

Thumbs UP

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

September 2013



Bob Fuller with his best friend, Jim, visiting from the USA (See Mail Box)

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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Aviva Pelham (M. Mus.)

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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



How time has flown by with this year rapidly coming to its end, and with the festive season just around the corner, it is time to think about



and Christmas cards



Please support our Association by ordering your cards from us – order form with illustration attached.



Christmas wishes to our readers who celebrate this holiday and a Happy and Peaceful 2014 to all



You will recall that “MND/ALS Global Awareness Day” was on 21 June and various events were organised with support groups to commemorate this day and we would like to share them with you:



Patients at the Awareness Lunch in Gauteng with a flower arrangement which formed part of the table decorations

In Gauteng, the Awareness Lunch held at the Killarney Country Club was well attended by patients and families as well as carers and sponsors. Dr Alison Richardson from Chris Baragwanath Hospital gave a brief talk on MND/ALS management and Sr Judith Young from Hospice explained how Hospice can assist MND patients. A patient, Kevin Jordan, spoke about his plans for the “No White Flags – Riding for MND” 94.7 cycle challenge (referred to in our previous Newsletter)



In Cape Town, Sheila Kendal and Peggy Saxon got patients, families, friends and caregivers together for their own Support Group Global Awareness Day and our Patron, Aviva Pelham, was there to encourage everyone. Heidi from Perry Hill, Patricia from Sleepnet and Berna, a Dietician, each delivered an interesting talk on their particular subject. The snacks were generously sponsored by Sleepnet and everyone enjoyed this get-together where they also received guidance and advice on how to care for their loved ones.



From KZN, **Kasturi Pillay** writes:

We had a lovely day on Friday and Saturday – I split the group so that we could cover 2 centres on Saturday - it was a fruitful weekend, bringing about awareness of Motor Neurone Disease. The bookmarks I had made had very useful information and the kids were happy to have their hands stamped with “I support MND”. The Henna Body Art idea came from patient Jasmine Moodley, who in spite of losing her voice still managed to be there with family and friends, in support of the day. The henna body art was of huge excitement for the children and adults alike, including the men folk : arm bands for the men, floral prints on the hands and palms of the ladies with some of the kids wanting art on their necks. I also sold, at a small price, some T-shirts left over from last year’s Fun Walk. Families and friends were very involved in this campaign and their support was amazing. I had people approach me, wanting to assist with the next Awareness Day we have. It was a good social and informative as well as emotional day for a lot of people and the mission to “create awareness” was accomplished - and raised R3,460 !



Gaynor writes from PE:

“We had an exceptional day on Saturday at the brunch we hosted. It was a complete sell – out with even an extra table and chairs being brought in for additional guests.

We had 4 and a half hours of culinary, comedy and musical delights by 6 of Port Elizabeth’s top & most respected entertainers – stage, lights, camera and professional sound engineer. Alan Solomons (manager & coach of Southern Kings rugby), delivered a very insightful talk into the history and development of Eastern Province rugby from virtually nothing, to the incredible professional team that they are today, meeting world class professional levels and standards, and his vital role therein.

The response to this event was overwhelming and surprised us beyond our expectations – my team (of just 5 people, one fully paralyzed and another unable to speak) and I, managed to pull off what seemed to be the absolute impossible, in just 4 weeks. Our guests were delighted and their comments and praise at what they experienced was evident all round. Many cited that this was one of the best entertainment mornings ever, and that it was so informative (yes, they all know much about MND/ALS now, some even for the 1st time), and that they would most definitely be back next year. Of course for next year, our aim is far bigger than this the very 1st ever in the Eastern Cape. The audience was very moved by the glaring reality of MND – we had patients involved as much as they wanted to be, as well as some volunteers who have lost their loved ones to MND.

The venue decor was absolutely beautiful in lavender and white, thanks to the donation from a new decor business. The whole event was just astounding and left us all in awe as we looked on – it felt quite surreal to be happening as it was. We had a very successful and fun auction done by a professional auctioneer and comedian Gino Fabbri – a delightful duo who had everyone in stitches! We were given so many lovely donations by generous people, also rugby memorabilia that was donated by Alan Solomons of the Southern Kings, Lions Uitenhage and J9 foundation (Nathania). I invited the press and they were present, photographers and all, interviewing guests and myself. We are apparently in tomorrow’s Herald (with photos). We had many lovely lucky draw prizes given to us by a number of businesses and other.”

“A big and special thank you” to Gaynor and her team, the sponsors and guests, for going out of their way to make this event the success it was and also for raising R14,732.85 !

BIG WALK (as mentioned in our previous *Thumbs Up*)

Cheryl Smith of Durban reports on the **BIG WALK** held in Durban to raise awareness:

“Surprisingly we had a lot of people on our Big Walk approach us and ask what MND was and I was little taken aback that so many people do not know what it is considering it being in the news and on TV lately. But it was a great success and we taught a few people about this dreaded disease, and we were interviewed by Damon Beard of East Coast Radio. There were 33,000 entries, so it was a big day.”



