

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



June 2006

Jacoline Brand and Gareth Kruth, contestants in the Mr & Miss Bellville pageant. (See "Closer to Home" 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."**

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
Kargo National for transporting our equipment.

As the year is trotting by and winter is with us, hope you are all taking the necessary precautions to prevent being laid up with that dreaded flu !

It is with regret that we need to inform you that Eden Place will be closing their doors in September due to lack of support. If something else should come about we will certainly keep you informed.

We are aware that quite a few patients are trying various alternate treatments and we would like to be kept informed should there be any change in quality of life or benefits derived from such treatments.

As we are currently updating our e-mail contacts, please let us

have your e-mail address details to : mndaofsa@global.co.za

Please note our address/telephone details:

**PO Box 789, Howard Place 7450.
Tel No 021-531 6130. Fax 021-531 6131**

Banking Details:

MNDA of SA - Account No 27 062 913 0 at Standard Bank, Rondebosch 025009

DUE TO THE HIGH COST OF POSTAGE – PLEASE ADVISE US SHOULD YOU NO LONGER WISH TO RECEIVE THIS PUBLICATION.

NEWS

Donations

Grateful thanks for donations received from:

AS MacFarlane, PA McGregor, HW Levy, JF Lang, JV Timm, SE Montclair, J Bevan, BJ Engelbrecht, J Moll, MM Balcomb, Cape Underwear Manufacturers, M Essen, M Knepscheld, PJ Moys, Masonic Bowling, ME Kraut Kramer, P Kaplan, S van Blerk, E Field, A Masters, I Peters, EMJ Fourie, Kurt & Joey Strauss Foundation, van der Lith, M Essen, OT Dods, D Nutting, Probus Club Hout Bay, R Mazinter, Davis, M Norman, JHI Real Estate, M Alborough, A Olivier, Dreyer & Statham, T Dal Lago, Sue Lane, Janie Zaal, WR Terry, JJ van der Merwe, G Carollus, Jean Moll, J Buchanan, Jacoline Brand & Gareth Kruth (Bellville High

School), Associated Industries, Dinah Watt, and donations where we were unable to identify the source.

Fundraising

The concert “A funny thing happened on the way to the Forum” on 18 April 2006 raised R13,600 and a big thank you goes to everyone involved. And to those generous supporters who gave cash donations in lieu of and/or as well as purchasing tickets – our sincere appreciation for your generous support.

Membership

It is that time again - membership forms enclosed.

MAIL BOX

Marlies Kraut Kramer of Waterkloof Ridge (Pta), whose husband Karl-Heinz passed away in November 2005 sent us a donation with this letter of 11 March:

On behalf of my family I would like to express our sincere gratitude and appreciation for the enormous support and encouragement which we received from the MNDA during my husband's illness. My husband Karl-Heinz was diagnosed with Motor Neurone Disease in early March 2004 and after a brave struggle passed away peacefully on 20 November 2005. During this most difficult time in our lives, we were fortunate to receive invaluable support from the MNDA in the form of information, newsletters, regular visits, advice and various items of equipment that helped us to cope as my husband's condition steadily deteriorated. My very special thanks goes to sister Liz Keth who paid us regular visits and never tired to encourage and assist us, both practically and by giving us moral support.

May God bless you all for the wonderful work you are doing, and all families affected by Motor Neurone Disease.

Kobus Bothma of the Strand (Western Cape) wrote this letter after his wife Marina passed away in March 2006:

Baie dankie vir die pragtige kaartjie met die gesiggies (blom-

metjies) daarop. Hulle het u mooi wense aan my oorgedra. 'n Spesiale dankie aan Vivien O'Cuinneagain vir al die moeite en opofferings wat sy gedoen het, niks was vir haar te veel nie. Sy het my huis baie besoek of net 'n boodskappie op my foon gelaat. Net die Here en goeie vriende kan jou deur hierdie moeilike tye dra. Dit is baie swaar alleen, en ek verlang baie, maar ek gun haar die rus, en die wete waar sy is, is self vir my wonde. Nogmaals baie dankie vir alles.

Rosalynd Els of Thabazimbi, whose father Gurth Harris-Dewey passed away in April 2006, writes:

As a family we would like to thank the Association, and Liz Keth in particular, for your support during my father's illness. He passed away on April 11, after spending a month with us on the farm. We are so grateful to the Lord for this very precious time, during which he was able to participate in many activities with us. In honour of his memory we will continue to support the Association, and I personally, will be looking forward to the day when a breakthrough will be made in finding a cure for MND. We pray for all your staff and patients, and thank the Lord for the gift of human love, care and support.



