

# Thumbs UP

**MND / ALS**  
ASSOCIATION OF SOUTH AFRICA 

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

February 2011



*Len (standing left) and Wena Dekker (seated) ready for their train journey  
(read their letter 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**  
Aviva Pelham (M. Mus.)

**NATIONAL CHAIRPERSON**  
Dr. Franco Henning

**VICE CHAIRPERSON**  
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**SECRETARY**  
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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



It seems quite a while since our last Newsletter !

At the Annual General Meeting held in October 2010, office bearers/committee members were re-elected and they have agreed to another term in office.

2011 is well on its way and presenting it's own challenges !

Time again to remind readers of membership fees which are due (our financial year runs from 1 April to 30 March) – good news though, it is still only R100 per annum (or part thereof).

***Our Banking details:***

Motor Neurone Disease Association of SA  
or MNDA of SA

Account No : 27 062 913 0

Standard Bank Rondebosch Branch 025009

*(Please insert your name and "membership" in the reference column)*

**Last year we had a fair amount of mail being returned to us** due to post boxes having been closed and/or where our patients and readers have moved to a different address, e-mail contacts that are no longer in operation and sadly, where patients have passed away and family not advising us. Please inform us of any changes that may occur, be it residential, postal, electronic or telephonic.

## Donations



Again, many many thanks for the regular monthly donations received from some of our members. Your loyal and ongoing support means so much to our Association.

Donations were also received from the following:

R Pelsler, Inner Wheel Sea Point, Laurie & Rita Chiappini Trust, Sue Lane, Philip Schock Trust, E van Zyl, Family of Julio de Macedo. The support and interest is greatly appreciated.

Carol and Sandy Mason both celebrated "big" birthdays towards the end of last year and requested their guests to, instead of gifts, make donations to MNDA. As a result of their kind gesture and their friends' and family's generosity, we received the grand sum of R10,670. Thank you to everyone concerned for making this possible.

*The happiness of your life depends on the quality of your thoughts.*

## Fundraising

### **Jolandie Rust – 'Stuck on the Bike' Fundraising Campaign**

*In her own words -*

"I have a dream. A dream to be the first woman to circumnavigate Africa. On a bicycle. On my own.

I have a dream. A dream to inspire. To be inspired.  
To learn. To connect.

To lead by example and inspire others to do the same

My dream is to become the first woman to circumnavigate the entire African continent on a bicycle, solo. My journey will see me covering a total distance of approximately 40,000 kilometers and travelling through 34 countries.

In March 2008 I cycled solo from Johannesburg to Cape Town - being only the second woman ever to do so and in the fastest time. In January 2010 I became the first person ever to have cycled around South Africa solo, covering a total distance of 5951 kilometers.



On 11 February 2011, I will set out from Cape Town. On my bicycle. On my own. The first pedal strokes to realise my dream of becoming the first woman to circumnavigate Africa.

While I am proud to say that the "Proudly South African" campaign endorses this expedition, I am personally responsible for raising all funds for the trip: This is a sole journey : no back-up vehicles, no management team, no administrative office.

In June 2009 by mother passed away from MND at the age of 45. In honour of her memory, I will be donating a portion of the funds I raise to the MNSA of South Africa (Motor Neurone Disease / ALS Association of South Africa)."

Jolandie's efforts in pedalling towards her dream, and raising funds, is truly commendable.

*We appeal to everyone for encouragement to enable her to realise her personal dream, and to support her in her quest to raise funds and help raise awareness of people with Motor Neurone Disease/Amyotrophic Lateral Sclerosis, and the MND/ALS Association of SA.*

We wish her a safe and successful journey towards realising her dreams.

