

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Rita Bartlett (right) of Somerset West and her brother-in-law Jeremy Hindley of Constantia (left) - (both MND patients) and a friend Jeremy Hazel, who is a paraplegic (centre) on a recent trip to the Bush. Rita writes: "We had a wonderful time, totally exhausting but worth every minute. Didn't think I would make every game drive but mind overcame body and I arrived back home totally tired but happy."

**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

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MNDA 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 have pleasure in announcing that Dr Franclo Henning (Neurologist, Tygerberg Hospital, Cape) has agreed to join our committee. We welcome him on board and look forward to his participation.

Thank you ! We had a good response to our plea in the last newsletter – if we could have that positive reaction every month, our aims don't seem that impossible !

REMINDER

**2008 Membership Fee of R75 now due. (Forms enclosed).
(Thanks for the subscriptions already received).**

Remember our banking details:

MNDA of SA

26 062 913 0 Standard Bank Rondebosch 025009

DONATIONS

Since our last newsletter, we received:

From D & R Milton and friends of Cirelle Cabion in lieu of gifts on her 70th Birthday; from family and friends of Peter Thorburn in lieu of gifts for his 70th Birthday; and from Philip & Michelle Krawitz in lieu of a gift to Aviva Pelham on her 60th Birthday.

Hope you all enjoyed your special days !

From AJ Peacock, Jeremy Hindley, N Dippenaar, Pat Jackson, Clare Jeffrey & family, and one anonymous donation, in memory of Prof Lafras Steyn who passed away in February.

From Mark & Johanna Ruffley, and Jean Gaiser & Jean Davidson in memory of Shawn Wessels who passed away in April

From: Morgan Pillay; Sylvia Campbell, Elaine Theron & Noeleen Thomas; L Fischer; Masonic Bowling Club; C Booyesen; PM Snyman; Philip Newton (friend from overseas visiting Jeremy Hindley); Mr & Mrs D H Tugwell; Len & Jen Hall; Sue Lane; John & Marge Dillon; Marion Thomas; Shelagh Gastrow; Sandra Bellingan in memory of her husband who passed away in January; JJ van der Merwe; Linda MacFarlane; Gavin Swanepoel; Mandy Snyman; AA Carrim; AL Steyn; Des Munroe; Ferdi Dorfling; Roy & Maureen Brown; Janie Zaal; Mark Agrella; Roslyn Els, Robert Hollings, Cirelle Cabion, CH Dosé, RJ Labuschagne, Prof Andy & Yvonne Gilbert, L MacFarlane, Lynne Dramat & family.

We are very grateful for and most appreciative of the response received to our plea in the last newsletter. A special thank you also goes to the Kurt & Joey Strauss Foundation and the GCG Werdmuller Charity Trust for their support.

Thank you to all – big and small !

MAIL BAG

Des Munroe of Tokai, writes as follows:

Attached please find cheque as a donation in memory of my beautiful daughter Michelle Gersie who died 10 years ago on 28 February 1998. The kindness and care given to her by all will always be remembered, in particular Vivien O'Cuinneagain, who excelled herself at all times with care and affection. Once again with very special thanks to all. Kind regards.

Patient Reuben Ramosepele from Karenpark writes:

Your latest "Thumbs Up" publication has an inspiring article by patient Dr A Steyn. MND can also be (?) formidable – this short and yet powerful (?).... can be a life-time to many MND patients like myself. I'm not writing to you for publication but instead asking for the contact details of Dr Andrew Steyn of Somerset West. Time is of the essence in MND as you would know.

Suzaan Sander, a patient from Fonteinriet, sent us an article (taken from MacDonald Optima, Div of Little, Brown & Co Ltd, UK, and written by Clare Drew), from which we quote:

“Those of us who experience partial mobility problems and fatigue are presented with a particular choice which may not be immediately evident and usually not desirable: the choice of making limited use of a wheelchair. The very thought of this possibility can create instant panic, anxiety and resistance. “I do not need a wheelchair”. I can walk and manage quite well on my own. Perhaps you can. But how many activities and events have you declined because you know that you cannot manage the distance? Alternatively, you give it your best shot, collapse from fatigue and are set back for days or weeks on end.

I believe that we do have a choice. We can choose to participate in life as fully as we are able. The choice for me has included using a wheelchair when my limitations have deemed it necessary. It enables me to cover distances that I otherwise could not consider. Here, I am not talking about marathon distances but the ordinary things in life I used to take for granted and that able-bodied people nothing of. Activities like shopping in the mall, meandering through Sun City or browsing through the local nursery with my husband. Simply getting from Point A to Point B and remaining whole in the process.

