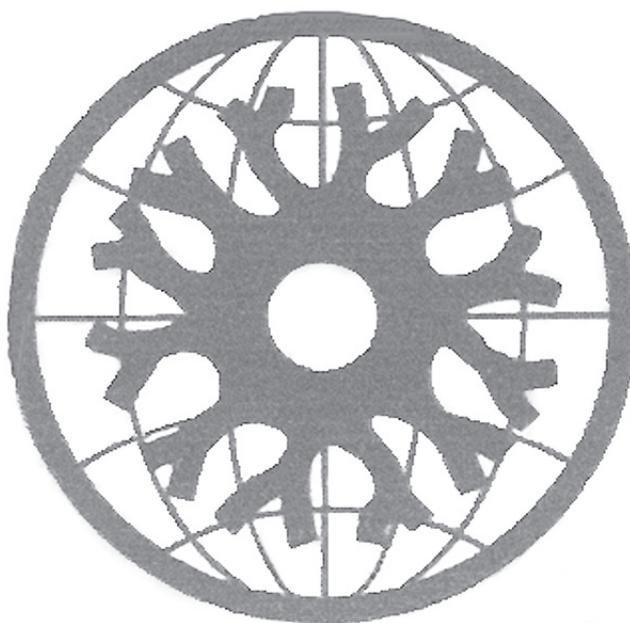


# Thumbs UP

**MND / ALS**  
ASSOCIATION OF SOUTH AFRICA 

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

May 2011



## MND / ALS GLOBAL AWARENESS DAY 21 JUNE

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**  
Sheila Kendal

**SECRETARY**  
Rina Myburgh

### ACKNOWLEDGEMENTS

John Hall for producing the design and DTP (desk top publishing) work.

(Maitland) for the printing of our magazine



### MND/ALS Global Awareness Day : Tuesday 21 June

You might be aware that Motor Neurone Disease or Amyotrophic Lateral Sclerosis, is not a well known illness. Some medical funds do not acknowledge it and patients are therefore unable to claim for medication, therapies, carers, or any other assistance needed. Drawing the public's attention and spreading awareness of MND/ALS, will make it a more recognisable condition and in many ways help us to help ourselves.

The MND/ALS Association of SA would like to get our patients and members involved in this awareness campaign and we request your input, not only for 21 June, but all year round. Please let us have your suggestions and ideas – we are all in this together !

### “My MND/ALS Association” Card

Some of our members and readers might recall that quite a while back we wanted to establish a “My MNDA” Card via the Woolworths “My School Card” concept. At the time we were requested to submit 200 completed signed application forms before Woolworths could set this up. We tried but only received about 120 completed forms.

We would really like to try and get this going and of course we will need the support of our members and readers and their families and friends and .... everybody you can think of ! to make it work. Are you prepared to help us ?

## Donations



We have been receiving annual membership renewals and we thank you for your response - and as quite often happens, there is sometimes that little bit extra added on ! Thank you so much.

Other donations were received from : R Jowell, S Derman, Richard Becker, Power of Inspiration, Masonic Bowling Club, Azima Amien, Dr Katz, OM Horn, Jean Gaiser, Carol van Wijk, Hilton Lappin, Erna Labuschagne, C Jordens, Deborah Coetzee, MG Norman, JJ Coetzzer, Justin de Wet, Kobus Vorster, Dekker, Family of the late Vinod Bhoola, Sheldene van Zyl, Graham Milner, AD Graham and of course our regular and monthly donors: PM Snyman, Gary Stewart, Jeremy Hindley, Tiffin Family, Richard Hollings, WR Terry, L MacFarlane - The support is greatly appreciated.

We also received bequests from E/L C Vorster, E/L NDO Bartlett and E/L TRV van Wyk in our last financial year (April 2010 to March 2011) totalling R209,273.33

## MAIL BAG



### Leon Groenewald, a patient from Oudtshoorn wrote to us in March 2011:

I am still using the Lightwriter you sent me. Thank you, it is a great tool to aid speech. In general conversation I find it very helpful. In one on one conversations people read as I write, from the front window. Pity, conversation in Afrikaans is daunting. In business conversations, long sentences to express myself is rather frustrating. By the time I have typed the sentence the conversation has moved on to another subject! Notwithstanding, I find the Lightwriter a great aid in communication.

Thank you sincerely.

### Karene Swanepoel of Durban whose husband Gavin passed away in May last year, writes:

Gavin passed away peacefully on 15 May. He bravely suffered Motor Neurone Disease even though his inability to communicate frustrated him to no end. It was so difficult to see such an intelligent man reduced to such a pitiful sight. Thank you for your newsletter which I always read to Gavin. We continue to pray for all those suffering from this awful disease.