Stuart MacFarlane and Rita Bartlett (both MND) patients at a recent support group meeting in Somerset West.

Gun-Run tradition (the Fun Run before the Two Oceans Marathon)

Dr Francois Majoos, a MND patient from Bellville, and a former Western Province and Stormers Super 12 medical doctor, shares his experiences of the Gun Run over the past 3 years:

In 2004 at one of our monthly MND support group meetings in Somerset West, I suggested to Mike Kellond that we should take part in the annual Cape Town Gun Run. Once the seed was sown we entered the 10km race and started with our preparations and would get people to push us in our wheelchairs. When the day of the race arrived we had a fantastic time and whilst being pushed by our sons, enjoyed the views of Robben Island, the Waterfront, the centre of Cape Town and Table Mountain. When we finished the race we were extremely proud to receive our medals, despite the fact that the medals were engraved with the words "Ladies 10km race". Yes, we were actually entered into the ladies 10km race which provided us with another view. We were seated in our wheelchairs and had a waist high view of hundreds of female bodies. Who needs Cosmopolitan magazine? After the race we had some champagne and beers with our families who supported us throughout the race.

In 2005 we entered the annual Two Oceans Fun Run, which started and ended at UCT. This time we were partnered by Mr Rabinowitz, a runner who at 101 years old is a legend in his own time. We all finished the race and again were very proud to receive our medals. We then planned that we would make this an annual event but unfortunately Mike passed away last year and it was up to me to continue the "tradition".

A few days before the Two Oceans race for 2006, my friend Paul Salkinder phoned me and said that he had entered us for the race. He was my "pusher" last year and he thoroughly enjoyed himself. I agreed and started preparing for the event, which was to be held over the Easter Week-end. The night before the race I made sure that I was carbo-loaded, taking in a few glasses of red wine and beer!. A word of warning, don't let the pusher of your wheelchair carbo-load to the same extent because in our first race my pusher did too much carbo-loading the night before (beer and whiskey), that after two kilometres into the race he could not continue because he felt sick. Fortunately my son Dylan was there to take over and we finished the race. This time we had no problems because Paul is Jewish and as it was their Passover he only had Matzos to

eat. The race started at UCT and there was quite a large turnout. We started off really slowly just to get out of the crowd and to make sure that we did not injure anybody with the wheelchair. We were a bit surprised that before we reached the two kilometre mark, the front runners passed us on their way back to the finish line. We were not disturbed by this because the first half of the race was all downhill and there was a lot of people behind us. The view again was fantastic along the M3 highway, past Newlands Forest, towards Kirstenbosch and back. During the race I did not take in any fluids because I was worried that my bladder might just need clearing but my "pusher" took quite a lot of fluid and at the 4km mark he had this great "need". Well, he parked me and the wheelchair while he quickly ducked behind a tree. After a few precious minutes lost we continued the race which was now all uphill. We were not going slower than before but with all the encouragement and cheering we made it back to UCT. Talking about our fellow runners, most were cheering us on, some actually asked us for a lift and some wanted to know when the two of us would swap around, i.e. I push and Paul sit in the chair. When we neared the finish, the crowd really cheered us on and the announcer, who had seen our race number, recognised Paul as one of the veterans of the Two Oceans and Comrades Marathons and also congratulated us.

We crossed the finishing line feeling happy and elated. When we collected our medals we felt ecstatic and grateful that one can still do these things, despite one's illness. One also felt blessed and grateful for the friends and family that supported you. Last but not least, when I put the medal around my neck, I silently said, "this one is for you, Mike". Come on 2007!



Francois showing off his medal, with wife Edna looking on

Suggestions at the time of any Terminal Illness

Gill Kellond of Somerset West sent this "check list" which she found to have made things much easier for the family and which she hopes with help others:

We made two lists – one which was for "officials" and the other for "friends" –

As soon as possible, whilst still reasonably fit and healthy, and

with the support of your family, suggest you contact your nearest Funeral Directors, discuss it all with him/her and make a 'down payment' for one funeral. The partner then is left with little financial burden regarding funeral expenses at the last minute. Once you have done this, it will/can last you for years. Keep all copies and file them away SAFELY, probably where you keep your Will. (We used Dove's and Donald was absolutely fantastic, he explained everything to us. He is one of the Funeral Directors.) The Funeral Director will put notices in the various papers should you require them.