This is a choice that my husband and I made together. There are many social and psychological barriers to be constantly overcome.

Cynthia Benz, in her book, “Coping with Multiple Sclerosis” looks at the expectations of society: “Society expects you to be either able-bodied or disabled and ignores the reality of middle-ground. This needs confronting because life is full of experiences never faced before, that each individual must be helped to cope with”.

One of the most difficult aspects of using a wheelchair in a limited way is the perceived perceptions of other people. It was not easy for me, but especially difficult for my husband to cope with the anxiety and embarrassment of wondering how observers were reacting when I reached my destination, got up and moved around normally. Again, a choice had to be made: was engaging more fully in life of greater importance than the perceived perceptions of others? We decided that it was. My husband is less sensitive now and my need for us to do more things together overrides my natural resistance to being in a wheelchair. Guilty fears that I will be perceived to be “giving up” or “taking the easy way out” have to continually be balanced against the reality. My abilities have been reduced but there are avenues open to me, there are possibilities to be explored, ways and means to be found to get around the limitations.

Mostly, these ways and means involve other people, especially my husband, whose openness to venture into sometimes scary situations is what encourages me to keep trying. We encourage you to explore your choices.”

Prof Andrew Gilbert of Nahoon, East London, writes with advice:

LOSING YOUR SPEECH? SOME WAYS TO KEEP COMMUNICATING.

I have ALS and was diagnosed in December 2006. The symptoms at present are mainly bulbar (muscles in the neck, throat and mouth) and as a result I have lost my ability to speak. Over the last year I have spent a lot of time doing research into maintaining my ability to communicate and I would like to share the solutions I have found.

I need to start by saying that my first symptom was slurring of speech and the person who picked up the possibility of ALS and got me to go to a neurologist was a speech therapist. She has been wonderful in helping me, not only with keeping my speech going for as long as possible, but also with swallowing. People have different needs and resources available to them, so my solutions will not be right for everyone. So please see a speech therapist for expert advice for your needs.

When I started looking for help I got very confused. There is a mass of information out there and many companies who offer devices and software. I found the MND A Pamphlet No 7 on “Speech Difficulties and Communication Aids” to be a good starting point. This gives very useful advice for the early stages for speech problems and swallowing and strategies for maximising the speech that one might have.

As I lost my speech, though, I searched for “Assistive Communication Devices” - as they are called by the manufacturing world - and have come up with two that have become part of my life.

The first is a Lightwriter which the MND A has very kindly loaned me. This is a portable machine made by a UK company called Toby Churchill. (Visit their website <http://www.toby-churchill.com> to see the range they have). It consists of a small keyboard with two small screens - one for the person “speaking/typing” and one facing the “listener/reader”. As one types, the text comes up on both screens so the person with whom you are having the conversation can read what you are saying. It also has a powerful built-in speaker which will speak the text when you press the ‘speak’ button. I have found it ideal for closer interactions such as conversations with one or two people, at meals with family or interactions in shops. It also works over the phone using the speaker. I carry it around wherever I go in a small shoulder bag and use it all the time.

It has predictive text which means one doesn’t have to

type every word in full. One can also save short messages to “keys” on the keyboard and call them up by pushing shortcut keys. So for example “Thank you” or “I am not able to speak but I can hear” or “Can I have a drink of water”, can be spoken by pressing two or three keys only. It has a very good rechargeable battery which lasts for many hours before needing to be plugged in. There are options for a range of voices – male, female, adult, child – but the machine I have only has voices with American accents.

If you are used to typing – I only use two fingers – it is quick and easy to learn to use. The more challenging thing is building up the confidence and skill to be part of a conversation. With more than one person present, dialogue flows faster than one can type one’s contribution. This means that entering the conversation at the appropriate time is difficult and it is tempting to slip into silence. I have found, however, that persevering pays off. I have called my machine “Paul” and when I meet new people I introduce them to him. This has meant that people are now familiar with the voice and the process and have got used to the delay in my response. As a result my family, friends and most of my colleagues have adjusted to it quite naturally. And when they don’t I use the two buttons specially designed to force people to listen! One is a gentle ding-dong and the other a harsh electronic zap, which stops people in their tracks!

The second tool I use is a very up-to-date and powerful software called “The Grid 2”. I have it loaded on my laptop and I am running it now while I type this. Grid 2 is produced by another UK firm called Sensory Software - <http://www.sensorysoftware.com>. Basically the software creates screens (called grids) of buttons (called cells). When one clicks on a cell this will activate a command which could be a letter, word or sentence or some other action such as jump to another grid.