You can reach Jolandie on - 076 167 2008 or  
Jolandie.rust@gmail.com  
<http://jolandie-rust.blogspot.com/>

## MAIL BAG



***Fiona Keyter of Newlands, Johannesburg, pays tribute to her husband, Leon, who passed away in September 2010:***

I would like to thank all our friends who have supported Leon and me for the last 18 months while he bravely suffered motor neurone disease, and especially for all the messages, emails, cards, flowers meals etc. For all the friends who travelled to attend the funeral on the 29th a special thanks. Also to all our friends in Dubai for making the effort to remember him at our favourite beach, I'm sure Leon was there with you too. I have received so many incredible emails which have brought many tears for all of us. He often said he should have taken ill years ago, as it was so good for him to catch up with so many old friends. With courage we have lived with this dreaded illness not knowing how it will progress, and yet Leon kept such a brave face whenever we saw his friends, and his constant sense of humour helped everyone to cope with how they saw him too. Our time was so dear, as we tried to do the things we both really enjoyed. We were so grateful for the wheelchair that gave Leon his mobility, plus the fact we were able to move to a new home within a few minutes from hospice. Leon was so grateful for the caring staff at the hospice and I am sure he touched their hearts with his wit and cheeky ways. He also got a lot of comfort from the monthly MND meetings and was very close to all the other sufferers of this illness. His light banter always cheered them up, whenever we were being given a serious talk from either a dietician or physio. We were also very fortunate that Leon never lost his mobility unlike other sufferers with this illness, and even drove his caddy till the end of July.

I will always cling to memories, sweet memories that I hope will bring him nearer. I can tell you that being Leon's wife has been the most wonderful blessing. He had such a talent for bringing special meaning to life, that it was such a pleasure to be his wife. He helped me to grow

and to realise the beauty and fullness and the beauty of our lives. My sadness and grief to watch him grow weaker and weaker every day wore me down, I shed so many tears, as I also recall the devotion and love through the years. I pray for strength that for his sake and in memory of his name I will be able to continue and to reach out to fill the hours with useful ways. I try to console myself .... This was God's greater plan, I must accept it if I can and reach for comfort and strength but to feel Leon's presence that one day we will be together again.

I loved Leon for so many reasons, for being a wonderful husband, my best friend. He meant the world to me and he had given me years of happiness. He was more than a husband to me and father to our children. He was also my best friend, to talk, laugh and to love, and the closeness we shared was the best thing in my life.

He made so many sacrifices for his family to give them a better life. The support on contacts we made during this illness showed us what an incredible husband, father and friend he was and we will always be so proud with these memories forever.

Though heaven and earth divide us and the distance is so great I count my blessings for the years Leon was my mate. I will live my life remembering while he waits slumbering.

*Friendship is love with understanding*

***Len, husband of patient Wena Dekker of Pretoria, writes:***

My wife Wena Dekker worked as a theatre sister at the Zuid-Afrikaanse Hospital, Pretoria. She realized that "something was wrong" with her hands, but did not realize what it was. After numerous tests in which every other possibility was excluded, she was diagnosed with MND during July 2010. It brought our lives to a standstill and with a shock we looked at the world from a new perspective.

Coming in contact with the MNDA assisted us in taking decisions to modify the way we used to live. Thanks to MNDA for its support and advice based on years of practical experience. My wife and I came to realize that God gives us our lives in small parcels "one day at a time". We therefore make optimal use of one day at a time to live life to the fullest for so long as God grants us the grace. Recently we toured Namaqualand to look at beautiful flowers in the garden of God's creation. We also travelled by train from Cape Town to Pretoria. (See front page) Thumbs Up made us realize that we are not alone in the struggle against MND. When reading about others and seeing their photos we add them to our prayer list. May the grace of God be with all of you.

*Shirley Maclennan of Grahamstown writes:*

Reading the article on cognitive impairment in Thumbs Up September 2010 and knowing that it may not happen, I feel I want to offer some encouragement to patients who dread this kind of deterioration:

My husband Don Maclennan had motor neurone disease for eight years before he died after a stroke. His legs became very weak but the rest of his body was scarcely affected by the MND. He went on teaching at Rhodes University and writing poetry until very shortly before he died.

No cognitive impairment was apparent, even after eight years. Dress Rehearsal, the last of his many collections of poems, was waiting for publication on his desk when he died, and they are as good as anything he ever wrote. It came out in March 2010.

