decision that feels right for them. Personal needs, current condition and wishes about future care may all play a part in decision making.

SUSAN was diagnosed with MND in 2004.

She is unable to walk or speak and has no power in her hands – but her mind is as active as ever and she has a zest for life. Susan has decided not to use ventilation or tube feeding.

“I have never felt ill and I am not in any pain” she explained. “The most devastating thing has been losing my voice, as I was, and still am, a chatterbox! The best gadget I could ever have is my Lightwriter, my way of communicating with the outside world”.

Susan explained why ventilation was not the right choice for her. “I don’t want medical interventions because I only have a short time to live, so the trauma of having procedures, just for a few extra months, is not for me. I believe in dying naturally”. Her careworker agrees that personal choice is of vital importance.

ROCH was diagnosed in 2009 and uses non-invasive ventilation for 15 hours a day – mostly at night.

He accepts his decision to use non-invasive ventilation (NIV) was a tricky one. He describes ‘being in the middle of a live-hate relationship with NIV’. He added: “I’d thought it was the difference between staying alive or not, but at first, it’s more to do with energy and the ability to get up and go”. However, he added: “It takes time to get used to NIV. In fact, it will probably never feel completely normal.”

Roch found NIV a difficult decision to make as it meant thinking ahead about end of life issues. He said: “What tipped it for me was that at any future point, I could ask for NIV to be withdrawn. And if, by that stage, I was unable to breathe independently, I would be made comfortable.”

RON began using a ventilator soon after diagnosis when his consultant referred him to the respiratory team.

He initially used a machine to keep oxygen levels up at night and relieve morning headaches and exhaustion. Although he found it difficult, he was encouraged to persevere.

Over the years his ventilator usage has increased and Ron is now dependent on the breathing machine. “We were very anxious to extend a good quality of life for as long as possible and the way to do that was to battle through with this wonderful machine”, he said. “I simply wouldn’t be here without it, and it’s well worth it as I still enjoy life”. The use of nose prongs during the day and a full face mask at night has relieved the impact on Ron’s nasal passages following infections. Ron’s wife and carer, has become an expert in setting and adjusting the machine. Ron’s current bilevel positive airway pressure (BiPAP) machine is portable and battery powered which means he can get out and about and enjoy visits to his local hospice, providing respite for his wife.

Finding out about the options for ventilation, as soon as possible, provides time to think and understand what choices mean, now and in the future. Early decision-making means wishes and preferences are known by everyone involved in someone’s care.

Types of ventilation:

Non-Invasive ventilation (NIV):

A portable machine helps boost intake of air through a mask. This covers the nose, or nose and mouth, depending which is more comfortable. NIV is usually needed overnight at first. As the disease progresses it is likely to be used more often. NIV can prolong life, but as breathing muscles continue to weaken, there may come a time when NIV is no longer effective.

Invasive ventilation (tracheostomy or trache):

A machine takes over breathing via tube inserted into the windpipe through the front of the neck. This is less likely to be offered, although some people with MND use this type of ventilation. Although the machine can take over breathing if needed, so plans for future care should be considered.

If ventilation is not suitable or the decision is made not to use it, the respiratory team can advise on other support,

including: posture and positioning
breathing exercises
help to cough
medication to ease symptoms and anxiety

In most cases, ventilation for MND uses normal air to support breathing. Extra oxygen is not usually recommended with MND as it may be harmful. However, it may be used with caution if someone's oxygen levels are low.

OUR NEWSLETTER: THUMBS UP

We aim to make our Newsletter interesting, informative and easy to read. Sometimes we have lots of things to tell you about, other times things are a little quiet, and therefore we would like our readers to make a contribution - let us know of anything interesting happening around you, send us photos and a short story of a special occasion or an outing you had, or just tell us about yourself. There must be many stories you could share with us and our readers : funny ones, happy ones, sad ones and also some of those embarrassing ones which you can now laugh about! Give us tips or suggestions which we can pass on to our readers, on how you found ways and means to cope and make things easier and more comfortable to do. If you don't want your name mentioned, we will respect your privacy.

Sending the Newsletter via email: the recipient's inbox is sometimes full or it does not have the capacity to accept it and it gets returned to us – in that case you can read it on our Website, ie www.mnda.org.za

Should 'Thumbs Up' no longer be of interest to you, please let us know. You can simply return it to us - write "Return to Sender" before opening the envelope and drop it in your nearest Post Office Box, or call the office on 021 531 6130 or send us an email (mndaofsa@global.co.za) to the effect that you want us to remove your name from our mailing list.

Global Awareness Day : 21 June

Any ideas/suggestions as to something special to do for that day? Remember, we are in this together!

**Condolences to the Family and Friends of:**

Stephen Brett (21/10), Philip Henning (24/10), Penelope Haswell (27/10), Tinus Linee (2/11), Nico Erasmus (3/11), Brigitte Sumner (6/11), Justin de Wet (7/11), Jacobus van der Westhuizen (18/11), John Eastwood (22/11), Kingsley McLeod (22/11), Tebogo Ramarumo (25/11), Valarie Rampersadh (28/11), Garry van Zyl (28/11), Daniël Louw (1/12), Anton van Heerden (1/12), Kobie de Jongh (8/12), Eveline Hendricks (9/12), Ockert Nel (17/12), Kobus Vorster (1/1), Dianne Boyce (5/1), Len Robinson (6/1), Krappie Ried (6/1), Moegsien Abrahams (8/1), Herman van Wymeersch (16/1), Ralph Sampson (18/1), Dora Bichener (29/1), Susan Power (24/1), Barend Botha (3/2)

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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