In its most basic form the standard grids, which come already set up, are like a basic keyboard. By moving the cursor to a letter and then another letter and clicking each in turn one can build up words and sentences. And once you have compiled what you want to say the programme will speak the text. However it is much more powerful than this because these basic grids also come with lists of “predictive” words which one can use to rapidly create sentences. In addition, if you save the phrases that you generated, you can call them back to use again, when needed, with one click of a button.

The software also comes with grids that use symbols instead of words which are also very powerful because one doesn’t have to spell out the words. This is especially useful for people whose fingers are unfamiliar with typing, or whose dexterity is poor, or for children who cannot spell.

But there are more powerful grids which enable you to surf the internet, use email, play music and control one’s

environment or send smses through bluetooth connections.

It is also possible to create your own grids or download those shared by others. I have set up a grid that enables me to import “Word” files. This means I can prepare for a meeting or write a report and then at the meeting bring the file into Grid and the programme will read what I have to say (even give a lecture if need be).

It is obviously not as portable as the Lightwriter but it is much more powerful. I find I use it in the work setting or in bigger gatherings where I can set up my laptop and connect small speakers. This means people can hear even if the gathering is in a largish room.

And then the most wonderful thing is that the programme can be used either with a keyboard or a range of “switches”. What this means is that if I am no longer able to use my hands I can operate the programme with a scanning option and a “switch”. In other words Grid 2 can work as a ‘hands free’ programme using a pressure pad or even head movements to control the computer’s cursor.

One needs a fairly up to date and fast computer or laptop if one wants to use the programme optimally. The agent in South Africa is Inclusive Solutions who have been most helpful. Their telephone number is 011 7985562 and their email: celeste@inclusivesolutions.co.za and website: <http://www.inclusivesolutions.co.za/>. The latest Grid 2 software cost me R5626. This includes the licence, free updates and access to the Grid 2 website which provides free grids that others have created and are willing to share.

I am very happy to answer questions and share more detailed information. I can be contacted at agilbert@mweb.co.za

Andy Gilbert

A little boy opened the big family bible. He was fascinated as he fingered through the old pages.

Suddenly, something fell out of the Bible. He picked up the object and looked at it.

What he saw was an old leaf that had been pressed in between the pages.

“Mama, look what I found” the boy called out. “What have you got there dear?”

With astonishment in the young boy’s voice, he answered

“I think it’s Adam’s underwear!”



David (centre) with his Mom Johanna (right) and his carer Sylvia.



David & friends with Jerry the Clown

FROM GAUTENG

Liz Keth invites you to join her monthly MND meetings which will be held at **“The House of Coffee”, Alberton City, at 11 am on:**

23 May, 18 July, 15 August, 19 September, 17 October, November 21

For more details you can call her on 011 791 4739.

Liz tells us David Mashegoana’s story:

In a small township of Etwatwa, near Daveyton on the East Rand, lives a close-knit family. But life dealt a cruel blow. David began to experience a constant, uncontrollable twitching in his upper arm which spread to his hand. He was diagnosed with debilitating Motor Neurone Disease.

David, who once had a wide circle of friends, sits in a wheelchair everyday, alone, difficulty with speech, struggles to walk and swallow.

The highlights of David’s life are the weekly visits to Hospice Day Care where for a few short hours he can spend precious time enjoying the company of other patients and sharing a meal.

On Wednesday 23 April, David celebrated his 29th birthday where Jerry the clown entertained patients.

Tea was enjoyed by all.

Thank you to Liz for making the Birthday Cake and another big thank you to Woolworths, Northwold, for supplying the other snacks.

Courage and Positive Thinking !

“I’m just grateful for what I have” says Tony Katzew, MND patient from Johannesburg:

These words should be spoken by each one of us, every day of our lives. And when we think of all that is really good in our lives, the world suddenly seems a better place. Yet when terminally ill Hospice patient Tony Katzew (61) said these words recently, one can’t help wondering just what he could possibly have to be grateful for.

In 1997 Tony began having symptoms, like being unable to get up from the ground after fixing his car, and falling for no reason; he visited his doctor who said he was suffering from stress and high blood pressure. Months later a cup slipped inexplicably out of his hand; he went to a neurologist. “What is wrong with me?” asked Tony after the tests were completed. Even today he remembers the specialist’s exact and chilling words: “There is no prognosis. You have Motor Neurone Disease and you will be dead within 2-5 years.”