We have a wonderful MND support group here in Durban without whom I would never have managed. I would really appreciate it, if you would give my contact details to anybody in this area who might be looking for a support group. Many thanks, Karene Swanepoel. Contact Details : 083 442 1355 or 031 572 3523.



*(Extracts from the Winter 2010/2011 edition of ThumbPrint, the Magazine of the Motor Neurone Disease Association, UK)*

### Brain Scans reveal exciting findings

A study funded by the MND Association in the UK, in collaboration with the Medical Research Council (MRC), has identified a common signature of nerve damage in the brains of people living with MND.

These are the first results to be published from this ongoing 'BioMOx' study led by Dr Martin Turner. Dr Turner was awarded the Association's first joint-funded MRC/MND Association Lady Edith Wolfson Clinical Research Fellowship in 2008 for the study.

The fellowships aim to attract and develop outstanding young clinicians in MND research, in order to create future scientific leaders in the field.

### First steps to developing a test for MND

MND research is being held back by the lack of an early diagnostic test and predictable markers of the progression of the disease – biomarkers. If MND biomarkers can be identified then they could dramatically improve the speed and accuracy with MND can be diagnosed, and how future treatments are assessed.

This study used an advanced magnetic resonance imaging (MRI) technique, to look for areas of the brain that are universally damaged in patients with MND as compared to healthy controls. From this, Dr Martin Turner and colleagues at the University of Oxford found a technique similarity of nerve damage in a region of the brain that connects the motor neurones to the brain as well as damage to a region that acts as a connection between the left and right sides of the brain known as the 'corpus callosum'.

Dr Turner said: "The finding of a common pattern of nerve pathway damage in a varied group of MND patients holds the promise of a much needed biomarker.

"This study confirms the ability of advanced MRI techniques to sensitively detect nerve damage in a wide range of people living with MND. It builds on a decade of international work, and shows that MRI is now a frontrunner in the quest to generate biomarkers of disease activity in MND".

### About the BioMOx study

The BioMOx study aims to develop a biomarker for MND by following changes in the brain, in the blood and in spinal cord fluid of people living with MND, every six months. People living with MND have made, and continue to make, a significant contribution in giving their time and

effort to make this research project possible.

Dr Brain Dickie, director of research development at the MND Association, said:

"The BioMOx study is one of the largest biomarker studies for MND in the world. It's very encouraging to hear the first exciting results emerging from this four-year initiative".

### Thinking outside the box

An Association-funded study, using a state-of-the-art technique associated with cancer research, has increased our understanding of motor neurone degeneration by revealing the cellular transport processes of motor neurones. Cancer researcher Prof Giampietto Schiavo has been collaborating closely with MND researchers to study the way in which essential nutrients and components are carried throughout motor neurones, known as the cellular transport process.

Prof Schiavo worked with colleagues at University College London and Cancer Research UK.

Stimulating debate and encouraging and funding collaborative working across different fields of medical research is a key element of our work to develop the UK and international MND research workforce.

This study is a great example of 'thinking outside the box' to progress MND research. Dr Brian Dickie, director of research explained: "This is a very good example of how knowledge and technology from one field of biomedical research, such as cancer, can be used to study a completely different disease such as MND. Such cross-fertilisation of ideas is essential in pushing progress forward as quickly as possible.

(More info on this and other research stories is available at [www.mndassociation.org/researchnews](http://www.mndassociation.org/researchnews) or visit their blog at [mndresearch.wordpress.com/](http://mndresearch.wordpress.com/).

### SHARING HIGHLIGHTS FROM THE WORLD'S LARGEST MND CONFERENCE

Now in its 21st year, the International Symposium on ALS/MND is the largest medical conference on MND. Organised every year by the MND Association, it's regarded as the premier event in the international MND research calendar representing the energy and dynamism of the MND clinical and research communities.

### Why me ?

A natural response to receiving a diagnosis of MND is to ask 'Why me?' Many question whether their MND could have been caused by something in their environment, their occupation or a lifestyle factor such as smoking, diet or exercise.

The study of environmental and lifestyle factors may predispose people to disease is known as epidemiology. Sporadic (inherited) MND is thought to result from the cumulative effects of numerous risk factors in people whose

overall genetic make-up makes their motor neurones particularly vulnerable to damage. The identification of these risk factors could provide insight into the development of MND and eventually help research aimed at preventing the disease. However identifying these factors with any certainty is extremely difficult.

Dr Ettore Beghi from the Mario Negri Institute in Milan discussed at the symposium why studies designed to assess environmental and lifestyle contributors consistently fail to generate conclusive evidence. He explained how previous studies on heavy metal exposure, diet, head trauma and the use of statins haven't provided enough reliable evidence to suggest a possible risk.

Dr Berghi did note that it's unlikely that statin use increases the risk of somebody developing MND explaining that despite a 10 fold increase in statin use, in recent years, there has not been the same pattern for cases of MND.