Cheryl's team with Renier Gertenbach (seated far right) who is the reason for their "exercise"

MAIL BOX

Bob Fuller was diagnosed with MND in July 2006, and the prognosis was 3 – 5 years. He decided from the start that he is going to trust God no matter how difficult it became to deal with the deterioration that occurs. He has been a wonderful testimony of having peace and joy during adversity.

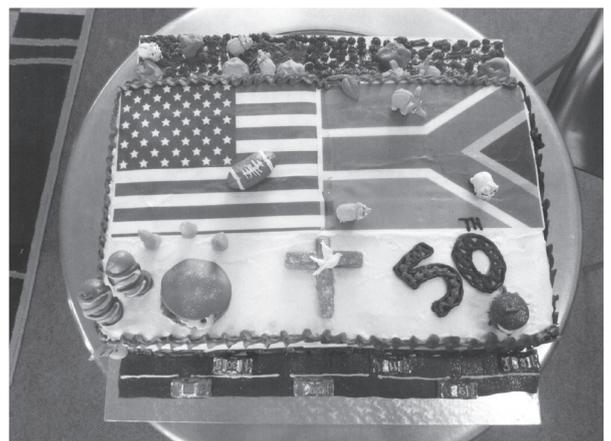
Bob and his wife, Nicky, head up the Student Affairs Department at The King's School in Linbro Park, and Bob has managed to continue to go to work and has probably only missed about 10 days per year. Sometimes that has only been because Nicky has put her foot down because of the weather! Thanks to wonderful technology he has managed to remain productive and able to communicate with everybody. The pupils have been amazing and often pop in to say hi to Bob and some have come to encourage and pray for him. In April this year Bob turned 50. Now this is a milestone in anybody's life, but even more so when few people thought he would be around to celebrate it. Bob is originally from the USA. In 1988 he came to South Africa to do work for a year for Youth for Christ, and he never returned except for visits. He has now lived longer in South Africa than in the USA.

Many festivities were planned for Bob's birthday – a huge family affair, a tea at the school and a few smaller dinners with friends. About 2 weeks before his birthday, his best friend from the States, Jim, phoned Nicky and asked her if he could surprise Bob and arrive for the birthday. The family party was on the Sunday and Jim was arriving the Saturday night. Nicky told Bob she was going out to collect his birthday cake, and walked in with Jim instead! It was the most special moment!

Because Bob is unable to speak, and we wanted the focus to be on him at his party we decided to share one of the power point presentations Bob has put together. So he shared on the fact that God does so much more for us than we can ever hope or imagine and that He can use us even when MND has ravished the body.

Nicky organised ahead of time for Bob to have leave the week while Jim was here and the 2 friends spent many wonderful hours together.

Bob and Nicky remain so grateful for the wonderful love and support from family, friends, colleagues, pupils, his amazing caregivers and Liz from the MND Association.



For the staff tea, one of his colleagues baked him a huge cake. One half was decorated to depict the first 25 years of his life in the USA and the other half to depict the past 25 years in Africa!

Donations

To all our friends who make regular and monthly donations, to other wonderful people who donated in lieu of gifts, in memory of loved ones, for a special birthday celebration, or just as a kind gesture – your generous contributions are greatly appreciated, THANK YOU !

Membership

You may not be aware, but the MND/ALS Association of SA receives no government grants or outside funding. For its income the Association relies on donations, bequests, its own fundraising efforts, and family and friends who arrange golf days, fun runs / walks, breakfasts, cocktail parties, etc. Due to ever-increasing costs and expenses, however, and bearing in mind that our membership fee of R100 has not increased for almost four years, the committee has taken a decision to up the annual membership fee to R200, effective January 2014. We trust you will appreciate the reasons for this step.

Fundraising

We are very grateful for and do appreciate any efforts made for fundraising, but would like to mention that when a fundraising event is organised for or on behalf of, the MND/ALS Association of SA, and any donations are made to the MND/ALS Association of SA, irrespective, the proceeds should be regarded as “for the Association”, and therefore any funds so donated or so raised, should be paid into the Association’s banking account.



Recipe for a Happy Life

Take several pounds of Faith, an equal quantity of Hope
 Mix well with an unlimited quantity of Love
 Add as much Courage and Prudence as possible
 Garnish freely with
 Self-Forgetfulness and Consideration for others



RESEARCH



(Extracts from Summer 2013 Edition of Thumb Print (Magazine of Motor Neurone Disease Association, UK))

Gene unravels more secrets

The C9orf72 MND-causing gene – found to cause nearly 40% of the inherited form of MND – is beginning to give up more of its secrets.

An international team of scientists, including three MND Association-funded researchers, identified the C9orf72 gene on Chromosome 9 in 2011.

Since this ground-breaking discovery, researchers around the world have been trying to discover more about C9orf72. Two recent papers have begun to piece together the clues.

