

# Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



February 2009

*Lena (SA Agri Academy), Sheila (MND), Rita (patient, Helderberg Village), Maura Hinton (Helderberg Village Golf Club), and Nedbank's representative at the Golf Day with the BIG cheques presented to MND of SA*

**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."**

## NEWS and REVIEWS

**PATRON**  
Aviva Pelham (M. Mus.)

**NATIONAL CHAIRPERSON**  
Dr. Franco Henning

**VICE CHAIRPERSON**  
Vivien O'Cuinneagain

**SECRETARY**  
Rina Myburgh

**MND of South Africa is a member of the International Alliance**

### ACKNOWLEDGEMENTS

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

We were very fortunate to have received partial sponsorship which made it possible for our Chairman, Dr Franco Henning, to attend the International Symposium on ALS/MND in Birmingham in November last year. He reported that he found it very interesting and was pleased to have been able to meet the other delegates, among whom Dr David Oliver, who has visited South Africa on a few occasions. The event attracts over 800 leading international researchers and Health Care Professionals who get together to present and debate key innovations in their respective fields.

A Website : [www.mndassociation.org/mysymposium](http://www.mndassociation.org/mysymposium), has been created which will allow anyone interested in MND research to find out just what is going on.

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**We say good-bye to:**

**Nicolene Reyneke** (Dietician), and our Support Group Convenor in the Southern Cape (George area) has taken up employment in the Cape Town City area and will no longer be able to help us out. We thank her for all her assistance in visiting various areas, getting our patients together and for arranging interesting visitors to talk to our patients. We are very grateful to Dave Moss, husband of Jozanne, who has stepped in to keep the ball rolling and hopefully we can relieve him of this task shortly by finding a suitable replacement for Nicolene.

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**And welcome:**

Sheila Kendal, who joined us in August 2008 and will be assisting Vivien O’Cuinneagain by visiting and assisting patients in the Northern Suburbs.  
 Sheila can be reached on 072 326 4477

**and**

Ester Strydom, a Nursing Sister, who joined us in November last year, and will be assisting patients in the Durban area. Ester can be reached on 078 939 5977.

**Annual Membership**

At the Committee Meeting held prior to the Annual General Meeting on 2 October 2008, it was proposed and agreed to, that as from April 2009 (our new financial year) membership fees would be increased to R100 per annum. Renewal reminders will be enclosed in our next Newsletter.

It was also agreed that the names of outside members (family of past patients, etc) who have not paid membership fees or made a donation during the last two years, will be removed from our mailing list to save on costs.

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***Banking Details:***

*Motor Neurone Disease Association of SA or MNSA of SA*  
*Account No 27 062 913 0 – Standard Bank – Rondebosch Branch Code 025009*  
*(Swift : SBZAJJ 02500911)*

**A sincere thank you for donations received from:**

SMJ Myburgh, Sandra Llewellyn, Vic Harms, Marina Mynhardt, AA Carrim, DH Tite, Retha, S Naidoo, K&M Barrett, Mary Davis (USA – friend of Rita Bartlett), Monte Vista Hardware, JE Skene, SM Anderton, MD de Klerk, F Dorfling, KLM Stephen, C Danin, Mary Watson, C Jordens, Leisure View, E van Zyl, Ray Smith, Rosalynd Els, Philip Schock Trust, Kenya Buildings, Marais Family, E/L Barthfield, Mr & Mrs Renshaw, S Derman, R Jowell, Inner Wheel Sea Point, Hilda van Zyl.

Various donations were also received where names were not available or identifiable.

Donations totalling R5,100 were received from family and friends, in the “Spirit of Di” (de Bruin) and R8,000 in memory of Ken Downhams. Thank you.

A very big thank you to all our regular and monthly donors: Pieter Snyman, Jeremy Hindley, Johnnie Thorburn, Gary Stewart, Linda MacFarlane, Rosyland Els, Robert Hollings – your ongoing support is so very much appreciated.

