

Thumbs UP

MNDALS

Association of South Africa

NPO 155-413

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

February 2017



*Emile van Lill, who designed our Website, with his wife Marietjie and daughters Amelie and Mila
(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

PATRON	NATIONAL CHAIRPERSON	VICE CHAIRPERSON
Aviva Pelham (M. Mus.)	Dr. Franco Henning	Sheila Kendal
SECRETARY		
Rina Myburgh		

ACKNOWLEDGEMENTS

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



Some happy news!



Our Vice-Chairperson, Sheila Kendal and Kosie Slabber were married on 22 October last year with a small intimate occasion in Albertinia, surrounded by family and close friends who witnessed and celebrated the happy event. We wish them both lots of happiness for their life together. We have known Sheila as Sheila Kendal and as that name is almost synonymous with the MNDA of SA, we will still refer to her as Sheila Kendal (hope her husband will not be offended!) but she will now be known as Sheila Kendal Slabber.

Although the festive season has come and gone, the Cape Town Support Group had a great time at the End-of-Year get-together held in November



But to business

DONATIONS



We again would like to thank each and every one who has contributed to our cause, for their generosity and kindness in donating to our Association. We have received donations in lieu of birthdays and donations in memory of loved ones, as well as from our regular supporters who manage to send us something every month - it is sincerely appreciated. Annual donations were received from E van Zyl, L Chiappini, and the Kurt & Joey Strauss Foundation.

We would like to say a special Thank You to Burlington Stables who once again organized a Memorial Day event for the late Dehlia Rezek, but due to the inclement weather the event had to be cancelled. Nevertheless, the Rezek family very generously donated their sponsorship money of R30,000 to MNDA.

And of course “You and Me vs MND” Kevin Jordan, his wife Carla and their loyal team, organized various events during the year and again managed to present us with R45,000. They plan on doing some more fundraising this year and should you see any “ads” for events they are hosting, please participate !!

Thank You! everyone !

While on money matters

A few years ago we tried to join the Woolworths' 'MySchool' awards program, but as we were unable to garner a meaningful response, our efforts had to be abandoned. But these days, most people have a "Woolies" card We are applying again and hopefully we will be more successful. From time of application to approval it will take about eight weeks before supporters will be registered. Please help us with this fundraising effort and register "MND/ALS Association of SA" as a charity to support (you can nominate up to 3 beneficiaries on one card !!) To join you can call 'My School' on 0860 100 445 or email cs@myschools.co.za with your particulars: Card Number, I/D number, Name of Charity you want to support and your contact details.

A REMINDER

It is that time of the year when the annual membership subscription of R200 becomes due.

A membership form with the banking details is enclosed for your convenience

MAIL BAG**Funny Book Titles !**

Parachuting by Hugo First
 I need Insurance by Justin Case
 Off to the Market by Tobias A Pigg
 Covered Walkways by R Kade
 Webster's Words by Dick Shunnary
 ~ (From the Real Deal) ~

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Marietjie van Lill's appeal which raised R60,000 to buy an Eye-tracker for her husband Emile.

"3 years ago in January 2014, our lives and everything we've planned so well, came to a standstill with Emile being diagnosed with MND. No cure, no medication. The prognosis was 6 months to 3 years to live, but the strength and grace of God carried us not only through but beyond 3 years.

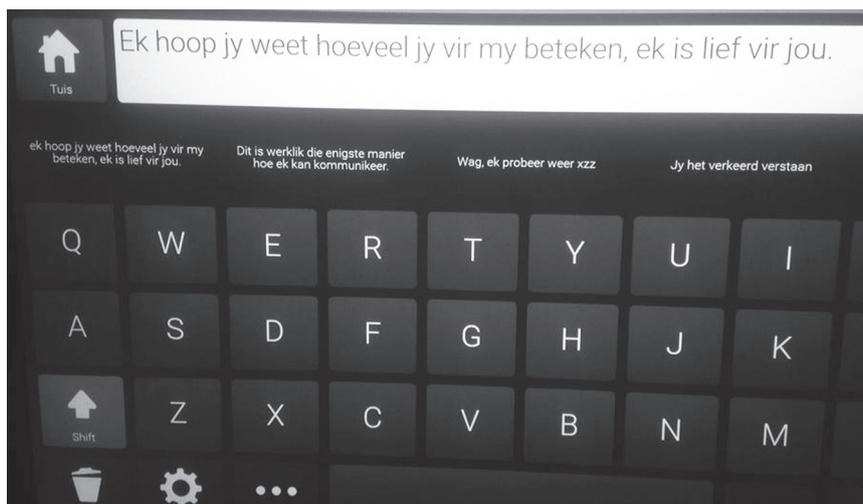
He slowly lost the ability to use his voice, then the use of his right hand, left hand, right leg and then his left leg. He is tied to mostly his hospital bed or on a strong day, he will spend some time in his wheelchair. Then his right arm lost all strength, then the left arm. Controlling the wheelchair by himself became almost impossible, swallowing became difficult, he has breathing problems, his saliva gets thick because of the muscle weakness in his throat and makes him choke and he has pain in his muscles all over. This has left him, 3 years later, totally paralyzed, entrapped and totally reliant on others for every possible thing (while his brain is brighter than ever), with one huge problem: I am the only one that still understands him with great difficulty and sometimes, even I need to rely on his winking to communicate.