I enclose a copy of the book because you may want to use

a poem or two in Thumbs Up just to show what many of your other patients have demonstrated, that patients can continue to think and write well. Like many of his books, it includes a lot of thoughts on death and dying, The Story, Spring and It's Time, are fairly upbeat. The Gold Earring, his favourite, is full of sad regret and grief but full of love and joy too.

You may wish to pass the book on to someone who likes poetry. That would please me.

We quote "Spring" -

Today is clean  
as the washing on the line  
Warm wind and sailing clouds.  
It's spring, the air  
tickling with syllables.  
Not only spring, but you  
Wearing that full white dress,  
a meadow of minute red flowers  
linked with pale tendrils.  
You dressed for this spring day  
amazing me with how  
you still can be  
so generous, so new.

Copies of this collection of poems "**Dress Rehearsal**" are available from Sheila, at [s.maclennan@ru.ac.za](mailto:s.maclennan@ru.ac.za)

*Believe everything happens for a reason  
If you get a second chance, grab it with both hands  
It if changes your life, let it  
Nobody said life would be easy, they just promised it  
would be worth it*

## RESEARCH



### **\*Studentship draws on scientific advances in stem cell research**

A new PHD studentship grant has been awarded to a research team based at the University of Oxford.

Under the supervision of three leading researchers at the University of Oxford, Dr Richard Wade-Martins, Dr Kevin Talbot and Dr Olaf Ansorge; Ruxandra Mutihac, a recent graduate from the prestigious Oxford MSc Neuroscience Programme, started work this summer on this innovative three-year research project.

The project is taking advantage of two major recent scientific advances: the discovery of the TDP-43 gene as a cause of MND; and the development of new stem cell technology to create induced pluripotent stem cells. This is the Association's second stem cell research project.

The project will create motor neurones, derived from the skin cells of MND patients with the sporadic (non-hereditary) form of MND. The skin cells will be 'reprogrammed' to generate induced pluripotent stem cells (iPS cells) which are very similar to stem cells derived from human embryos. The iPS cells will then be modified to turn into motor neurones.

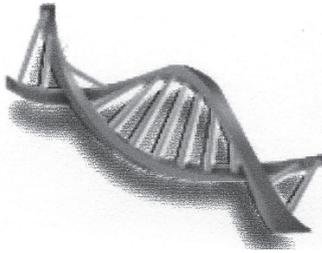
This project complements the first Association-funded iPS cell initiative, being led by Prof Siddharthan Chandran at the University of Edinburgh. The Edinburgh team will be examining cells obtained from MND patients with TDP-43 gene mutations. The Oxford approach has the advantage that it can be used to create motor neurones with a specific genetic cause of MND, even when there may not be a patient with that precise form of MND available to donate a skin sample.

The University of Oxford is an international leader in stem cell research in neurodegenerative diseases and is one of only

a handful of institutes in the world with the expertise and technology on-hand to attempt this ambitious study.

Dr Brian Dickie, director of research development at the MND Association, says: “This project ticks all the boxes for a PhD studentship project: cutting-edge research in a world-class research and training environment”.

Dr Kevin Talbot, one of those supervising the project said: “By the end of this study we hope to have developed the tools to allow us for the first time to work directly with the cells that are the key to unlocking the cause of MND”.



### ***\*DNA bank plays crucial role in largest MND genetic study***

MND researchers working in collaboration across Europe and the US have confirmed that a region of DNA within chromosome 9 plays an important role in both sporadic and familial forms of MND and a form of dementia called fronto-temporal dementia (FTD).

Previous research has revealed that a DNA region in chromosome 9 can pre-dispose people to developing a familial (inherited) form of MND. This, however, is the first research to show that chromosome 9 plays an important role in the development of all forms of MND.

The research study, the results of which were published in *Lancet Neurology* on 31 August 2010, was led by Prof Ammar Al-Chalabi at King's College London. It studied the entire human genome to identify chromosomes that hold disease-causing genetic areas.

The researchers scanned 599 DNA samples from the MND Association's DNA Bank. These samples were donated by people with the sporadic form of MND. In addition, 4144 MND (control samples) from other DNA Banks were analysed. The researchers then verified these results using a total of 4312 samples from sporadic MND patients and 8425 control samples. Samples collectively came from the UK, Netherlands, Belgium, Ireland, Sweden, Italy, France and the USA.