**GOLF DAY & CHRISTMAS FARE****GOLF DAY (See front page)**

On Saturday 17 January 2009 a Golf Day was held at Helderberg Village Golf Club in Somerset West and the Motor Neurone Disease Association of SA was selected as a beneficiary. One of our patients in the Village, Rita Bartlett, was the “liaison” with Maura Hinton, Chairlady of the Club. We thank everyone involved, sponsors, players and “workers”, for having made it possible for us to receive a cheque for R6,000. Your efforts are greatly and sincerely appreciated.

We would like to say a big thank you to SA Agri Academy, who presented us with a most welcome donation of R20,000. We appreciate the hard work that went into this event and we are most grateful for the interest shown and the generous support of the MND Association.

**End of Year Get-together:**

*Patients from the Somerset West support group enjoying “Christmas fare”  
at the get-together held at Helderberg Hospice*



*Christmas get-together at St Lukes*

**Dr Franco Henning submitted the following article for “Thumbs Up”**

*- We are sure you will find it informative and reassuring :*

***Making sense of treatment options in Motor Neuron Disease***

As most of you reading this newsletter know (from your own or a family member’s experience), ALS / MND is a progressive disease for which no cure is available. Many different treatments have been tried in the past, most with no or little effect. Research on the disease is conducted worldwide, and the amount of time, money and effort spent on the search for an effective treatment is increasing continuously. As some of you may have noticed, the internet is riddled with reports about “new” treatments for MND. These “new” treatments are often not new as such, but are mostly drugs that are used in different conditions which are now promoted as a treatment for MND. Although many of these treatment modalities are endorsed by medical professionals and scientists, they mostly are not proven to be effective in well-performed clinical trials of patients with MND, but have only been tested in the laboratory or, even worse, are only effective in theory. Due to the absence of an effective treatment, patients and their families are often desperate to try new treatments (which is absolutely understandable), and therefore often fork out large amounts of money to pursue one of these treatments in good faith. However, a number of facts about treatments that have not been tested in well-performed clinical trials involving patients with MND should be kept in mind:

1. A drug that is effective in theory or in the laboratory is not necessarily effective in practice. A good example is Minocycline (an antibiotic), a drug which slows down

degeneration of nerve cells in the laboratory. When it was tested in patients however, it had no positive effect on the progression of MND.

2. Some drugs that are generally safe may have harmful effects in patients with a specific disease like MND. Once again, Minocycline is a good example. When it was tested in patients with MND, the drug was associated with a faster progression than placebo. In other words, it was worse than taking no drug at all.

3. If a treatment was not compared to placebo (a tablet that looks exactly like the drug but contains no active ingredient), very few conclusions can be drawn regarding the efficacy and safety of the drug. That is why the gold standard for testing a drug is a randomized controlled trial. This means that patients are randomly assigned to receive either the drug being tested or placebo, and neither the patients nor the researchers are aware of which of the two each patient is getting until the final analysis is done.

Of course it is extremely difficult for patients and their families to understand the scientific literature and therefore make a well-informed decision about whether to pursue a treatment. Although many of the proponents of these newer treatments are sincere, some are opportunistic and lure unsuspecting patients into buying their product.

The purpose of this article is to provide some insight into the different treatment options promoted for patients with MND. The discussion will be limited to disease modifying treatments (treatments that aim to change the course of the disease) and will not include symptomatic treatments (e.g. treatment for muscle cramps, excessive drooling etc.). For the purpose of the discussion the treatment options will be divided into 3 groups:

1. Treatment options that have been shown to be safe and beneficial.
2. Treatment options that are still under investigation.
3. Treatment options that have been proven to either have no effect or to be harmful.

**1. Safe and beneficial treatment options**

There are basically 3 treatment options to consider in this group, namely Riluzol, non-invasive ventilation (NIV) and nutritional support by means of a percutaneous endoscopic gastrostomy (PEG).