The shock was almost more than this family man could bear. His anger and resentment mounted up – as did his sense of grief at everything he was going to lose. He felt like a victim until he sat down and talked things over in his head. Fear, regret and saying “If only ...” were just too easy, he decided. It was time to do some hard work

on himself, time to live with what he had, rather than what he didn’t have. Tony realised that what he did still have, was choice.

The outcome was a quest to unearth opportunities that didn’t exist before. “Why couldn’t I help others?” he asked himself. Since then he’s made a DVD called Living with MND, which tackles living with this disease from the patient’s point of view. He’s also made trading videos for doctors and nurses, and became part of the training programme for current medical and palliative care students. They spend time with him weekly, ask him questions and get to know about the needs and emotional roller coasters experience by the terminally ill. This helps doctors and nurses feel more at ease with other terminal patients, and when dealing with death itself. “I try to make an impact on their professional lives” says Tony. In addition he is now giving motivational talks to corporate groups who visit him in Hospice.

He wakes up each day making the choice to feel appreciative that he has that day to live. It takes some doing! Enormous courage is involved in being grateful and cheerful in Tony’s situation: he’s now unable to move almost any part of his body, requires 24-hour care which his family is unable to provide. He’s been admitted to the In-Patient Unit where he will stay until his death.

Tony Katzew is a living reminder to us all of how the choices we make – such as choosing to be positive and enjoy life – affect our own lives and the lives of those around us, and of how to live to the full just one day at a time, even in the most difficult of circumstances.

(Taken from Hospice Voice, February 2008)

RESEARCH**An extract from the Winter 2008 issue of “Edit” The Alumnus Magazine of The University of Edinburgh:**

Tara Womersley reports on the Euan MacDonald Centre for Motor Neurone Disease Research, a centre of excellence that will strengthen University researchers’ understanding of motor neurone disease.

On his morning commute to work at investment bank Dresdner Kleinwort in London, Euan MacDonald realised something was not quite right when he started having difficulty changing gears on his bicycle. A loss of power in his thumb, coupled with a twitching in his left arm muscles, were the first telltale signs that he needed to seek medical advice.

In 2003 – just three years after finishing his law studies at the University of Edinburgh – Euan was diagnosed with motor neurone disease (MND), a debilitating and ultimately fatal condition for which treatment is limited and no cure exists.

Since then, Euan, now a staunch advocate of raising

awareness of the disease, has returned to his home town of Edinburgh, where he lives with his wife Liz, and two young sons. Together with his father, Donald, also an Edinburgh law graduate, Euan has made a substantial donation to the University to create the Euan MacDonald Centre for Motor Neurone Disease Research.

The Centre, which will form part of a worldwide drive to research for a cure, will bring together experts from a wide range of disciplines with the aim of furthering understanding of the disease.

The generous seven-figure donation from Euan and his father, who is co-founder and Vice-Chairman of the City Inn hotel chain and Joint Chairman of Caledonian Brewery, has enabled the University to expand and already existing consortium of 20 scientists and physicians undertaking MND research. The world-class Centre will combine expertise from areas such as regenerative medicine, stem cell research, neuroscience and molecular medicine.

Euan, who is actively involved with the Scottish Motor Neurone Disease Association, says: "The University already has a strong research base with a lot of strong science in this area. The setting up of a dedicated centre will build on that. By bringing scientists together from different fields and with a clinical focus, we hope to improve patient care and work towards better treatments.

"At present, nobody really knows what causes motor neurone disease although in a small minority of cases it can be inherited. It can affect anyone, no matter how fit and healthy they may seem. It is only by understanding the exact mechanisms of the disease that improvements in treatments can be made."

At any one time, some 5000 people in the UK are affected with MND. Most diagnoses are made in patients over 40, but Euan was told he had the condition when he was just 29.

MND affects the motor neurones (nerve cells) in the brain and spinal cord. As the motor neurones gradually die the muscles stop working, which can lead to paralysis and severe breathing difficulties. It is a progressive disease with a stark prognosis – life expectancy for most patients is estimated at two to five years.

The University is now recruiting a senior clinical fellow to co-ordinate its clinical and basic research for the Euan MacDonald Centre. The Centre will be based next to the Royal Infirmary of Edinburgh, where the University already has a solid research presence. It will also run alongside the University's Scottish Centre for Regenerative Medicine, which is set to benefit from a purpose-built facility to develop stem cell lines where researchers are already working towards medical therapies for illnesses including MND, cancer, Parkinson's and liver disease.

Last August, shortly after announcing the Euan

MacDonald Centre, the University hosted a two-day symposium into the condition, which was attended by internationally renowned experts. The event featured presentations on the latest research carried out in Edinburgh, as well as talks from senior investigators from around the UK. Keynote lectures were delivered by three of the world's leading experts on MND, Prof Don Cleveland of the University of California, Prof Nigel Leigh of Kings College, London and Prof Jeffrey Rothstein, Director of the Robert Packard Centre at Johns Hopkins University, Baltimore.

