





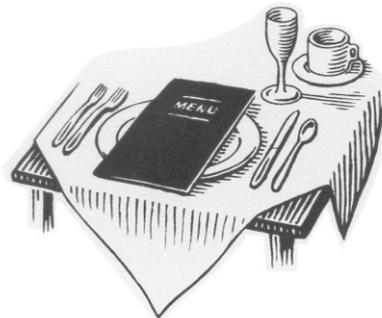
### *From the Office*

As can be seen from the front page ***“People who care make a world of difference”*** and as 21 June is MND/ALS Global Awareness Day, we need to “spread the word” as far and wide as possible to make people aware to enable them to care !

We have caring people doing Cycle Races, Running Marathons, entering Iron Man competitions, climbing Mountains, organising Golf Days, arranging Fun Walks and Big Walks, Cocktail Evenings etc, all to spread awareness and to help raise funds and we are so grateful and appreciative of all the effort that goes into organising these events.

*If you never learn the language of Gratitude  
You will never be on speaking terms with Happiness*

## MND/ALS GLOBAL AWARENESS DAY LUNCHEON



Ronnie van Wijk, whose wife Carol passed away from MND at the end of April this year, has made a substantial contribution in her memory, to help sponsor a Luncheon which Liz Keth, our Consultant in Gauteng, is arranging for that day -

**21 June 2013**

at

**Killarney Country Club**

11.30am for 12noon

### **Guest Speakers**

A Neurologist

A Representative from Witwatersrand Hospice  
and Mr Kevin Jordan, “No White Flag” Riding for MND

***Contact Liz on 082 878 3716***

to secure tickets for you, your family, friends and acquaintances at R250 per person. Please, where possible, also encourage companies and businesses/corporates to buy a table ! Their support will be acknowledged. Ample and secure parking is available at the venue which is also wheelchair friendly.



## Golf Day

Mark Chapman of Hillcrest (KZN) is arranging a Golf Day in memory of his wife, Vereen, who passed away from MND in February this year. The success of the day will depend enormously on the support and generosity of all who get involved and an appeal is for:

\*\* 4-Ball prizes

\*\* Lucky Draw/Auction Items (eg art work, weekend away, etc)

\*\* Sponsorship of a hole, i.e. a tee or a green (an opportunity for corporate advertising)

\*\* Wine to be placed on the tables for dinner

The event will receive some media coverage and all sponsors will be acknowledged on the Golf Day programme.

Details are as follows:

VENUE	: Camelot Country Club, Hillcrest
DATE	: Sunday 4 August 2013
COMPETITION	: 4-Ball Alliance
ENTRY FEE	: R2,000/4 Ball (which includes green fees, golf carts, halfway snack, dinner & prizegiving)
SPONSORSHIP	: R500/tee box or green R750 for 1st hole and putting green
CONTACT	: <b>Gina Ryan on 082 870 0196 or rrice@telkomsa.net</b>



## No White Flags - Riding for MND : Momentum 94.7 Cycle Challenge on 17 November 2013

Kevin Jordan of Wilgeheuwel (Gauteng) writes:

My name is Kevin Jordan and I was diagnosed with Motor Neurone Disease (MND) almost 5 years ago. I feel fortunate in that I was diagnosed at a fairly early state and that although I now only earn a disability pension, I still have the financial means and support to obtain medication, therapy and other assistance that I need on a daily basis. However there are many people that are not as fortunate as I am. They were not diagnosed early enough, they don't have the financial means to obtain medication and treatment, they do not have physical and emotional support.

Unfortunately the awareness of MND as a disease is not prevalent in South Africa, not only in the rural areas, but everywhere. How many of you had heard about MND before you or someone close to you was diagnosed?

Creating awareness of MND within our society will not only help people become more aware of the symptoms, but should also result in specialists being consulted at an earlier stage and diagnosis made earlier. By raising awareness in our country, more funds could be raised in support of the MND Association of SA, who will in turn be able to provide more robust support for MND sufferers and ultimately trigger actions such as petitioning the government to grant a subsidy to fund medication and support to those who suffer from MND.

