

Thumbs UP

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

February 2012



Kasturi Pillay (2nd from right) with two of her "helpers" Sevella and Sacksha, visiting patient Len Robinson and his wife Ellen, to show off their T-Shirts for "Walking in support of Motor Neurone Disease" (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."

MND 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.
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It seems such a long time since our last Newsletter when we were looking forward to the Christmas and New Year festivities (and holidays !) but with that well behind us, we look ahead to a happy and peaceful 2012 for all. We hope to bring you News and Views which will be interesting and informative. Remember, we look forward to your input, so please send us your ideas and perhaps a story and a photo you would like to share with us and fellow readers.

REMINDER !
Annual Membership Fee of R100 due in April
(Form with details enclosed)

In our previous Thumbs Up, we advised about the forthcoming trip of our Chairman, Dr Franco Henning, to attend the annual Symposium of the International Alliance of ALS/MND Associations in Australia. We are pleased to report that Dr Henning was awarded the Travel Grant by the International Alliance which enabled him to represent the MND/ALS Association of SA.

Dr Henning's report

I recently had the privilege of attending the 19th Annual Meeting of the International Alliance of ALS/MND Associations as well as the 22nd International Symposium on ALS/MND. These were held in Sydney, Australia from 27 November to 2 December 2011. In this edition of the newsletter, I would like to report back on the Alliance Meeting, and leave the Symposium for a future edition.

The meeting serves as an opportunity for representatives from ALS/MND associations from all over the world to share experience and knowledge, and to establish relationships. One of the main objectives of the meeting relates to strategic planning, which took place on the first day of the meeting. During this planning session, it became clear to me how important it is for developing countries like SA to be represented at this meeting, as our needs and resources are quite different from those of developed countries. I was very impressed by the sincerity of representatives at this meeting, and I can truly say that the fight against ALS/MND is regarded as a united, worldwide effort without borders. On the second day of the meeting, delegates from a number of countries were asked to give a presentation about their respective associations, and I had the opportunity to tell the meeting about the MND/ALS Association of South Africa and MND/ALS in South Africa in general. During my preparation for the presentation, I came across a number of very interesting facts, and I thought it may be worth sharing some of these with our members by summarizing my presentation:

Our association serves a population of approximately 50 million people. We currently have approximately 200 registered members. This is only a fraction of the estimated number of patients living with MND in South Africa, which is 3000 (based on an estimated prevalence of 6 per 100 000 population, which is the recorded prevalence in Europe and North America). Prevalence refers to the total number of cases of a disease in a given population at a specific time. If the membership is assessed based on population group, it becomes clear that especially Africans are vastly underrepresented. This is possibly related to poor referral of patients from low-income areas to the association, although the question arises whether the recorded prevalence of ALS in other populations (e.g. Europe) is applicable to the South African population. It has been suggested that ALS may be less common in ethnic populations, but there is very little data on this. Unfortunately this is very difficult to investigate in a country with a fragmented health care system (public and private) such as South Africa.

The MND/ALS Association of SA faces a number of challenges, now and in the future. First, there is a huge need for consultants / field workers. If one looks at the distribution of membership according to province, it is clear that really only the provinces with active consultants have significant numbers of members. Secondly, financial resources are severely limited, and we receive no support from government. The largest portion of our income consists of donations and bequests (about 70%), while active fund raising and interest on investments contribute about 10% each. A third problem is related to our referral basis. There are only about 100 neurologists in active practice in the country, and, with the exception of a handful, virtually all of them are located in the big cities. Furthermore, less than a third of these are employed in the public health sector, which serves about 80% of the population. Therefore, access to neurology services is severely limited. Lastly, access to patients limits the provision of continuous care to our patients. Some patients live in remote regions hundreds of kilometres from the big centres, where the consultants are based. This is especially problematic in provinces like the Northern Cape, where the population density is as low as 3 persons / square kilometre.

Many delegates were extremely interested to hear about our organisation and the conditions under which we operate. Some were astonished to hear how small our annual budget actually is (about R400 000) and wanted to know how on earth we get by.

