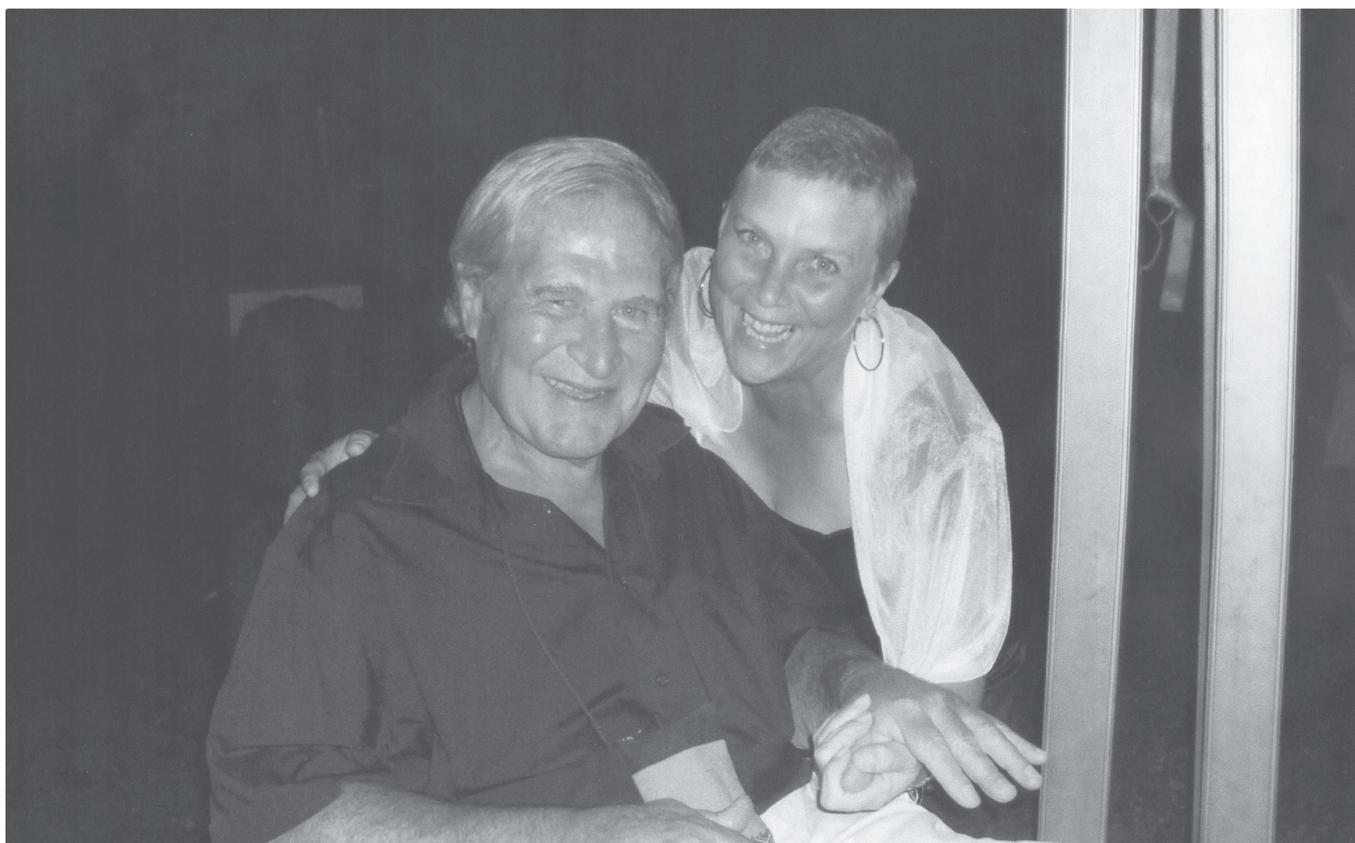


Thumbs UP

MND / ALS
ASSOCIATION OF SOUTH AFRICA 

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

May 2012



Richard Peall (patient) and Sheila Kendal, MND/ALS Consultant at the function held in Zimbabwe see 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

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VICE CHAIRPERSON
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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

Dear members

We have been made aware of a number of patients with MND / ALS undergoing stem cell therapy, either on the advice of doctors, family members or on own initiative. The opening of stem cell clinics in South Africa has led to an increased number of patients pursuing this therapy at great financial cost and with high expectations. With regards to this technology, we would like to emphasize the following:

1. There is a complete absence of sound clinical evidence for the efficacy of stem cell therapy for MND /ALS (and neurodegenerative diseases in general). No randomized, controlled studies or even open-label studies with long-term follow up exist. Furthermore, a prospective case series in the Netherlands showed no benefit from treatment with olfactory ensheathing cells (one of the cell lines used in stem cell therapy) in patients with MND / ALS.
2. Long-term safety information on the use of stem cell therapy in neurological disorders is lacking.
3. Currently the main utility for stem cell technology in neurological disorders is the ability to offer human models for understanding disease mechanisms and possibly paving the way for drug discovery. Although the potential for cell-based therapy exists, current claims of efficacy in MND / ALS and other neurodegenerative disorders are premature and unsubstantiated.

We have strong scientific, ethical and economic objections to clinics offering stem cell therapy on a commercial basis, as well as medical practitioners recommending (or not advising against) this treatment for neurological disorders. Patients with incurable diseases such as MND / ALS are desperate and emotionally vulnerable to the claims of institutions allegedly being able to heal a number of diseases which modern medicine is unable to. Although we respect the autonomy and right to self-determination of every individual, we must emphasize that the information available in the lay media often is a misrepresentation of the facts. In addition, regulations guiding stem cell research and therapy are sorely lacking in South Africa. Patients and their families therefore need to be provided with relevant and substantiated information in an understandable manner to guide decision making. We would therefore like to encourage you to discuss these issues with your treating medical professional (general practitioner or specialist) before spending substantial amounts of money for no discernible benefit.

Although there is no denying the potential benefit of cell-based treatments, the technology is not yet beyond the experimental stage, and therefore should not be offered or pursued in a commercial manner.

Dr Francio Henning, FC Neurol (SA)

FROM THE OFFICE

You might be aware that **21 June is MND/ALS Global Awareness Day**, and in helping us get this message across, these 5 campaigners have offered their time, effort and "stamina" to raise awareness in support of people with MND/ALS



i) ALEXANDRE TORRAO is 27 years old and so impressed with the will, strength and power of MND/ALS patients and the challenges they face every day that he is dedicating his participation in the **SABC3 Reality TV Show, The Bar One Manhunt** in honour of people with Motor Neurone Disease. He wishes to make viewers at home aware of MND/ALS and raise support. The prize pool is R1m + and he will contribute a share of whatever he wins towards the MND/ALS Association of South Africa. Please watch out for the announcement of this event on SABC3, and view the following facebook page of the Bar-One Man Competition and add a comment to support his cause <http://www.facebook.com/TheBarOneManhunt>

(ii) CHRISTINE BARROW

Is a long distance runner who will be **running her 3rd Comrades** from Pietermaritzburg to Durban on **3 June** this year – a distance of 89 Kms. She is looking at being sponsored R1 for each kilometre she runs in support of people with MND/ALS and the MND/ALS Association of SA.

Please support Christine by pledging your sponsorship. She can be contacted on cannabarow100@gmail.com so make your pledge.

**(iii) JOLENE PERKINS**

Has undertaken to **run from Cape Town to Johannesburg** to raise awareness and support for people with MND/ALS and the MND/ALS Association of SA. She will be accompanied by Louw Pretorius who sees this as a worthwhile opportunity to do an ultra-run.

They will be leaving the Global School of Theology in Cape Town on **26 May**, finishing at the London Road Church in Johannesburg on 28 July 2012. The route will be along the N1, visiting towns and schools along the way where “civvies” days are planned and stickers handed out to those participating, and supporting her run.

Please watch out for Jolene and her team and support her in her efforts to raise funds and make it a safe and successful event.

Jolene can be reached on 079 782 6161, email joleneperkins@gmail.com and Blog mnda-campaig2012.blogspot.com

**(iv) ANDRE VENTER**

After meeting Elsie, a MND patient, and taking her out for her birthday, Andre said “I am going to **climb Kilimanjaro** in support of Elsie and others who suffer from MND”. Andre is not doing this to benefit financially, having already paid for the trip and his equipment. He is doing this to raise awareness of MND/ALS and the people with the disease. Andre is taking up a MND/ALS “flag” to leave on the Uhuru Peak on **summit night – 25 August 2012**. Andre wants people to refer to our website to contribute by making donations to the MND/ALS Association of SA.