Your first list and contact numbers would consist of:

| | |
|------------------|------------------------------------|
| Funeral Director | Lawyer/Attorney |
| Doctor | Nursing Staff if used |
| Church | Hospice, if used |
| Bank | If you are connected with MND, |
| Accountant | contact Vivien |
| Medical Aid | Financial or investment persons if |
| S.A.R.S | you have them |

The second list we made, consisted of our close family and friends, business contacts, with the contact numbers – even if only an e-mail address, you can send a short message. Then you can notify everyone of the date and time, name of church, of the Funeral/Celebration of Life. If you have a favourite charity, you can nominate it and ask for donations to that charity.



Barrie van Zyl of Diep River using his page turner.

Mandy Snyman, a patient from Port Elizabeth, sent us this little prayer to share:

I asked the Lord to bless you as I prayed for you today
To guide you and protect you as you go along your way
His love is always with you, His promises are true,
And when we give Him all our faith, He's sure to see us through
So when the road you're travelling on, seems difficult at best
Just remember I'm here praying and God will do the rest.

RESEARCH

Research moves closer to a diagnostic test*

As people with MND and their families know to their cost, the diagnosis of MND can take a long time. This is partly due to the fact that there is no test that confirms that someone has MND; rather, neurologists have to systematically exclude other possible conditions. Some exciting research published in March 2006 may change that in the future.

Researchers, led by New York-based Prof Giulio Pasenetti, reported that they were able to correctly identify which patients had MND from the levels of three specific proteins found in their cerebrospinal fluid (CSF). {The CSF is the fluid that bathes the brain and spinal cord within the central nervous system (CNS)}. This pattern or 'fingerprint' of MND was identified when the CSF of people with MND was compared with samples from people with other neurological conditions and from people with no history of neurological disease.

Initially, using modern laboratory techniques they simultaneously analysed the levels of hundreds of proteins in each CSF sample. At this stage, the proteins were characterised only by their relative size and shape. The researchers observed that three proteins were present at lower levels in people with MND. The next step in this research was to identify these three proteins and to understand more about their function in the body. So far, two of the proteins have been identified by Prof Pasenetti. Lower levels of one of these proteins has also been found in an earlier study looking at fingerprints of MND

in CSF.

In this study, the three-protein 'fingerprint' has been found in over 40 people with MND. More research is needed to confirm this result and to investigate the feasibility of developing a routine test for MND using these proteins. Prof Pasenetti and colleagues plan to continue their work in this area, investigating how the levels of these three proteins change as the disease progresses. It is also hoped that this research will shed light on the disease process itself, enabling new drug targets to be identified.

New research shows NIV (BI-PAP) benefits people with MND*

Non-invasive ventilation (NIV) or the Bi-Pap as it is known in South Africa, works by assisting people with MND, who have weakness of the respiratory muscles, to get a good night's sleep by helping to prevent carbon dioxide build-up.

New research results have been published by researchers at the University of Newcastle-upon-Tyne. They follow the completion of the first ever randomised, controlled trial of NIV. The study shows that people's quality of life is better as a result, and that they also live longer, on average by more than six months. In some people, NIV can prolong survival by several years.

Dr Brian Dickie, Director of Research Development at the MND Association (UK) said: "Many people with MND know

that using NIV has made a big difference to their daily lives, not only a fraction of people who could benefit actually receive it, because we only had anecdote rather than evidence. We now have 'gold-standard' evidence, from a clinical research trial.

As the disease progresses, poor sleep can be a common symptom. When the respiratory muscles weaken, it can be difficult for people to clear carbon dioxide from the blood, leading them to wake many times a night. And in the morning, instead of feeling refreshed, they can suffer from morning headaches and marked daytime sleepiness.

Having a good night's sleep adds a lot to a person's quality of life and using NIV also means that the respiratory muscles continue to be exercised."

At the moment, Dr Dickie believes that less than 5% of patients are referred for NIV by their neurologists, but research shows that up to two thirds of people living with MND could benefit.

The use of NIV is simple, involving basic equipment and a mask over the mouth and nose. Proper training is needed to ensure the person with MND uses it correctly.