As you can see from above, there is plenty of room for growth. We desperately need to get the word out about our association. There are many people living with MND/ALS in South Africa that would benefit from the support we can give them. For this we need the help of our members and their families. A fantastic example is the recent Fun Walk held in Durban, organized by Kasturi Pillay. Not only was the public exposure phenomenal, they also managed to raise a substantial amount of money for the association. Well done Durban!

But of course it is of no use to join the association if we cannot be of any service. And for this we need consultants that can care for our patients. At the moment, there are consultants only in Gauteng and the Western Cape, and we are in desperate need of consultants in the other areas.

Finally, I would like to wish all our members and their families a wonderful 2012. We at the MND/ALS Association would love to hear from you if we could be of any assistance. I hope you enjoy this edition of Thumbs Up.

DONATIONS

A big thank you to everyone for their donations: big and small, monthly or at intervals, in lieu of gifts, in memory of friends and loved ones, or just a donation in support of our Association and its members - Pieter Snyman, Jeremy Hindley, Gary Stewart, Tiffin family, Kobus Vorster, R Hollings, Rosalyn Els, Adri Engelbrecht, S van Blerk, JS Orrock, GR Scallan, L Chiappini, John & Angela Wootton, Family of Adrie Stimie, N1 City Hospital, In memory of Finnie van der Walt, In memory of Joy Becker. Thank you also for those where we were unable to identify the donor as no name appears on the deposit/transfer

FUNDRAISING

As mentioned in Franco's report, Kasturi Pillay of Pinetown (whose husband Dhevan passed away in May 2010) went that "extra mile" to raise awareness of people with MND and the MND/ALS Association of SA. When Kasturi first mentioned the idea, we had no notion that she was planning such a big event! With the help of her children, family, friends, patients and business associates, 10 December 2011, became the 'Motor Neuron Disease Awareness Campaign' Walking in support of MND.

M N D
MOTOR NEURON DISEASE
AWARENESS CAMPAIGN

WALKING IN SUPPORT OF MND

PUBLIC ALLOWED TO HAVE A STALL @ A RATE OF R100

LIVE ENTERTAINMENT, FOOD STALLS, RAFFLES etc.

Our Mission is to promote and provide the best possible support for people living with MND, their families, caregivers and to raise public awareness

BRING THE FAMILY AND JOIN US FOR A FUN WALK TO RAISE AWARENESS
 REGISTRATION WILL BE DONE AT VARIOUS CENTRES

5 km walk

DATE: 10TH December 2011
 VENUE: Pinetown Cricket Club
 Lahee Park
 Pinetown

TIME: 9:30 am
 FEE: Adults - R40.00
 Children under 12yrs - R30.00

JUMPING CASTLE AND FUN AND GAMES FOR ALL

FREE T-SHIRT WITH EVERY ENTRY

MEDALS FOR COMPLETION OF WALK



Stalls (available at R100 rental per stall payable to MNDA) sold hot dogs, breyani, snacks, juices, etc. There were also lucky draws and even a jumping castle for the little ones. Special MND T-shirts were given to each entrant at the walk and the winner(s) were awarded “trophies” and certificates. This was truly an amazing effort and we would like to thank Kasturi and each and everyone involved with this event, whether by means of hard work, donations, participation or support, for making it all happen, and for the overall proceeds of R22,334.73 to be paid over to the MND/ALS Association of SA. Without the representative MND Office / Consultant for a formal group in that area, this was truly a great way to garner support for patients in the KZN area. Liz Keth from Gauteng went to Durban for the day to show support and represent the MND/ALS Association of SA.



From further afield :

In April 2011, **John Veale**, son of patient Dorothy Veale of Rondebosch, was part of Team Stonehage, which successfully completed the 2011 Virgin London Marathon.

The Stonehage Charitable Trust (SCT) is the primary vehicle to implement the Stonehage Group’s philanthropic mission, which is to create a tangible legacy supporting innovative projects in the fields of education and healthcare, with emphasis on children and the aged, in the regions where the Group is active.