For further details and to show your support, Andre can be contacted on av@umtsa.co.za

His Facebook Page : <http://www.facebook.com/KilimanjaroMnda>

You can also follow him on Twitter : [@Kilimnda](https://twitter.com/Kilimnda)

(v) CALLYN BOWLER

from Port Elizabeth, wants to arrange a function to coincide with MND/ALS Global Awareness Day on 21 June, and she writes:

MND became important to me because my boyfriend has a direct family member that has a form of it. I saw how much pain the disease caused, not just to the patient but also the family. I started doing research to find out what it is or what can be done only to see there isn't much. Everyone lost hope and sort of just gave in because doctors had no compassion towards them and made them feel like they had a couple of minutes to speak before he could hoof them out and take the next one. I then met people that suffered or lost a loved one to MND and heard their stories and their pain. They all had similar things in common. Most felt alone and that they were the only ones out there, none had knowledge about the disease, or a fellow sufferer to confide in just to feel reassured that certain things were normal (normal as in MND normal), all wanted tips just to help with doing everyday things such as showering etc, and all felt that what the doctor says is the final verdict for how they will carry on living for the rest of their lives. My aim is to create awareness, have people working together instead of apart, get doctors to be active in helping MND awareness and actually giving options to people, I want everyone to not feel alone but positive. I believe that with positivity lies a cure. I believe knowledge is power and it is their right to have it at its full potential, it's not for the patient only but the family as well. Have everyone on a database where they are emailed any new information or events and are able to email back.

I want to have this awareness event on the 21 June which happens to be world MND\ALS day. I have asked Sheila to come down to help address this since she has knowledge. I want professionals to attend and share what they know. Have health and lifestyle companies offer samples in goodie hampers such as eg. vitamins. This is a chance for all the patients and their families to attend and get the most out of it, and if they want, have the option of meeting other sufferers and see if there is someone they enjoy speaking to. It will be in a conference room at a hotel in Port Elizabeth that can facilitate people that have disabilities so it makes things easier for them. We will have not only handouts but audio\visuals as well and a tea\coffee\snacks break.

I'm not trying to save the world, I'm just trying to make a few people more positive and feel less lonely. I am an able body and I don't accept defeat and don't see why other people should either.

Anyone is more than welcome to contact me. You guys of course have been such a help it really means a lot. I've also attached a story for you to read, it seems irrelevant but it paints the picture of who I am and why this is important to me. I would love more help and I don't mind how you choose to advertise it.

Regards, Callyn Bowler callyn@triangle.cc or 071 892 1755



Thanks for all the membership fee payments received as well as those “extra little bits”. We are very grateful. To our regular monthly donors, friends and family, thank you! Donations were also received from Jean Gaiser, C Jordens, Carol van Wijk, Sue Lane, Erna Labuschagne. JJ Swart, MJ Johnston, WR Terry, Merle Greenwood and Hilary Beningfield on the occasion of Hilary’s birthday, Masonic Bowling Association, Methodist Church (Wesley Parow), Kurt & Joey Strauss Foundation.

Sarah Boulle shaved her hair for cancer day and donated the funds to us in memory of her dad. So, to everyone, a big thank you for your generous and loyal support.

In mediaeval England, pots and dishes were made from a clay called “pygg” and spare change was often saved in such a pot.

Around 1600, an English potter unfamiliar with this custom, was asked to make a “pygg bank”

Misunderstanding the instructions, he created a clay vessel in the shape of a pig.

This is how the piggy bank came to be !



Golf Day

The golf day held on 16 March which was organised by Michelle Fritz in memory of her dad Mickey, went off well despite the weather “not scoring!” The inclement weather did not dampen everyone’s spirit though and with donations and support Michelle managed to raise R12,000 (after all expenses) for the MND/ALS Association of SA. We say a big thank you to her and everyone who supported this day to make it the success it was. Michelle has expressed the desire to make this an annual event, so watch out for the announcement.