Emile outlived many storms and still he miraculously fights without any medical intervention to keep him alive, but his need to communicate has become urgent. A week ago he asked me to put a laser beam on his cap so that he can point at the alphabet on the wall in order for him to communicate. I could see how this solution will frustrate him even more and have decided to look into a well-known and tested solution. I've started looking into an eye-tracker to enable Emile to communicate again and release all his thoughts. But the cost of a good one is very high: R60,000.

The last 3 years have shown me not to stop at anything and nothing is impossible. Emile desperately needs the eye-tracker to communicate and left some of his frustrations.

I leave you with this though: If you live through the most difficult and challenging time in your life, you will not only be stronger but you will never again take living for granted. Stripped of everything you discover the will inside you to survive, to be victorious and to never be a victim."

Some first eyetracker moments. Joy!!! And the most beautiful words I've ever heard



Emile getting some lessons to master the Eye-tracker !

The hot dry weather of the summer has made us all uncomfortable and rather lethargic, but **Mandy Gurr-Snyman of Port Elizabeth** (one of our longest surviving patients – she was diagnosed in September 1998) found an excellent way to cool off and “re-charge”. Here she is enjoying her once-a-week water-therapy and says that it is wonderful, as she can move her arms and legs and walk in the water !



Excerpts from the Winter 2017 issue of Thumb Print (Magazine of MND Association, UK)

This poem was written by Stephen Bluff (UK) who is living with MND, and published in the Winter 2017 issue of Thumb Print (Magazine of MND Association, UK):

My mirror sees me every day, it watches how I change, it watches facial features, which to me remain the same
 If my mirror could save images and record what it had seen, I could then evaluate the changes there have been
 It is my body movements that give the game away, strength declining gradually, as muscles fade away
 I sometimes feel emotions which tend to get me down, they make me disillusioned, and at times they make me frown

Sometimes I'm grumpy, abrupt and somewhat rude. Frustration changing character by fluctuating mood
 MND picks anyone, and it has chosen me, how long I will endure it only time itself will see
 I don't know when or why my symptoms did first start. I know it started gradually and breaks the toughest heart
 I keep on being positive, no matter how I feel, negativity is common but that does not help, or heal
 This is an illness where nature guides the course changing the lives of everyone from how it was before!

.....
*Do not pray for an easy life
 Pray for the strength to endure a difficult one
 ~ (Unknown) ~*

RESEARCH**Report back on the 27th International Research Symposium on ALS/MND held in Dublin in December 2016:**

“A record number of MND Researchers, clinicians and health and social care professionals (HSCP) attended this International Symposium, organized by the MND Association (UK). Over 1,100 delegates from 41 countries attended the meeting in Dublin, making it the largest Symposium in our history. The key to defeating MND lies in fostering strong collaboration between leading researchers around the world and sharing new understanding of MND. We also know the care received by people living with MND today can be greatly improved by HSCPs sharing their learning and understanding on how to best manage the disease.”

“Dr Brian Dickie, Director of Research Development said: We will beat this disease through global collaboration. Bringing the world's MND researchers together in one place to share ideas and expertise enables them to go back to their laboratories with new knowledge to complement their own research. They also return to their clinics with new ideas and insights into how to change practice for the benefit of people living with MND.

“MND research is in an exciting place with more projects underway and more money invested than ever before. To see the commitment and dedication shown by teams around the world, keen to share their knowledge and experience with one another is very heartening.”

The Symposium was opened by Dr Richard Bedlack, who presented findings from ALSUntangled, a resource for people affected by MND to help provide scientific rationale to some of the unproven treatments discussed online.

ALSUntangled was one of the ten main themes from the Symposium that we focused on our Symposium Live pages on the website.