Each Marathon runner had been given the opportunity to nominate a charity of their choice and on behalf of SCT, John nominated “*The South African Motor Neurone Disease Association*”.

A letter of acknowledgement and thanks was addressed to John and his Team. We are very appreciative of being nominated and receiving the award of £1,000 (R12,562.70) which was transferred to our banking account in December 2011.

Alison Passmore, daughter of patient Malcolm Passmore of Emmarentia, runs a pub “The Grosvenor Bar” in Brighton, England. She made her friends and patrons of the pub, aware of people with Motor Neurone Disease/ALS and the MND/ALS Association of South Africa, and “inspired” them to donate to this cause. It was with great thanks and appreciation that we received an amount of

R13,192.78 in January this year. A “Certificate of Appreciation” has been sent to them to be displayed in the Pub !

We also received a donation (R450) from 2 contributors to “doit4charity” which was also “inspired” by Alison !





Golf Day

Michelle Fritz (daughter of the late Michael Fritz – MND patient who passed away in March 2009) is arranging a ‘Mickey’ Charity Golf Day in memory of Michael, on 16 March 2012 at the Modderfontein Golf Club, with all funds raised being in aid of Motor Neurone Disease Association of SA.

Please encourage your family, golfing friends and acquaintances, to take part, support and/or sponsor events in this upcoming golf day, to ensure its success.

To participate in this MND Golf Day, you can **contact Michelle on 082 303 3171 or at mndgolfday@gmail.com** and you can also follow the link on our website www.mnda.org.za to get more details.

Success depends on support !

MAIL BAG



(This letter was received in September 2011 but too late for that month's Newsletter).

Hello, my name is Monique Pelsler. On the 27th of June 2010 my father Elwyn passed away peacefully after two years of living with the motor neuron disease; progressive bulbar palsy. He is survived by my mother, my two sisters and me.

The disease took us all by surprise. We had never heard of it and did not understand what a motor neuron disease was/ is, we had no idea what to expect. We all went onto the internet (not the best idea but it was mostly informative) and got our hands on the novel called Tuesday's at Morrie.

My father's version of the disease, bulbar palsy, started in the soft pallet of his mouth and from what we can piece together seems to have been triggered from toxic shock. He had a number of anaesthetic injections into his pallet in the dentist chair which his body, unbeknownst to him and the dentist, could not take and his speech never recovered. In fact it declined and a year and a half later he would totally lose the use of his mouth for both speech and food.

We learned a lot of ways to cope and support him along the way. Some things we got from the Motor Neuron Association South Africa (<http://www.mnda.org.za/>), some from the website from the UK MND association (<http://www.mndassociation.org/>) and other things we learned ad hoc. My mother cared for my father for two years and she came up with some very practical things that can really make life easier.

I thought I'd try to remember these things we did and ways we learned to cope and put them into a letter for anybody experiencing something similar. Hopefully some of these tips will help you.

For this newsletter I want to talk about how my father dealt with the news and how his body and mind reacted to the disease.

Panic:

In retrospect before we knew he was ill my Dad showed signs of apprehension which gradually increased. He started to have panic attacks and felt as though he did not want to go into work and do his normal routine. Once the diagnosis had been confirmed and we were waiting for a prognosis he had moments when he would panic and while every person with motor neuron experiences it differently, I witnessed how stressful and frightening it was for him to come to terms with it. We found that a mixture of lavender and noli oil diluted in a base oil put on the sleeve and under the nose helped him. You can also put a drop or two in a warm bath. I think the smell is nice and comforting but also the act of applying the oil and smelling it gets you to take a deep breath with helps with anxiety and panic. For more severe anxiety four drops of rescue remedy on the tongue when needed. These tips are gentle home based support and obviously need to be managed according to each specific case and discussed with your doctor.