Following on from Dr Beghi, Dr March Huisman from the Rudolf Magnus Institute of Neuroscience in Utrecht described how a register of people with MND in the Netherlands has allowed him and his colleagues to investigate possible occupational risk factors. To date these include increased risk for farmers and electricians. Their next steps are to ascertain what underlying exposures may be linked to these jobs to increase or decrease the risk of somebody developing MND. The Dutch register also suggested that a family history of other neurodegenerative diseases may increase the risk of MND, while a family history of cardiovascular disease may reduce risk.

There are still many questions regarding lifestyle and environmental causes that need to be answered. To answer these, we need reliable, conclusive evidence so that the

research community will be in a better position to start asking why, instead of what, particular risk factors can contribute to the cause of MND.

### Thinking outside the neurone

MND isn't just about motor neurones going wrong in an otherwise perfectly functioning nervous system. A group of cells called glia, which surround motor neurones and normally provide them with support and nourishment, can dysfunction too. Until recently, their role in the development of MND has been underestimated but it's becoming clear that they seem to hold most of the cards when it comes to determining how MND progresses, so they're not to be overlooked.

Many types of glial cell have already been implicated in MND. But at this year's symposium, Prof Jeffrey Rothstein from Johns Hopkins University in Baltimore, USA, revealed that a glial cell called an 'oligodendrocyte' is heavily implicated in MND.

This is another step forward in understanding the causes of MND, because oligodendrocytes are the primary support and nourishment cells of motor neurones.

There is still an enormous amount to do to understand the exact role of oligodendrocytes in MND, but Prof Rothstein and his team's preliminary work in a mouse model of MND has suggested that by 'fixing' injured oligodendrocytes, survival is increased. Studying what causes these major support cells to go wrong in MND is of growing importance to be able to develop new treatments.

"MND research is so complex that no one scientist or research centre can do it alone."

## DISABLED TRAVEL



### New Additions:

- i) Ela's House in Milnerton (Cape Town) is self-catering or B&B
- ii) Tulbagh Hotel in Tulbagh (Western Cape)
- iii) Manley Wine Lodge in Tulbagh (Western Cape)
- iv) Bakkies B&B in Bainskloof, near Wellington (Western Cape)

### Port Elizabeth City Lodge Group

- v) Courtyard Hotel
- vi) Town lodge
- vii) Road Lodge
- viii) Stonecutters Lodge in Dullstroom (for fly fishing !)
- ix) Satara Campsite in Kruger National Park, Mpumalanga



*Epic Guesthouse in Noordhoek, where all four rooms and bathrooms cater for people in wheelchairs - probably the only one in SA!*



*World of Birds in nearby Hout Bay is accessible with slightly uneven pathways. There are 3000 birds and small animals and close encounters are possible with some animals and owls.*

## Dates and Venues for Cape Town Support Group Meetings for the rest of this year:

The meetings scheduled for December will be “year-end functions”.

Please contact Sheila Kendal on 072 326 4477 for further details and/or to advise your attendance, which will be welcomed.

June	21	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	22	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	23	Thurs	2:00 - 4:00	NG Church Bellville
July	12	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	13	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	14	Thurs	2:00 - 4:00	NG Church Bellville
Aug	16	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	17	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	18	Thurs	2:00 - 4:00	NG Church Bellville
Sept	13	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	14	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	15	Thurs	2:00 - 4:00	NG Church Bellville
Oct	18	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	19	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	20	Thurs	2:00 - 4:00	NG Church Bellville
Nov	15	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	16	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	17	Thurs	2:00 - 4:00	NG Church Bellville
Dec	13	Tues	2:00 - 4:00	St Lukes Hospice Kenilworth
	14	Wed	2:00 - 4:00	Helderberg Hospice Somerset West
	15	Thurs	2:00 - 4:00	NG Church Bellville

## ENCOURAGEMENT



### Walking in Water

(by Alan Gardner, a patient in the UK)

I have lost the use of my arms, hands and legs, and being a very hands-on, practical person, I was surprised to find that the thing I miss most is the ability to walk.

My wife, Wendy, my full-time carer, and I decided to try our local swimming pool. It provides first class facilities for the disabled.

I take my scooter to the pool-side and Wendy and one of the attendants assist me into a special wheelchair, which they push into the pool. I can float on my back, but my main enjoyment is getting in up to my shoulders, when I become weightless and can start to walk! I was surprised to find that I can walk two or sometimes three lengths.

What I then wanted to do was walk in the sea and we found an ideal location at a local beach. It consisted of a concrete slip and a steel handrail, which on high tide took me into the sea. We have done this on a number of occasions, but the sea must be very calm.