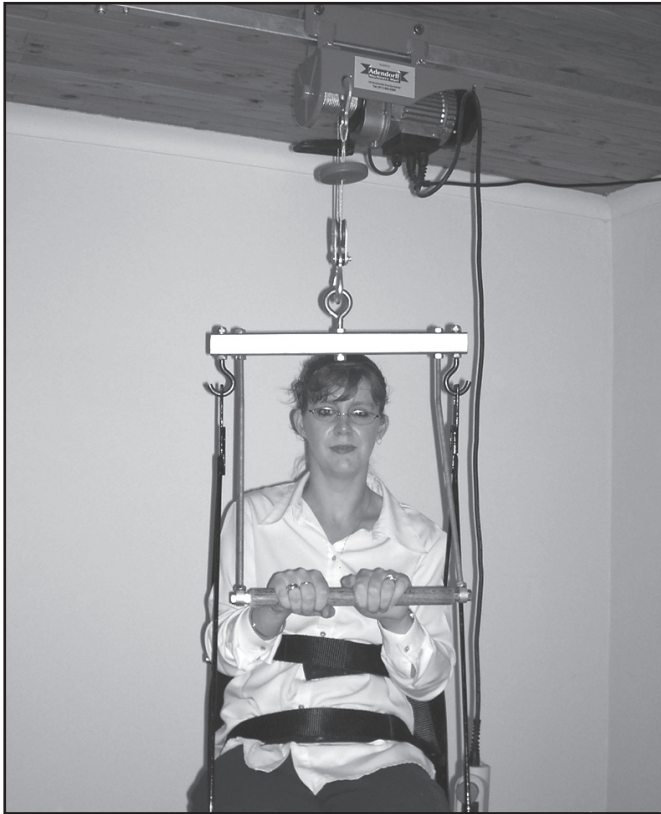
Prof Richard Ribchester, Chair of Cellular Neuroscience at the University of Edinburgh, coordinated the event and has played a major role in the setting up of the Euan MacDonald Centre. He comments: "While there may be no one answer to motor neurone disease, it is by working together on an international stage that we hope that the Euan MacDonald Centre will have a major impact on shedding light on this pernicious illness. We all have a common goal and the Centre will place a strong emphasis on the sharing of research and building up research collaborations."

The Euan MacDonald Centre is the only one of its kind in Scotland and staff will work closely with the Scottish Motor Neurone Disease Association. Researchers will also liaise with other centres of excellence such as the Packard Centre in the US and King's Motor Neurone Disease Centre and Research Centre in London. The donation from the MacDonalds will also enable the University to establish key clinical and scientific training posts, with a view to the Centre becoming self-sufficient through funding, grants and donations within five years.

Donald MacDonald says: "There is just one drug currently licensed in the UK to treat motor neurone disease. But this drug riluzole, has been shown to slow down the disease by only a few months.

"To target the disease, scientists need to understand exactly why motor neurones, which control voluntary muscle activity, such as speaking, walking and breathing, break down. Edinburgh has a worldwide reputation for cutting-edge medical research and the setting up of a centre into motor neurone disease will further provide insight and knowledge into the condition, ultimately leading to improved treatments."

(For more information on the Euan MacDonald Centre for Motor Neurone Disease Research, email: chloe.kippen@ed.ac.uk.)



Colin Anderton put up this hoist to assist his wife Sheila (a MND patient). Demonstrating is their daughter, Beverley.

Anyone interested and would like to have more information can call Colin on 076 914 3694.

Condolences to the family and friends of:

Prof Lafras Steyn, Hennie Swanepoel, Rudi Stoltz, Lorinda Claasens, Stephen Loeb, Leonard Ngcobo, Willie Labuschagne, Shawn Wessels, Kay Cecil.

SAVES - The Living Will Society

We have been approached by The Living Will Society, to bring their services to the notice of our patients. Brochures are available from our Office, MNDA of SA, PO Box 789, Howard Place 7450, or you can contact them direct as follows: The Living Will Society, 22A Westville Centre, Norfolk Terrace, Westville 3629, Durban, or PO Box 1460 Wandsbeck 3631. Telephone: 031 266 8511 / Fax: 031 267 2218.

Email: livingwill@3i.co.za

Web: www.livingwill.co.za

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 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) 791-4739

CELL: 082-878-3716

E-mail: keth@telkomsa.net