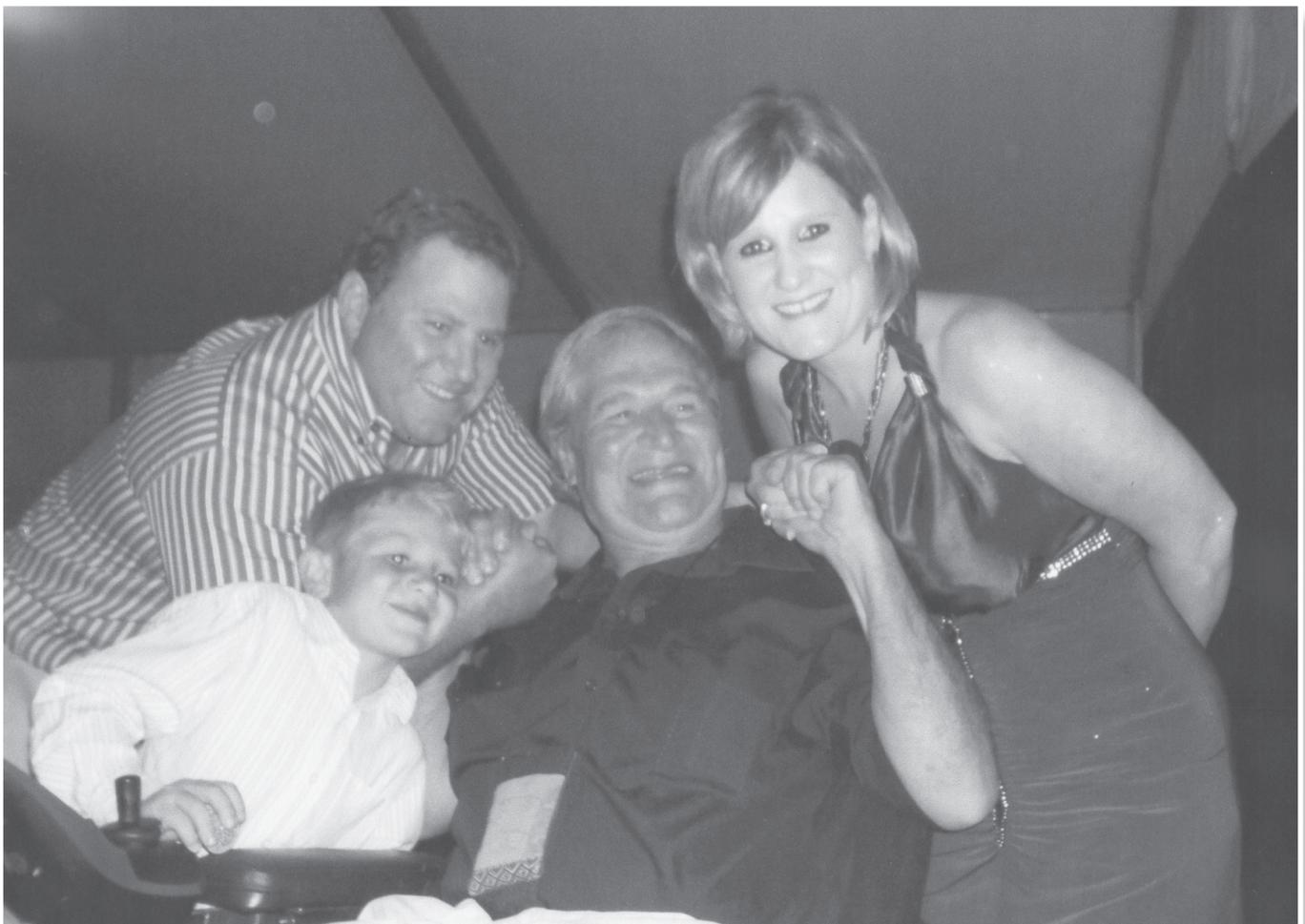
Michelle and brother Richard at the Golf Day

We are trying to make contact with as many as possible of our patients and families in other centres -

Sheila Kendal,

our Consultant in the Cape Town area, visited **Port Elizabeth** in February this year where a support group meeting was held at the St George's Hospital, organised by Ian Wiseman, and some of our existing patients went there to meet her. Sheila was also introduced to new patients and had a meeting with the Indigo Caregiving Agency. We are hoping to make use of the services of a nursing sister for that area and patients in PE and surrounds will be advised when arrangements have been concluded. Sheila is hoping to arrange her next visit for some time in June.

Towards the end of March, Sheila was invited to an Awareness and Fundraising Campaign in **Zimbabwe** which was organised by Mandy Rousseau, the daughter of patient Richard Peall who was diagnosed in the UK in 2009. Dancers from various studios took part in the extravaganza and sponsored items ranging from a case of whiskey, leather reclining chair, Stormers rugby jersey and paintings, etc, were auctioned. The whole event was sponsored by Richard Peall himself, to raise funds and awareness for people in Zimbabwe with MND/ALS. The event was very well attended, with ±140 people showing their support and enjoying the evening.