This letter has been written using my Dragon Naturally Speaking Speech Recognition Software, version 11. It has been difficult getting used to it as I have no previous experience with computers. However, the voice recognition facility is excellent and anyone with existing computer skills would find it much easier.

Avid poetry writer Pauline Hardy, presented one of her poems at a symposium for nurses and therapists in the field of MND in the UK. Here is an extract:

Hey, you, I'm in here, this is me,  
Inside this broken body, can't you see?  
I have a perfectly functioning brain,  
And my mental faculties remain;  
It's just that my extremities have failed  
My moving parts, they are derailed.

I have difficulty to eat, wash or dress,  
My toileting abilities, they are a mess,  
But I can converse with the best of them,  
Hold my own with the brightest of women.  
I can work from home to earn a crust; it's a must.

It also keeps me from going slowly insane  
As I sit here each day, and my energies drain.  
But I would like to help those less able,  
By bringing governing bodies to the table.  
Explain that we're the forgotten many;  
Recognition? No, we don't have any.

We slowly lose each body movement,  
Become a beached whale to a great extent.  
Legs, arms, neck, speech, are just a few  
Of the things taken for granted by you.  
How would you cope in my position ?  
You, "Joe Public", my supporting physicians;

Perhaps, for a day you could all try  
To live the same life that I  
Live each day, going slowly down hill.  
Not for me, just popping a pill  
To cure my disease, but I still pray,  
That a cure will be found, maybe one day.

And wisdom .....

If anyone should hurt you and say a thing unkind  
Remember what I tell you and keep these things in mind  
For every one who makes you cry there are three that  
make you smile  
That smile will last a long long time, and the tear a little  
while  
If someone says a thing that's cruel, don't let it get to you  
There's so much good about us, and your faults are very  
few

Don't let someone who hates you, cause you to hate it too  
For behind the clouds there is a golden sun and a sky  
that's bright and blue  
So if a certain someone should act a certain way  
Just think of those who love you and don't let it ruin your  
day.  
~Unknown~

**From Mandy Snyman, Port Elizabeth**

A good life starts only when you stop wanting a better one  
and start living the one you've got to the fullest

Trusting God won't make the mountain smaller but will  
make climbing easier  
I pray that you will be able to climb all your mountains  
today and everyday !

## CONDOLENCES



### Condolences to the family and friends of:

Winston Savage (3 February), David Balentine (5 February), Elsa Lambert (19 February), Pieter Austin (18 February), Lydia Page (25 February), Graham Milner (27 February), Ina Beukes (28 February), Hentie Schoeman (6 March), Mdu Ndlovu (15 March), Marlene Duvenage (19 March), Dawid Daniels (6 April), Jim Lapien (7 April), Wena Dekker (8 April), Jacoba Lawrence (14 April), John Harris (16 April), John Braaf (19 April), Frank Seed (21 April), Marius van der Merwe (21 April), Ishwarlal Naik (30 April)

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

**HAVE  
YOU  
SIGNED  
THE  
LIVING  
WILL?**

***The Living Will...***

**SAVES** *S*uffering and pain

**SAVES** *A*nxiety for loved ones

**SAVES** *V*alueless prolongation of terminal illness

**SAVES** *E*xistence without quality of life

**SAVES** *S*pending life savings unnecessarily

**Enrolment Form**

To: The Director Date: .....

**SAVES - The Living Will Society**

P.O. Box 1460,  
WANDSBECK 3631

Phone: (031) 266-8511

Fax: (031) 267-2218

E-mail: livingwill@3i.co.za

www.livingwill.co.za

Please enrol me/us as a member/s of the Society and forward my/our Living Wills, Wallet Card/s and Stickers.

I/We enclose my/our membership fee:

- R 80.00 per person (including Pensioners)
- R 150.00 per married couple (including Pensioners)
- R 30.00 per person receiving a Government Old Age Pension, or Disability Grant.

PLEASE PRINT

Surname: .....

First Names (Mr): .....

First Names (Mrs / Ms): .....

Postal Address: .....

..... Post code: .....

Residential Address: .....

..... Post code: .....

Tel: (.....) .....

e-mail: .....

**ANNUAL SUBSCRIPTIONS** fall due on member's receipt of the Annual Newsletter: R50 per person (including pensioners) or R20 per person receiving a Government Old Age Pension or Disability Grant.

**CHEQUES, POSTAL ORDERS OR DEPOSITS** to be made payable to **SAVES-The Living Will Society**

**DIRECT DEPOSITS:** Standard Bank (Westville Branch Code No. 04 54 26), Current Account No. 05 307 4416. Please give your **FULL NAME** and Fax or Post the deposit slip to us with your completed enrolment form.

**Electronic:** Please give **FULL** details (as required on the enrolment form) and furnish proof of payment therewith.

***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