A patient diagnosed with MND in 2003 has been using NIV for over two years and said: "I'd been unable to sleep at night and was waking almost 40 times an hour. I was not taking in enough oxygen and not breathing out waste gases properly. As a result I felt dreadfully ill. It was like one of the worst hangovers I've ever had, every morning. Without NIV, I'm not sure I would have managed. I probably would have given up by now."

Getting involved*

Getting involved in the Association is something everyone can do, regardless of their age. And you're never too young to start as dozens of youngsters are finding out. A number of young people start their volunteering 'career' because they have been directly affected by MND. Some have had to cope with the devastating loss of parents or grandparents early on in life. And it seems that seeing the effects of MND first hand only serves to galvanise their determination further.

Amy Smith from Leeds, was the youngest person to take on the MND Association's Mount Olympus Challenge last year and managed to raise over £2,500 in sponsorship. The eighteen-year-old did it in honour of her dad Derek, who died from MND. She raised the money through sales and sponsorship in order to take on the mountain challenge last September. Amy, who is taking a gap year before going to Leeds University to read law, liked the idea of doing something different to raise money and awareness.

*(From Thumbprint Spring/Summer 2006 edition)

And closer to home (Front page photo)

Two matric students from Die Hoërskool Bellville (Western Cape), Jacoline Brand and Gareth Kruth, were finalists in

their annual Mr and Miss Bellville competition which was held on 4 May 2006. One of their projects was to raise funds for a charity of their choice. As two of their friends had lost family members due to MND, they decided to raise funds for the MNDA. A get-together was held at the school on 23 May when the students who collected for their various charities, hosted a tea party to hand over the donations. The MNDA is extremely grateful to Jacoline and Gareth for giving their time and their effort, juggling with their normal studies, and other school activities, to collect the sum of R1.500 and they are commended for their keen interest in their community. We also thank those who contributed to this donation for their support.

Fundraising !

Have you or your family & friends thought of an easy way to raise funds for MNDA ?

Have a "Morning (or) Afternoon Tea" and charge guests for a cup of tea and a slice (or 2 !) of cake. It could also be a "fancy hat" competition or a "bring and buy" with a raffle !

OR

Why not send us a donation in lieu of a friend or relative's birthday (or any other occasion) and we will acknowledge that gift /donation to the person concerned. Just remember to let us have their name and address details !

In English pubs, ale is ordered by pints and quarts

So in old England, when customers got unruly, the bartender would yell at them:

"Mind your pints and quarts, and settle down"

It's where we get the phrase "mind your P's and Q's"

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.

Latest feature on website*

Personal experiences of living with Motor Neurone Disease are now live on the Association's website. The new 'Experiences of MND' section features each person's special story: One explains how the disease has seen him fulfil a life-time ambition, a mother of two tells of how she has found ways to communicate again, a 55 year old talks about the trials of buying an electric scooter and a 24 year old describes life as one of the youngest people in the UK with MND.

New stories will be published each month, covering a range of experiences of living with MND, including stories from carers and volunteers as well as people with the disease. It also includes a page where website users are invited to contribute their Hints and Tips.

If you feel inspired to share your experiences please send your story, in no more than 300 words, through the 'Experiences of MND' section. (Visit <http://www.mndassociation.org> – find Experiences of MND in the Life with MND section.)

New Communication software for people living with MND

Log on to: <http://www.als-project.com> on the home page, click on "download here" then click on "TWOnScreenPower". The file is approximately 5MB but can only be downloaded on WindowsXP.

ALS / MND Registry

It is a registry that has detailed information from the patients who want to share it.

For more information about "PatientsLikeMe" you can email support@patientslikeme.com or robertb@mitchell.main.nc.us or go to <http://www.patientslikeme.com/registry>

Hold fast to dreams

For if dreams die

Life is a broken-winged bird who cannot fly

Condolences to the Family and Friends of:

Alec Clifton, Jonah Knepscheld, Lydia Holland, Pieter Oelofse, Pat McGregor, Michael Collins, Marina Bothma, Eva Burree, Peter Holling, Barbara Evans, Anton Sonnekus, Gurth Harris-Dewey, Kor Muller, Loretta November, Geoff Jones, Pamela Masterson, John Crossley, Silvia Carollus, Walter Gaiser, Allis Ndluvu

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

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