Richard Peall and his family who organised the event

Liz Keth,

our Consultant in the Gauteng area, has undertaken to look after the KZN area where possible, with visits scheduled during the year, until such time as we are able to also have someone there on a more permanent basis. In the meantime, support group meetings are scheduled to be held at Highway Hospice, 59 Locksley Drive, West Riding, Durban, and we hope it will help our members gather socially, share their concerns and also get help and advice. Patients there will be advised on what dates it will take place.

You are welcome to give Liz Keth a call on 082 878 3716 should you need further information.

NEWS from further afield

In February this year, David Visser of Wellington, New Zealand (brother of patient Wilfred Visser of Parklands, Milner-ton in Cape Town) and a friend, Tony, also from Wellington NZ, covered 4,429 kms over 7 days riding their motorcycles from Wellington to Bluff to Cape Reinga and back to Wellington “for the love of my brother” and to raise funds and support for the Motor Neurone Disease Association of New Zealand. David reported that at the time of writing they had received \$8,485.

(Sadly Wilfred passed away on 4 April this year).



David and Tony setting off on their journey

RESEARCH

(Extracts from “Thumb Print” the magazine of the Motor Neurone Disease Association, UK, Winter 2012 edition):

The 22nd International Symposium on ALS/MND held in Sydney in December, attracted more than 600 delegates, which made it the world’s largest scientific and medical conference dedicated to the disease.

Seeking new disease marker

A key speaker at the neuro-imaging session was Dr Martin Turner from Oxford University and the Association’s Oxford MND Care Centre. He’s now three years into his groundbreaking research study to identify a new MND disease marker. Dr Turner presented to delegates the latest findings from his BioMOx project, which is co-funded by the Association in the UK and uses advanced imaging techniques to look at the relationship between brain function and the rate of disease progression.

Dr Turner has identified a significant difference in levels of activity for certain neurones, which are indirectly linked to movement, in the brains of people with MND compared with healthy individuals. The amount of neurone activity was directly related to the progression rate of the MND patient.

Challenging ‘orphan’ disease concept

Headlining the genetics session was Prof Teepu Siddique, an eminent MND researcher from North Western University USA, who was invited to provide an overview to delegates of how genetic advances have identified overlaps with other diseases to help drive MND research forward.

Prof Siddique has a long and distinguished career in MND research. He was responsible for identifying the SOD1 gene in 1993, the first MND-causing gene to be discovered, and findings from his labs have featured heavily in MND research headlines in 2011. He explained that emerging findings are challenging the concept that MND is an 'orphan' disease. Due to the recent discoveries of MND-causing genes, we are starting to see other diseases that are clinically and biologically linked to MND. This knowledge increases researchers' understanding of multiple diseases, where similar activities within the body may become faulty but lead to different diseases.

Sharing clinical trial findings

Progressing clinical trials is an area that all researchers and clinicians are committed to.

The symposium always sees researchers sharing and debating the design of more efficient trials as well as discussing latest findings. Here's a round up of new trial results that were presented in Sydney –

Stem Cells

A handful of Americans with MND have taken part in one of the first properly conducted trials of a stem cell treatment for MND, developed by a company called Neuralstem. The trial team identified that injections of the unique type of stem cell into the lower section of the spinal cord were well tolerated by people with MND at various disease stages. Permission has been given to advance this trial to higher sections of the spinal cord; protection at this level may help with breathing.

Nogo-A (GSK drug)

Dr Pierre-Francois Pradat from the Centre for MND in Paris France, presented the newly released results of the GlaxoSmithKline (GSK) Phase 1 safety clinical trial which involved UK centres. The drug was shown to be safe and well tolerated by people with MND and the investigators reported trends suggesting the drug may slow the decline of respiratory function. Tentative plans are underway for a larger clinical trial in 2012.

Lithium

Prof Leonard van den Berg, from the University of Utrecht, The Netherlands, presented results from the Dutch lithium carbonate clinical trial. Unfortunately, although they found the treatment to be safe, no beneficial effects were seen. The UK based clinical trial for lithium carbonate is now complete with results due in spring 2012 and will provide UK clinicians with the definite answer as to whether they should prescribe lithium to patients who request it.

Prof Carolyn Young, a neurologist for over 20 years, is very clear about what drives her:

"My first and last love is care in the clinic because I'm a doctor – a clinician driven to help patients. I'm interested in how we can deliver better care that's timely, effective and provides patient dignity. I'm always asking the question, 'How can we treat people better?'"