My first major step to raise awareness of this disease is through a charity bond for the **Momentum 94.7 Cycle Challenge**. Support in anyway will be appreciated. First prize would be if you could ride for this charity on the day. If you can't do it, get friends and family to do it. In essence just pass the details on to everyone you know!

We would like to attract 100 riders, each raising R2,000 for charity and all proceeds raised will go to the Motor Neurone Disease Association of South Africa (MNSA of SA).

It's a simple process to enter. The first step is to go to the website (<http://www.cyclechallenge.co.za>)

When you register for the race, you will have an option to join a group. On the "join Group" page, the name of the group to join is under **Motor Neuron Disease Association of South Africa**. The name of the charity is **NO WHITE FLAGS – RIDING FOR MND**.

Alternatively, if you have already registered and would like to ride for **NO WHITE FLAGS – RIDING FOR MND**, please email me your full name and ID number and I'll complete the process for you.

My email address is : [uandme.vs.mnd@gmail.com](mailto:uandme.vs.mnd@gmail.com)

I've also created a Facebook page to raise awareness of MND called '**YOU AND ME VERSUS MND**'

Search for it on Facebook or follow this link: <http://www.facebook.com/YouandMeVersusMND?ref=hl>

and remember to click the "like" button ! I use it not only to promote MND awareness but also as a motivational tool and to showcase charity and fundraising events. Please remember to share the page with all your Facebook friends – more 'likes' = more exposure for MND!

I have been fortunate to have lots of support from my wife, family, friends and the MNSA of SA. Through these and other initiatives in the pipeline I hope not only to raise awareness of MND in SA, but also to create a support network for MND patients, as well as their loved ones, families, friends, carers.

I hope you will join me on this fantastic and inspirational journey – come and join the fun !

**Cheryl Smith of Durban writes:**

A group of Friends have got together to do the forthcoming BIG Walk along with our brother/brother-in-law/husband/father and dear friend Renier who was diagnosed recently with MND just to support and bring awareness to the disease and its devastating effects on a person. We also lost our mom to this disease in 1993.

Cheryl requested to use the MNDA of SA logo for their T-shirts but as we had T-shirts available, we could let them have 22 for their team. Cheryl also appealed to East Coast Radio's BIG FAVOUR to assist. We wish them well and may the best team win!



*Team Gary who all made it over the finish line*

**Linda Stewart of Links Hill (KZN) writes about their undertaking:**

**'A mad idea that turned into a wonderful adventure'**

My husband Gary was diagnosed with MND in 2007 and for the past 2 years has been living with the help of a ventilator.

During this journey of living with MND we have met many wonderful supportive people.

Drinking coffee with a group of friends spurred the notion that with a little effort we could dust off our bikes and ride the Cape Argus 110km cycle tour in CT in March. What mad ignorant fools we were, we had no idea what we were letting ourselves in for.

With this goal in mind we decided to dedicate our efforts to create more awareness of MND.

We organized a group of like-minded cyclists to embrace this challenge under the banner 'Team Gary' and within a matter of weeks the team had grown to 22, curtailed only by the Argus entries having reached full capacity.

We set about the next 8 months to prepare and train. Each and every member contributed time and expertise in different ways to assist those of us who were not as proficient or very fit. Cycling shirts were designed and ordered to give maximum impact and exposure for our team and its endeavours.

Many happy and hard training sessions ensued including cycling in all weather conditions, sweltering heat, freezing cold, mist and rain, before we knew it the big race day arrived.

The Cape Argus was a real challenge but all 22 of us finished, albeit with very sore bodies.

The spectators were absolutely amazing and made the race a pleasure and joy to participate in.

From this mad idea and humble beginnings we have learnt that if one believes in what they are doing then you will find the will to make it happen and hopefully enjoy yourself and make good friends along the way.

I would like to thank Julie Platts, my very good friend who made this all happen, without her enthusiasm and very good organizational skills we would never have managed and the Maziappi family for all their support with our training, and everyone else who helped to make this happen.