To supplement the care my Dad was getting from his neurologist we found a Chinese doctor in Auckland Park Johannesburg who did acupuncture on him. Dr Jardine and I spoke about how acupuncture could help my Dad as I was very sceptical of this kind of therapy and she spoke about how it stimulates the body and aids in the transition from able body to learning to live with developing disabilities. It had positive effects on my father.

Quite long into the illness my father eventually went onto anti-depressants. One side effect of his version of MND was that he would get very upset and cry and would then get distressed that he was behaving like that. At first he would get shy and not want to show this behaviour and his grief so openly to us. The anti-depressant really took the edge of that stress off him and we wish he had decided to take those earlier.

Choking:

I would strongly suggest that you take a first aid course and also learn how to do the Heimlich Maneuver. Also have the numbers of the local paramedics and hospital close to the phone or saved on your cellular telephone. Eventually my Dad went to the local emergency room and introduced himself and informed them about his condi-

tion and logged his medical aid details in the case of an emergency. He never really needed that but I think it was good for his peace of mind. The MND association South Africa came over to our house and showed us how to do the Heimlich maneuver. Liz, their nurse, also told us a few things to expect and gave us some tips on preparing ourselves for the disease.

When my Dad choked, saliva, food, liquid or phlegm was going down his wind pipe. He would gasp for air and panic because he could not breathe. We discovered that when you are choking you can take air through the nose so the best thing to do is gently instruct the person to think about taking air through the nose, this allows the substance the person is choking on to make its way down the correct pipe. It is horrible and stressful to hear someone choking and after a while you learn to immediately discern whether it is serious and you need to intervene or if they are able to manage it themselves. My Mom and I found that constantly hearing my Dad choke was stressful for us and we were constantly on alert and experienced a lot of adrenaline. Maybe it's not a bad idea to have some lavender and neroli oil for yourself:) And to find a therapist to talk to or phone lifeline 0861 322 322 <http://www.lifeline.co.za/> because it does get tough and you have to care for yourself too. We were informed by a doctor early on that we were already starting a mourning period so take ourselves into consideration so that you can remain strong to care for the person with MND.

We were constantly on edge worried about my Dad choking. While choking is a big big worry and a danger we found that there are ways of managing it. Progressively you will be able to see which liquids and foods are more difficult to take orally. Slowly start to avoid those and eventually remove them completely. Unfortunately I can't recall exactly which foods were the hardest for my Dad at first but I remember him being advised to really really enjoy what he could eat when he could eat it and have what ever he wanted to have. He really enjoyed poached eggs and would take himself off to the local coffee shop for a pot of tea and eggs Benedict. He would have a bunch of napkins and sit at the door so if he started to choke he could excuse himself and manage the lodged food outside in private. Eventually my Mom bought a lot of very brightly coloured facecloths from Pick 'n Pay (which were easy to put into the washing machine daily) and my Dad would carry one of those around and use it for any saliva or escaping foods.

Writing/ communicating:

At first when the speech started to become indecipherable my Dad would carry a note pad around and write the words down. Eventually he had a strong clipboard with paper on it and a pen and he would write notes to us. The MND Association lent us a light writer which is an old machine that allows you to type text and it speaks on your behalf. The problems we found with this was that it was very heavy and bulky and as my Dad's hands started to lose their grip he dropped it and it broke. It was one of very few machines in the country and to replace it was extremely expensive. So we looked at alternatives.

There is a program on-line called speak it! which is a very user friendly application. Here is a link:
<http://itunes.apple.com/us/app/speak-it!-text-to-speech/id308629295?mt=8>

The only trick is that it seems to only works on an iPhone however I think they are updating the software for Blackberry and it will soon be available. How we overcame that was we were lucky that someone was upgrading their phone and they donated my Dad their old one. What I would also suggest is that you can buy old second hand iPhones these days for much less than what a light writer costs. (Perhaps that is a project for someone: to contact Apple Mac and see if we can get old iPhones donated to the MND Association South Africa with the speak it! application already uploaded).