This study reflects the huge commitment and willingness of the worldwide MND research community to share research information – representing the genetic information of more than 12,000 people.

Combining efforts of the international MND research teams has allowed the largest genetic study of MND to have taken place.

Prof Al-Chalabi explains: “We already know that a DNA region in chromosome 9 is involved in some people with familial MND but our work has confirmed that this chromosome actually plays a role in sporadic MND. In fact, our study has narrowed the DNA region to one that contains just three genes. Finding which gene in this DNA region causes MND and why, will unlock another piece of the MND puzzle and may allow us to understand enough about the disease so that we can design a specific treatment.”

Dr Brian Dickie, director of research development, adds: “Chromosome 9 has been a suspect for MND genetics detectives for a long time. But pinning down the precise genetic factor involved has proved elusive! It's exciting that we are making significant progress in understanding this part of the overall MND jigsaw puzzle. Our DNA bank is a relatively simple study to take part in but it really means a lot to the researchers who use the samples. I'm excited that we are seeing the first results of the DNA bank project. There are many people to thank: to everyone who has donated their DNA sample, the doctors, nurses and lab technicians who helped collect the samples and the principal investigators of the project.”

There are currently 2936 samples in the DNA bank from 1503 MND patients, 956 controls and 477 family members. People who take part in the DNA bank study are asked to give a blood sample and answer some clinical questions.

(More information about the DNA bank is available on the website at: [www.mndassociation.org/dna bank](http://www.mndassociation.org/dna%20bank) or the research development team at [research@mndassociation.org](mailto:research@mndassociation.org)

You can read more about this research on the 'news in research' pages of the website at: [www.mndassociation.org/chromosome9](http://www.mndassociation.org/chromosome9)

*\*(Extracts from Thumb Print {Magazine of the MND Association, UK, Autumn 2010 edition})*



Often people wonder how they should react when they meet a person who has a disability or is in a wheelchair. These people are active members of society and have identities beyond their disability. They should be included in all aspects of daily life and have common courtesies extended to them when interacting with them. A

limited understanding of a person's situation may lead to an embarrassing situation that may have been avoided. Here are some things to be kept in mind:

- It is appropriate to shake hands with a person who has a disability, even if they have limited use of their hands or wear an artificial limb
- Speak directly to the person in the wheelchair, not to someone nearby as if the wheelchair user did not exist. There's no need to speak in a patronising manner
- Ask the wheelchair user if he or she would like assistance before you offer help. It may not be needed. If your assistance is needed, then listen or ask for instructions
- If you are unsure about something, ask the person. The wheelchair user will best be able to answer any questions you may have about special needs or assistance techniques. They more than anyone have a vested interest in seeing that things go as smoothly as possible
- If a conversation lasts more than a few minutes, consider sitting down or kneeling to get yourself level with that person
- Don't use "I have a friend in a wheelchair ..." as a conversation starter. Think about how many times a person who uses a wheelchair hears this every day
- A wheelchair user will see the wheelchair as being a part of their own personal body space, so don't lean on it, rock it, etc. There is a sense of security there because it allows a person to be mobile and independent
- Don't assume that using a wheelchair is in itself a tragedy. It's a means of freedom that allows the user to move about
- It is OK to use expressions like "running along" when speaking to the wheelchair user. It is likely that they will use similar expressions.
- Do not discourage children from asking questions about the wheelchair. Open communication helps overcome fearful or negative attitudes
- When a wheelchair user transfers out of the wheelchair to a chair, toilet, car or bed, do not move the wheelchair out of reaching distance
- Ignore guide dogs or other service animals. Don't pet them ... they are working

**Remember**

- Emphasise the person, not the disability. People are not conditions, so don't label them with the name of the condition or as part of a disability group.