**Linda Stewart**

**\*Correction to a previous report by Fiona Keyter-**

*In the February 2013 issue of Thumbs Up, Fiona Keyter reported on the Fun Run she had organised in Pretoria on 17 November 2012 but she feels the wording was perhaps a bit confusing and it did not come across clearly that the total raised was actually **R41,954 ! Great stuff !!***

Human Life Would Be Perfect –  
 If...  
 Anger Had A STOP Button  
 Mistakes Had A REWIND Button  
 Hard Times Had A FORWARD Button  
 And Good Times A PAUSE Button



## Breathing problems – testing diaphragm pacing

*(From Spring 2013 edition of “Thumb Print” – MND Association Magazine, UK)*

It has long been recognised that non-invasive ventilation (NIV) can improve the lives of some people living with MND who experience breathing difficulties. A health care research trial, part-funded by the UK Association and involving people with MND, is now testing the safety and effectiveness of a potential new supportive therapy, diaphragm pacing.

Some people living with MND experience breathing problems. This is because MND can weaken the muscles involved in breathing leading to shortness of breath, disturbed sleep and headaches.

Non invasive ventilation (NIV) – a portable ventilation machine – has been found to improve daily quality of life for those who experience breathing difficulties, by improving sleep and energy levels and increasing their appetite.

Evidence from clinical trials of NIV led it to being recommended for use in MND patients, where suitable, by the National Institute for Health and Clinical Excellence (NICE) (UK)

Dr Chris McDermott, based at Sheffield University, is leading a trial to test whether diaphragm pacing provides benefits for people with MND, extending survival and quality of life, over and above those provided by current respiratory care including NIV.

The trial, part-funded by the Association in collaboration with the National Institute for Health Research (NIHR), is the first of its kind. It relies heavily on the involvement of people living with MND, placing those living with the disease at the heart of the research.

Dr McDermott explained: “This trial is important research as the technique has been previously shown to be safe, but it has not been shown to be effective for early breathing problems in MND. This trial will therefore investigate the effectiveness compared to standard respiratory care, including NIV.

“NIV is good but not perfect ! We want to improve the management of breathing problems in MND and diaphragm pacing has a number of advantages. Unlike NIV, there is no mask involved so it reduces discomfort caused by the mask and the fear of anxiety. Diaphragm pacing may be an effective alternative for patients who struggle to use NIV.

“Using diaphragm pacing and NIV together may lead to more benefits in terms of improving breathing, than using NIV alone.”

### *What is diaphragm pacing ?*

Diaphragm pacing is a way of maintaining the strength of the diaphragm – the main muscle involved in breathing – by providing it with regular pulses of electricity that stimulate the muscle to contract.

This is done by placing small electrodes into the diaphragm muscle during a minor operation, under general anaesthetic. These are then connected by fine wires to a small box that can be easily carried about.

### *Next Steps*

This trial aims to provide the level of evidence that will be required for diaphragm pacing to receive approval from NICE, and make it accessible to everyone in the UK who has MND with respiratory difficulties.

Dr McDermott said: “If we were to show that diaphragm pacing is effective, we would then show this evidence to NICE. If we show both clinical and cost effectiveness for those with early breathing problems in MND, then NICE would assess this evidence and hopefully give approval, allowing diaphragm pacing to be used within the NHS.”

Dr Brian Dickie, Director of Research Development said funding healthcare research is essential to ensure care provided to people with MND is of the highest quality of life. He added: “Diaphragm pacing has been shown to be very effective in people with spinal injury, but the evidence is much less clear-cut for MND. We all know how tight funding is within the NHS, so if new medical interventions are going to be made available, you have to provide really good evidence that it works.

“A rigorous clinical trial, run along similar lines to drug trial, is the most effective way of finding out whether diaphragm pacing has benefits over NIV – or indeed in combination with NIV”.

## Linking brain degeneration to level of disability

*(From Spring 2013 edition of “Thumb Print” – MND Association Magazine, UK)*

Association-funded researcher \*Dr Martin Turner at the University of Oxford has identified a pattern of degeneration in the brains of people with MND that is linked to the level of disability.

This is the latest finding from his ongoing BioMOx study looking for biomarkers in MND. The study has been funded since 2008 to look for a marker of the disease to help speed up diagnosis, which can currently take up to a year. Three findings have been published to date.