Her passion lies in healthcare research, dedicated to improving quality of life for people with MND, and patients are her key 'research partners'. 'Good treatments cannot be approved and funded if we cannot objectively measure the effectiveness and the benefits'.

One area which highlights her passion is the use of non-invasive ventilation (NIV). A UK Association funded clinical trial showed that in the majority of cases NIV, a medical intervention to support people with MND who have respiratory problems has a positive impact on quality and length of life. Evidence from research contributed to guidelines being developed for the use of NIV.

Prof Young is also interested in the psychological impact of this disease. In another project, she is looking for factors that affect quality of life. Her research requires patients to complete in-depth questionnaires and to be tracked over a period of time with regular feedback sessions. 'Good science requires good knowledge which is why every view is important. It's essential that the views of the widest range of patients are reflected to ensure the results represent the 'typical' patient.

So what continues to drive her?

"The fact that MND is a difficult disease is a challenge but this is why I and many others are here. I'm in this for the long haul and I want my research to show which treatments will work."

Dr Brian Dickie, Director of Research Development, explains that Prof Young's research has a direct and tangible impact on healthcare provision. With ever-tightening budgets, healthcare funders want clear evidence on how treatments impact on the patient. Whether a treatment is aimed at altering disease progression or at treating specific symptoms of MND, it is vital to also be able to clearly demonstrate improvement in quality of life.

(Wise words sent to us by Ron Nosworthy, MND patient from Milnerton, Cape)

One Day at a Time

There are two days in every week that we should not worry about
Two days that should be kept free from fear and apprehension

One is **YESTERDAY**, with its mistakes and cares, its faults and blunders, its aches and pains

Yesterday has passed forever beyond our control
All the money in the world cannot bring back **yesterday**
We cannot undo a single act we performed, nor can we erase a single word we've said - **yesterday** is gone!

The other day we shouldn't worry about is **TOMORROW**
With its impossible adversaries, its burden, its hopeful promise and poor performance

Tomorrow is beyond our control
Tomorrow's sun will rise either in splendour, Or behind a mask of clouds - but it will rise
And until it does, we have no stake in **tomorrow**, for it is yet unborn.

This leaves only one day - **TODAY**

Any person can fight the battles of just one day
It is only when we add the burdens of **yesterday** and **tomorrow** that we break down
It is not the experience of **today** that drives people mad, it is the remorse of bitterness for something which happened **yesterday**, And the dread of what **tomorrow** may bring.
Let us, therefore, **LIVE ONE DAY AT A TIME!**
LIVE FOR NOW, TODAY, leaving the rest to God to handle!!!

SORRY !!

We do apologise for an error in our September 2010 issue of Thumbs Up, when we advised you of the launch of a book co-written by patient Jozanne Moss of George, "I Choose Everything". Unfortunately the contact number to acquire the book was incorrect – the number for Dave Moss should be 079 494 9049 – please call him to order your copy. (Sadly Jozanne passed away in February this year).

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



Travel News

The West Coast National Park has boardwalks and tarred roads for lovely walks/rides and a pool -
Duinepos Chalets in Langebaan is part of the West Coast National Park.

Hermanus has two beach wheelchairs at the blue flag Grotto Beach.

Eastcliff House in Hermanus has 4 bedrooms and 3 roll-in showers.

Hospice Palliative Care Association of South Africa (No end to Caring) – Celebrating 25 years

We would like to remind our members that we are affiliated to the Hospice Association and as such use their NPO number 003-462. Hospices throughout South Africa promote quality of life, dignity in death and support in bereavement for all people living with a life-threatening illness, and also for members of their family. The hospice multi-disciplinary approach to patient care is a practical, hands-on approach and is provided mainly in patients' homes, but can also offer respite care at some Hospices which are equipped for it.



Condolences to the family and friends of

Debra Scott (Sept 2011),
Rentius Nel (Oct 2011),
Elizabeth Mannall (Nov 2011),
Tilly Fortune (Dec 2011),
Desmond Riddles (24 Jan),

Angela Wootton (29 Feb), Jozanne Moss (6 Feb),
Richard Chandler (14 Feb), Anette Breytenbach (7 March),
Done Stewart (8 March), Derek Rimmer (11 March), Michael Grobler (13 March), John Nickols (18 March), Ida Horton (19 March), Wilfred Visser (4 April),
Laetitia Kotze (19 April), Zeela Brint (20 April),
Harrylall Sewlall (21 April)

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

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