Another key theme in Dublin this year was Project MineE, the international genetics project analyzing DNA from people with MND. Its goal is to find out more about these subtle genetic risk factors, using a technique called whole genome sequencing. Much of the research presented at the Symposium linked to this project highlighting the importance of this resource in the global effort to find the causes of MND. The Symposium provided an opportunity for those contributing funds and analyzing DNA samples as part of Project MineE to share progress made in analyzing the data and how people are interpreting the results.

To read more about the extensive research presented at the Symposium visit the Symposium Live pages on the website:

www.mndassociation.org/symposiumlive

VENTILATION

This subject has featured in one of our previous Newsletters, but we would like to highlight it again:

With MND, the use of ventilation may need to be considered - where a machine helps support breathing. Deciding whether or not to use this support can be difficult. 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. Your 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.

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 MNS use this type of ventilation. Although the machine can take over breathing if needed, 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 exercise
- 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.

We approached

Associate Professor Richard van Zyl-Smit

MBChB, MRCP(UK), Dip HIV(Man), MMED, FCP(SA), Cert Pulm(SA), PhD

Head Lung Clinical Research Unit

University of Cape Town Lung Institute (Pty) Ltd

Consultant Pulmonologist

Division of Pulmonology and Department of Medicine

University of Cape Town

..... for professional advice, and he advises as follows:

Hypoxia in a patient with neuro muscular weakness – be careful with the oxygen

We cannot live without oxygen – but giving too much oxygen may not always be the best strategy...

Hypoxia (low concentration of oxygen in the blood) usually develops when not enough oxygen is entering the blood stream from the lungs – either as a result of poor ventilation (no oxygen coming in and out of the alveoli) or inability to get oxygen into the blood from the alveoli.

In a patient with hypoxia, it is critical to evaluate what the underlying cause is – especially in a patient with neuromuscular weakness. In pneumonia for example (aspiration or other) – there is a “shunt” where blood passes through the area of pneumonia without gaining oxygen. In this situation – giving supplemental oxygen will increase the amount of oxygen being absorbed in other areas and will partially resolve the hypoxia. The patient here will often have a high respiratory drive.

In progressive neuromuscular weakness – the low oxygen saturation is not a function of poor diffusion or shunt (like in pneumonia) but a function of poor delivery of oxygen to the alveoli – and similarly poor removal of CO₂. In this situation giving supplemental oxygen, changes the pattern of blood flow to areas of poor oxygen delivery in the lung (vasodilation with deadspace ventilation) and to a small degree the drive to breath (hypoxic drive) potentially resulting in an a large increase in CO₂ (acute hypercapnia) which may result in the unintentional death of the patient. One cannot however ignore the low oxygen – and so careful- low concentrations of oxygen should be given with regular checking of blood gases to ensure that the CO₂ does not increase dramatically and the oxygen concentrations are raised to relatively safe levels. Ventilation (non-invasive) may be required to provide adequate oxygen with an increased respiratory rate to “blow off” the CO₂.



Sympathies to the Family and Friends of:

Mervin Saunders (2015), Dale Rancchod (3/16), Roy Pike (1/16),
 Albertus Hopley (7/2016), Guy Tostee (8/16), Hilda Ekermans (9/16),
 Neil Coertzen (9/2016), Donald Scott (10/2016), Willem Kok (10/16),
 Marion Harvey(10/16), Kenneth Blake (10/16), Bruce Braithwaite (11/16),
 Sylvia Sutherland (11/16), Carmelita Henriques (11/16), Gary Stewart (11/16),
 Madeleine Lamb (11/16), Makhosazana Ntshingilo (11/16), Gunter Wagner (11/2016),
 James Diener (12/16), Terence Maart (12/16), Bongani Noruka (1/17), Jan de Beer (1/17),
 June Milligan (1/17), Pat Fourie (2/17), Andre Wicomb (2/2017), Carel (Vos) Höll (2/2017)

*Perhaps they are not stars, but rather openings in heaven
 Where the love of our lost ones pours through
 And shines down upon us to let us know they are happy
 ~ (Eskimo Proverb) ~*

FOR SALE

Tobii PCEye Go with accessories and attachments
Original price R60,800 - Now selling for R30,000
For more information contact Hannes Otto (HOTO1@fnb.co.za)

Mercedes-Benz Vito 116CDI, Arctic White, with hoist and park assist - Registered July 2016.
Immaculate Condition – only used 4 times. Selling price : R820,000.
Previous owner was a MND patient.



**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.*

MOTOR NEURONE DISEASE / ALS ASSOCIATION OF SA

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