Using an advanced brain scanning technique called ‘whole-brain magnetic resonance spectroscopic imaging’ Dr Turner and colleagues found that the levels of a chemical found in the brain called

N-acetylaspartate (NAA) decrease when the level of disability of people with MND increased.

Dr Turner explained: “This type of MRI scan can be thought of as producing a ‘chemical’ picture of nerve damage. We knew that NAA was quite a sensitive marker in MND, but until now we were not able to study the whole brain at once in a standardised way.

“It’s another example of the enormous value of research that involves the actual patient living with MND, and healthy volunteers. This type of research is fundamental to translating the really exciting findings emerging from the laboratory test tube”.

Dr Brian Dickie, Director of Research Development, commented: “These latest findings from the BioMOx group adds the finding of alterations in brain chemistry to their previous research on structural and functional changes occurring in MND. Together, they are building up a clearer picture of the pattern of degeneration during disease progression, linking what is happening on the ‘inside’ with the physical changes happening on the ‘outside”.

*(Dr Turner has recently been awarded further funding for his research)*



1. Pine Cottage in Pinelands is conveniently situated near Cape Town Airport and the City Centre
  2. Vrede Self-Catering Units overlook the beautiful mountains and bay of Somerset West
  3. High Season Farm Cottage is situated in the picturesque Hemel-en-Aarde Valley near Hermanus
- For more information visit [www.disabledtravel.co.za](http://www.disabledtravel.co.za)

*This little story was sent to us (in Afrikaans) by Ben Viljoen of Pretoria, and we hope the translation has not caused it to lose its meaning:*

## Bicycle Ride with my Father –

After first meeting Him, my life felt like a tandem ride with Him sitting on the back seat, helping me pedal. I'm not quite sure when we changed places but since He took over the front seat, my life has not been quite the same.

When I was in control, I knew the road and it was fairly predictable – always the shortest route between two points for me. But since He took over the steering, the road ahead is interesting and exciting, even though I sometimes have to hold my breath. He takes us on breathtaking and mountainous roads with steep declines at breakneck speeds and all I could do was to hang on. Even when it seemed like complete insanity, he encouraged me with “keep on pedalling!”

In panic I shouted out “where are You taking me? He would just smile and not answer and I learnt to trust Him.

I forgot about my predictable lifestyle and got used to the adventure of pedalling from the back seat with no controls in my hands.

When I sometimes got scared, He would lean back and touch my hand.

He took me to people with the gifts I needed, gifts of healing, acceptance, friendliness. He ordered me to give away my own gifts as it's too much baggage, too much weight. So I gave away to people I met along the way, just to find that the more I gave away, the more I gained, but my load got lighter.

Initially I did not trust Him and I was in control of my own life. When I started riding on the back seat I thought He was going to cause us to crash – systematically I found that He had cycling secrets – He knew how to negotiate sharp bends and how to climb mountains which seemed too high for me, and to race to get passed the dangers sooner.

I learnt how to keep quiet and just keep pedalling, sometimes at the most unlikely places. I started to relax and even to enjoy the beauty of nature around me – the cool breeze on my face in the permanent companionship of Someone who would never let me down or forget me.

And every time I felt sure that it was the end of my own strength and would not be able to carry on, He smiles and encourages ....  
“Pedal My child, pedal!”



## Condolences to the Family and Friends of:

Vereen Chapman (14/2), Johannes Oliphant (23/2), Elza Scheepers (24/2), Neville Wiblin (3/3), France Birsner (Mitchell) (Mid March), Stephanie Els (26/3), Gert Kruger (11/4), Arthur Pilkington(27/4), Carol van Wijk (29/4), Petrus Fourie (3/5), Dante von Wielligh (3/5), Peter Janse van Rensburg (4/5), Adri Engelbrecht (7/5), Sona van den Berg (11/5), Tobias van der Mescht (18/5)

**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

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

Gauteng  
CELL: 082-878-3716

Port Elizabeth Area  
CELL: 079-591-2148

Durban/KZN  
CELL: 083-777-2029