If you don't have a computer boff in your family and struggle to get that sorted out please feel free to contact me and I can talk you through how to access the application and get it working. This text-to-speech application is an amazing tool! It gave my dad a voice and took a large proportion of the frustration of not being able to communicate away.

Identity bracelet:

The last thing I would like to write about in this newsletter is an identity tag we got for my father. As he lost his speech and was prone to choking we thought we would get him this tag that he wore on his wrist when he was out. This way, if anything happened someone could immediately be informed that he had motor neuron disease and so could act accordingly. I have attached a photograph of it so you can see what I am referring to.

Here is the website www.iceid.co.za

Here is the contact person (ila@iceid.co.za)

Next time I'll give you more information on the amazing recipes my Mom came up with and how helpful it was to go to the MND Association meetings.

All the very best. Monique Pelsler
(www.moniquepelsler.com)



We have been made aware of instances where collections are being made by, and/or for, individual MND patients, under the auspices of the MND/ALS Association of SA. We do wish to stress that this practice is unethical/fraudulent.

Any funds collected on behalf of the MND/ALS Association, or donated to the MND/ALS Association, must be paid over to the MND/ALS Association of SA in support of all patients.

We again respectfully request our readers to inform us of any change of telephone numbers (landline and mobile), address (residential, postal and/or or electronic) in order that we may keep our records up to date. Please also note that where e-mail addresses are given, to advise us which method of communication you would prefer. (This would also include our Newsletters).



The MND Association in the UK issued the following bulletin on Wednesday 21 September 2011 - Major cause of MND discovered on chromosome 9

An international research team, co-funded by the Motor Neurone Disease Association, England, Wales & NI (MND Association) has identified a new gene on chromosome 9 that appears to cause nearly 40% of cases of the inherited form of motor neurone disease (MND). This is the most common cause of the disease found to date and the discovery could lead to tests for families who have a history of MND.

The investigators studied a large group of Finnish patients and a family from Wales who have lost relatives to early onset MND and the neurodegenerative disease frontotemporal dementia (FTD and also known as Pick's disease). The team comprising of scientists from six different countries, including scientists from Cardiff, Manchester and University College London, discovered that the Welsh family and the Finnish patients share a genetic mistake on chromosome 9.

Chromosome 9 has been of interest to international researchers for a number of years. Previous work had identified an area that appeared to be significantly associated with both MND and FTD but up until now researchers could not pinpoint the gene on chromosome 9 which is involved in the disease.

In this new work, funded by the MND Association, the Medical Research Council (MRC) and the ALS Association, the genetic mistake was identified in the Finnish and Welsh DNA samples as a repeated six letter DNA sequence. Unaffected people carry up to 20 DNA repeats in a gene called C9orf72 whereas the patient samples carried hundreds of repeats. This is known as a 'repeat expansion'.

The genetic variant had been difficult to identify with the researchers locating it in the most unlikely of places – in the stretches of DNA that do not provide instructions for manufacturing proteins (proteins are the 'building blocks' of cells), otherwise known as non-coding DNA.

The exact role of this repeat expansion in the C9orf72 gene is currently unknown but it probably disrupts multiple mechanisms in motor neurones leading to their failure and death.

Although this gene was first identified in the Finnish and Welsh samples, further research has shown that it also occurs in familial (inherited) MND patients from North America, Germany and Italy and appears to account for the disease in 38% of patients with the inherited form of MND.

Dr Brian Dickie, Director of Research Development, at the Motor Neurone Disease Association, said: "Discoveries in genetics are driving the ever-increasing momentum of motor neuron disease research. Chromosome 9 has

been a prime suspect in motor neurone disease for some time but pinning down the precise genetic factor involved had proved elusive. The discovery of this rogue gene has the potential to significantly advance our understanding of motor neurone disease, helping scientists to home in on the pivotal cellular changes underlying all forms of the disease."

Association-funded researcher Dr Huw Morris, based at the MRC Centre for Neuropsychiatric Genetics, Cardiff University and the Royal Gwent Hospital, who worked as a member of the international scientific team is now working on a test for those with a family history of the disease that could be rolled out by early 2012.