**a. Riluzol**

Riluzol is the only drug that has been shown in well-performed clinical trials to be effective in MND. It increases survival on average by at least 3 months, but

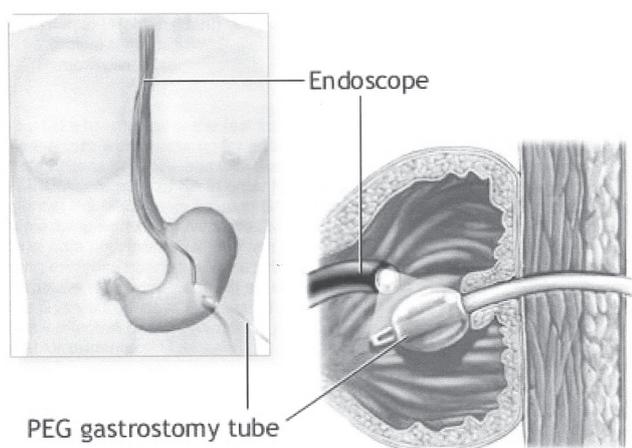
probably more. Its effect is probably greater the earlier in the disease course it is started. Everyone diagnosed with ALS should consider this medication. Unfortunately this drug is very expensive and some patients may choose not to continue taking it due to side effects.

#### b. NIV

Non-invasive ventilation is done by means of a BIPAP machine. This essentially is a form of a ventilator that delivers air to the mouth or nose under slight pressure via a pipe and a mask. The fact that the air is “blown” into the airways ensures better oxygenation and clearing of CO<sub>2</sub> (carbon dioxide) from the lungs. This is not something that everyone with ALS should use, but only if breathing becomes a problem. In ALS, the first signs of breathing difficulties often develop at night, leading to poor sleep, poor concentration in the daytime and headache in the morning. Patients with these symptoms improve substantially on BIPAP, and feel refreshed and energized again. Furthermore, a number of studies have shown prolonged survival with the use of BIPAP.

#### c. Nutritional support

Most patients with ALS develop swallowing difficulties, which lead to malnutrition and weight loss. Once a patient has lost more than 10% of baseline weight despite food modification, supplementation etc, enteric feeding should be considered. This can be accomplished by means of a PEG (percutaneous endoscopic gastrostomy), which involves the insertion of a small feeding tube through the stomach wall (see picture below). This procedure is easy, quick and done with only a little sedation and local anaesthetic. Special formulations are then provided by a dietician for injection through the PEG. Other fluids and food can still be taken orally, so you don't have to give up on your favourite snack or sweets.



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## 2. Treatment options under investigation

### a. Lithium

Lithium has recently been in the news after an Italian study suggested positive effects over 15 months treatment with Lithium. This, however, was a small trial and needs confirmation. Interestingly, this study sparked the initiation of an international, web-based, patient and family-led study to test these results. This study ran for 6 months and involved 191 patients. Contrary to the Italian study, Lithium was not found to be effective in slowing progression of ALS. Several patients reported an apparent faster decline, prompting them to stop the Lithium. Side effects are also very common, and may be severe, including kidney problems. At this stage, we would not recommend the use of Lithium for ALS, as this is a fairly dangerous drug without any definite evidence for slowing the course of ALS.

### b. Stem cell therapy

Although stem cell therapy is theoretically a promising treatment, no evidence for its efficacy exists yet and regarding this as a treatment option would be premature at this stage. In Western Europe, many people spent huge sums of money to have stem cell therapy in e.g. China, but the results were very disappointing. The technique is still in its infancy however, and it is quite possible that it can become important in the future. However, at this stage, we would advise against pursuing stem cell therapy as treatment for ALS.

## 3. Ineffective or harmful treatment options

The following is a list of some of the treatment options that have been investigated and found to be either ineffective or harmful. The list is by no means exhaustive.

- Minocycline (antibiotic)
- Gabapentin (anti-epileptic)
- Lamotrigine (anti-epileptic)
- Insulin-like growth factor type I (IGF-I)
- Vitamin E (anti-oxidant)
- Creatine
- Pentoxifylline

We would like to emphasize the fact that this information is no substitute for guidance from health care workers caring for patients with MND. We strongly recommend that treatment options be discussed with the responsible health care worker or a staff member of the MND Association of SA in order to make an informed decision. The mission statement of the MND Association of SA starts with: “To provide the best possible support for people living with Motor Neurone Disease, their families and carers, via a support service of both physical assistance and psychological counselling.” We

believe that practising evidence based medicine is the best way of accomplishing this. Of course this means that we may advise against an experimental drug which may ultimately be proven effective 5 years from now. However, the likelihood that the experimental drug may turn out to be ineffective or even harmful is probably higher. Either side is a “gamble”, hence the need for evidence.