## DISABLED TRAVEL

**New Additions**

- i) Hermanus 169 on 10th in Hermanus
- ii) Bakgatla Resort in Pilanesberg
- iii) Newton Sands Guest House in Port Elizabeth
- iv) Makhato Lodge in Warmbad, Bela Bela
- v) Erinvale Estate Hotel in Somerset West
- vi) Opikopi Guest House in Pretoria
- vii) Bordeaux Haven in Vereeniging
- viii) Lourens River Guesthouse in Somerset West
- ix) ATKV Goudini Spa (Boland House) in Rawsonville
- x) River Meadow Manor in Irene
- xi) LovanE Guest House in Stellenbosch
- xii) The Wild Mushroom Boutique Hotel in Stellenbosch
- xii) Cornerhouse on Conan Guesthouse in Moreleta Park, Pretoria
- xiii) Len's Bed and Breakfast in Benoni



*The cute baby owl*



*The cheetah*

The cute baby owl and cheetah can be seen at Spier Wine Estate in Stellenbosch - a wonderful place to visit. Please note that there is a long gravel pathway to access the cheetah and bird-of-prey sanctuary. Hopefully it will be made wheelchair accessible if you all send them an e-mail with a request ! to [marievw@spier.co.za](mailto:marievw@spier.co.za)  
The restaurants and wine tasting room are accessible.

*(More to come in our next Thumbs Up.)*

## WORDS OF WISDOM



*Be kinder than necessary because everyone you meet is fighting some kind of battle.*

### Getting it Perfect

There is often great beauty to be found in imperfection. No tree is perfectly straight, no mountain peak perfectly symmetrical, and yet the world is filled with beautiful mountains, trees and other magnificently imperfect things.

When a friend is hurting, you don't have to put together the perfect combination of words to let that person know you care. All you must do is speak from the heart.

When there is a challenge facing you, it's not necessary to come up with a perfect solution. Effective, focused, appropriate action, will do just as well.

It's fine for perfection to be your goal. Just don't let the lack of perfection be an excuse for doing nothing.

There are countless good and valuable things in life that are far short of perfect. In fact, if everything were always perfect, life would not be nearly as interesting.

Certainly you always want to do your best. Just make sure that getting it done takes priority over getting it perfect.

*(Author Unknown)*

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

*Ron Noseworthy of Milnerton sent these wise words:*

When I was young and free and my imagination had no limits, I dreamed of changing the world. As I grew older and wiser, I discovered the world would not change, so I shortened my sights somewhat and decided to change only my country. But it, too, seemed immovable. As I grow into my twilight years, in one last desperate attempt, I settled for changing only my family, those closest to me, but alas, they would have none of it. And now as I lay on my deathbed, I suddenly realise: If I had only changed myself first, then by example I would have changed my family. From their inspirations and encouragement, I would then have been able to better my country and, who knows, I may have even changed the world. (Anonymous)



**DID YOU KNOW ?**

An empty purse frightens away friends  
An apple a day keeps the doctor away – an onion a day keeps everyone away !

A good example is the best sermon  
A good conscience is a soft pillow

A loveless life is a living death  
Be swift to hear, slow to speak

A monkey in silk is a monkey no less  
Better flatter a fool than fight him

Elbow grease is the best polish  
Gardens are not made by sitting in the shade

*(Taken from the “Real Deal” – July 2010)*

**Condolences to family and friends of:**

Martie Meyer, Sydney Aylwarf, Doriah Nyembe, Annetjie van Leeuwen, Johann Kruger, Renier Janse van Rensburg, Leon Keyter, Dave Becker, Ian Steyn, Renie Pantony, Retha Themistocleous, Nicolas Potgieter, Willem du Preez, Seymour Ryke, Boet Hall, Flouris Smith, Cyril Shlagman, Pieter Roode, David Mashegoana, Enslin Burgess, Maxi Lubbe, Hilda Gomes, Stan Butcher, Daniel Cloete, Ingrid Gall

**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 ASSOCIATION of South Africa**

P.O.Box 789, HOWARD PLACE, 7450,  
TEL: (021) 531-6130  
FAX: (021) 531-6131  
E-mail: mndaofsa@global.co.za

JOHANNESBURG  
TEL: (011) 701-5001  
CELL: 082-878-3716  
E-mail: keth@telkomsa.net