He said: "This work is the culmination of many years work by doctors and scientists studying this condition and it is due in large part to the courage and tenacity of many patients facing MND, particularly the Welsh family and the Finnish cohort. Although this work is the end of our long hunt for this gene, it is the beginning of our search for therapies based on this discovery that can stop this brutal disease in its tracks."

We recommend that anyone who has a family history of MND and who would like to know more about the new test discusses this with their doctor/specialist nurse.

The International Alliance of ALS/MND Associations also reported the following in September 2011: Big ALS Breakthrough – Researchers discover common cause of all forms of ALS – News from Chicago

The underlying disease process of ALS has long eluded scientists and prevented development of effective therapies. Scientists weren't even sure all its forms actually converged into a common disease process. But a new Northwestern Medicine study for the first time has identified a common cause of all forms of ALS.

The basis of the disorder is a broken down protein recycling system in the neurons of the spinal cord and brain. Optimal functioning of the neurons relies on efficient recycling of the protein building blocks in the cells. In ALS, that recycling system is broken. The cell can't repair or maintain itself and becomes severely damaged.

The discovery by Northwestern University Feinberg School of Medicine researchers, published in the journal Nature, provides a common target for drug therapy and shows that all types of ALS are, indeed, tributaries, pouring into a common river of cellular incompetence.

"This opens up a whole new field for finding an effective treatment for ALS" said senior author Teepu Siddeque, MD, the Les Turner ALS Foundation/Herbert C Wenske Professor of the Davee Department of Neurology and Clinical Neurosciences at Northwestern's Feinberg School and a neurologist at Northwestern Memorial Hospital. "We can now test for drugs that would regulate this protein pathway or optimise it, so it functions as it should in a normal state."

The discovery of the breakdown in protein recycling may also have a wider role in other neurodegenerative diseases, specifically the dementias. These include Alzheimer's disease and frontotemporal dementia as well as Parkinson's disease, all of which are characterized by aggregations of proteins, Siddique said. The removal of damaged or misfolded proteins is critical for optimal cell functioning, he noted.

The breakdown occurs in all three forms of ALS: hereditary, which is called familial; ALS that is not hereditary, called sporadic; and ALS that targets the brain, ALS/dementia. In related research, Feinberg School researchers also discovered a new gene mutation present in familial ALS and ALS/dementia, linking these two forms of the disease.

Siddique has been searching for the causes and underlying mechanism of ALS for more than a quarter century. He said he was initially drawn to it because, "It was one of the most difficult problems in neurology and the most devastating, a disease without any treatment or known cause".

*The happiest of people don't necessarily have the best of everything,
They just make the most of everything they have*

TRAVEL NEWS



1. In the Knysna Elephant Park you can take a tractor ride to visit and feed the elephants – the wagon has a ramp and space for a wheelchair on the ridge
2. The Bontebok National Park has beautiful picnic sites and accessible ablutions on the banks of the Breede River

Accommodation

1. Judy's Guest House, Kimberley
2. Bontebok National Park, Swellendam
3. Table Mountain Guest House, Malmesbury
4. Elizabeth's Guest House, Bloubergstrand (www.elizabethsguesthouse.com) worth a peek!



Condolences

Condolences to the family and friends of:

Silvia Edworthy (1/9), Irene van Staden (10/9), Franscois Adonis (16/9), Annalie de Wet (18/9), Nicola Veotte (2/10), Janie Zaal (5/10), Eddie Stehlik (20/10), Finnie van der Wilt (23/10), Margaret Mynhardt (5/11), Abel Coetzee (8/11), Johnny Thorburn (17/11), Boets van der Merwe (24/11), Carol Eisenstein (29/11), Randell Damons (3/12), Johanna Swart (4/12), Edward Absalom (11/12), Johan Bräsler (23/12), Kevin Pope (23/12), Wynand Pieters (5/01), Charles Booysen (10/01)

**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

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