*Franco Henning*  
Neurologist  
Tygerberg Hospital / Stellenbosch University

### **Reality**

- *Stories from the August 2008 edition of “Thumb Print” (Magazine of MND Association, Northampton, UK)*

#### **John Watkins was seriously wary when he heard he needed a ventilator- the reality was very different:**

I was diagnosed with MND in February 2007. I am mainly affected with mobility difficulties in my lower limbs and hands. However, last autumn I contracted a severe chest infection. Though I recovered well, my breathing was greatly reduced and I was waking up five to six times a night

I was referred to a specialist respiratory consultant at Gloucester Royal Hospital and after a few appointments he suggested that I should have a ventilator for night-time use to improve my quality of life. This sounded like terrible news, a real backward step – and it meant four days in hospital. My consultant reassured us that the ventilator would hopefully make a considerable difference to my energy levels.

The first night I was monitored for my sleep pattern. On the second day, I was issued with my ventilator and mask. It did look very daunting. It wasn't comfortable to wear as it was a full face type and it seemed very strange. I slept better for the next three nights but I took a while to get the fixings set. I was shocked when I took off the mask and realised how my breathing had deteriorated. As I left the hospital I was assured the ventilator would change my life!

At home we persevered with the mask though I didn't look forward to putting it on at night. It wasn't quite right and not really comfortable so we went back to hospital and were given larger mask insert. After that I was away! The mask fitted properly with a good seal and since then most nights have been far less interrupted.

Six weeks on the benefits are being felt. I sleep better which means I wake more refreshed, my daytime breathing is much improved, my voice is stronger and I have more energy in the day. The hospital was right: it's not a cure but it has changed my life. I now look forward to the ventilator at night for the benefits it brings the following day.

If a ventilator is recommended, don't see it as a backward step. Go for it and persevere! It really has worked for me, but be patient. It's not the best looking piece of kit but it will make life easier and more comfortable and give back some of your lost energy and self-esteem. We recently went on a short cruise. Without the ventilator we couldn't have gone. It is enabling us to do some things we would not have done before.

Don't be afraid of your new ventilator. Don't see it as a backward step. Use it and see it as your night-time gateway to a better tomorrow.

#### **Annie Walters was really worried about visiting her local Palliative Care Unit for the first time. Here she assures readers that the experience was a very positive one:**

In March I was admitted onto the Lung Ward at Gloucester Hospital for three days to be assessed to see if I would be suitable to use a ventilator. I'd been having restless nights for months, was very tired during the day and becoming very breathless. My quality of life was greatly reduced.

After the first night I woke up feeling totally alert, not tired at all and with only a slight headache. My feelings of elation were short-lived when my Consultant came to see how I was. He told me he wanted to arrange an appointment with the Palliative Care Unit – he said it was good to have them involved early.

I felt sick. 'Palliative' – the word 'dying' immediately hits you in the face. That final end to our journey, a destination we know we are going to reach and here we are being offered the care that comes at the end. How wrong I was. During my journey with MND I have gone through all sorts of feelings and emotions, but on the day of my first appointment I felt the same as I did on the first day at school and when I attended my first MND meeting. My stomach was churning and I wanted a hand to hold onto and never let go.

The building was totally separate from the hospital. Two lovely people welcomed us. One took my friend into a sitting room for a cup of tea and the second person took me into her office. She asked me how I felt, mentally and physically. Unlike when friends and family ask the same question, I could actually tell her how I felt.

She knew the right questions to ask to establish if, when and what type of pain I was in and how it could be controlled. By the end of our two-hour meeting I understood that the term “palliative” really means specially trained people controlling and caring for any stage of a terminal illness.

I cannot begin to put into words the relief I felt that my “new friends” were taking control. Immediately one of my medications changed and within days the pain I had in my legs from the nerves under the skin had stopped. I am so grateful that my Consultant introduced me to the team sooner rather than later. It’s given me the best care and quality of life that I need and am entitled to have. Our GP’s are just that – general practitioners. They can’t be expected to have the same knowledge as the people who specialise in pain control.

I felt comforted in the knowledge that from now on, no matter how many weeks, months or years I have left I will be monitored through my journey. Medications will be changed, ventilator increased and face mask checked for a correct fit. I know that if I or my carer may have any problems, help is only a phone call away.

My concerns for my eventual final ending have been greatly reduced by the kind and gently-given explanations that will not only help me but more importantly, my family and friends will not be left with a memory of seeing me suffer.

I hope my own experience helps other people make a very difficult turning point in dealing with a journey into the unknown.

### Change of Strategy

*(Extract from February 2009 edition of Village Ads)*

A man was standing outside a building with a sign written: ‘I am blind, please help’.

A ‘creative publicist’ was walking by and stopped to observe. He saw that the blind man had only a few coins in his hat. He dropped in a few more coins and, without asking for permission, took the sign, turned it around and wrote another announcement. He placed the sign by

the blind man’s feet and left. That afternoon the creative publicist returned to where the blind man sat and noticed that his hat was full of bills and coins. The blind man recognised his footsteps and asked if it was he who had re-written his sign and he wanted to know what he had written on it. The publicist responded: ‘Nothing that was not true, I just wrote your sign out a little differently’. He smiled and went on this way.

The new sign read:

*‘TODAY IS THE FIRST DAY OF SPRING AND I CANNOT SEE IT’.*

Sometimes you need to change your strategy when something does not go your way and you’ll see it may just be for the best. Remember, if you always do what you’ve always done, you’ll always get what you always got .....

*(Author unknown)*

*Sara was 6 when her new puppy became seriously ill and the vet didn’t know if he could save it. Everyone felt very sad for Sara, because this was her first pet and it had been a Christmas gift. They said to her: “Don’t worry precious, just remember, if Fluffly dies, we’ll see her in heaven”. Sara looked as if they were simple-minded and said, “Well, yes, but heaven’s a long way off for me – I’m only six!”*

### Ester Strydom, Nursing Sister, reports:

We in Kwa-Zulu Natal had our first Support Group Meeting on Friday 30 January 2009. There were 3 patients and their spouses, and 2 caregivers who lost their loved ones last year. While everybody was apprehensive in the beginning, there were lots of laughs about shared experiences.

### Some of the comments:

The support group is something that was necessary, educational as well as motivational.

To have had the 2 caregivers who lost their partners, was very good. It will help with the healing process and moving on afterwards.

It also helps the caregivers because they really understand

Well the next date is set for 27 February at 10 am at : 350 MacDonald Road, Glenwood.

Anyone in that area will be most welcome to attend – please contact Ester on 078 939 5977.

Our condolences to the family and friends of:  
 Aziz Carrim, Doreen Udemans, Di de Bruin, Pauline Dyers, George Lee aka George Larnyoh, Simon Schalit, John Dillon, Johannes Fouché, Ralph Segers, Donald Dick, Louis Pretorius, Minnie Whittal, Marion Barrett, Horst Muller, Frederick Carstens, Sayed Hakim, Antionette Kilian, John Deavin, Irvan Vermeulen, Cyril Koeries, Tracy Owen, Awie du Toit, Ann Langston, Rael Levitan, Angamma Chinwasamy, Marion Thomas

***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.*



**Disabled Travel**

On the red, double-decker bus in Cape Town. "The bus is wheelchair accessible, it lowers itself hydraulically and has a ramp that folds out." City Sightseeing Cape Town offers tours of the city and peninsula. [www.city-sightseeing.com](http://www.city-sightseeing.com)



*Peter Marx, husband of Marion, devised this "headgear" for holding up the head when it flops forward:*

**Prototype Headgear**

I bought a construction site helmet from a hardware store and removed the plastic light weight insert. These helmets do not come in different sizes but the plastic insert is adjustable to fit various head sizes. To start with I taped the laser with insulation tape to the plastic insert and we found that it is far more stable than the elastic headband. The headband tended to slip and move and talking for Marion has become more difficult if the band moved as her neck movement is very much reduced with the progression of MND since we started using the laser. The plastic insert is very stable on her head and surprisingly comfortable. We then experimented with a plastic Oros bottle filled with driveway stones and attached to the plastic insert with string. It seems to work well but some more trials are needed to get the balance right.

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

**MOTOR NEURONE DISEASE ASSOCIATION of South Africa**

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