Prof Christiaan Haass, from the Munich Centre for Neurosciences in Germany, who presented at the 23rd International Symposium on ALS/MND, published a paper in the journal

Science. And Prof Leonard Petrucelli, of Mayo Clinic USA, had a paper published in the journal Neuron.

The C9orf72 gene was previously thought not to code for a protein, or have a function. However, surprisingly, these researchers found that it does make a protein. They went on to discover that these proteins formed large clumps in the brain, and throughout the central nervous system, of people with C9orf72 MND and/or frontotemporal dementia (FTD). Importantly, they did not find these clumps in healthy individuals, or those with other neurological disorders. It is not yet known whether these protein clumps are involved in MND and/or FTD, but they may be a potential biomarker, or therapeutic target, in this type of MND. The researchers’ next steps will be to attempt to discover whether these proteins actually cause MND or FTD.

Tissue Donation – a lasting legacy for MND Research

Many people living with MND play a vital role in research into the disease by taking part in treatment trials.

Some choose to make a highly valuable contribution to MND research after their death – by donating brain and spinal cord tissue, as Samantha Price from the Research Team explains:

Our bodies are made up of millions of cells, some of which become so specialised they work together to form tissues. These tissues make up all of the organs in our bodies, including the brain and spinal cord.

Some individuals choose to donate body tissue after their death, making a lasting gift to help researchers understand how diseases, including MND, start and progress.

Tissue donation is different to organ donation. While organ donation means the body is used for transplant purposes, donated tissue is used for research and education.

MND researchers are particularly interested in exploring the brain and spinal cords of people who had the disease, to enhance their knowledge and understanding of MND.

By careful examination of the parts of the body affected by MND, they can look for changes that may help explain the causes of the disease and ultimately help the search for effective treatments. Researchers also examine tissue from people who did not have the disease, so that comparisons can be made.

Dr Brian Dickie, Director of Research and Development explained: “Whilst research on laboratory models, such as cell cultures, fruit flies and zebrafish are vital in helping us understand what goes wrong with motor neurones, we inevitably need to compare these findings with the events occurring in people”.

Scanning brains

An exciting new project funded by the Medical Research Council (MRC), features a unique collaboration between physicist Dr Karla Miller, neurologist Dr Martin Turner and pathologist, Dr Olaf Ansorge. The project will see Dr Miller utilise the Oxford Brain Bank, which contains a large number of brain samples donated by people who had MND. She will scan the brains in a Magnetic Resonance Imaging (MRI) scanner, which uses strong magnetic fields and radio waves to take very detailed pictures.

The longer the body is in an MRI scanner, the better quality the images. By running the MRI scanner overnight, when it is not in use by the hospital, Dr Miller aims to present the most detailed images ever taken of the brain of someone who had MND.

A ‘virtual brain bank’

Dr Miler hopes that the images will provide non-invasive markers of disease progression for use in drug discovery, and possibly lead to earlier diagnosis in the future.

These images, along with microscope data from Dr Ansorge, will be used to establish a ‘virtual brain bank’. This will be freely available to other researchers online – a great example of promoting the exchange and sharing of information between researchers around the globe.

This exciting development in MND research would not be possible without the generosity of individuals who donate their tissue, making a lasting contribution to MND research.

Dr Dickie added: “This collaboration not only has the potential to provide us with a clearer window on the MND brain, but of course the tissue can also be studied in great detail in the lab, to see what is happening at cellular level. It will allow researchers to build up a unique picture of MND, quite literally from the microscope to the MRI scanner”.

Dr Karla Miller, researcher and lecturer at the University of Oxford answers some questions about tissue donation:

Why do we need tissue donation ?

Brain and spinal cord donation has been absolutely critical to furthering our understanding of MND. Our study is completely dependent on this ultimate gift from patients.

Why is this project so important ?

We have great hope that imaging will provide non-invasive markers of disease progression for us in drug discovery, and possibly earlier diagnosis. At present, though, these methods are ‘flying blind’; we can’t confidently link these markers to the underlying changes to the tissue because this cannot be biopsied during someone’s life. Our study aims to provide exactly that link.

What will this research mean to people with MND?

This research focuses on one of the most promising weapons we may have in the long war against MND, namely MRI-based biomarkers. They aid the study of disease mechanisms, providing important clues for future research directions. MRI biomarkers may one day enable earlier diagnosis. By participating in this study through a commitment to tissue donation, people can make a lasting contribution and a tangible step towards a world free of MND.

My Shoes

I am wearing a pair of shoes
 They are ugly uncomfortable shoes
 I hate my shoes.
 I wear them each day and wish I had another pair
 Some days the shoes hurt so
 I do not think I can take another step.
 Yet I continue to wear them, even though I get funny looks –
 Looks of sympathy.
 I can tell by the looks that they are glad
 They are not their shoes.
 They never talk about MY shoes.
 BUT once you put them on, you can never take them off.
 I am not the only one who wears these Shoes.
 No person deserves to wear these Shoes
 But because of them I am a stronger person
 And they have given me the strength to face anything.
 ~Author Unknown~



With the holiday season coming closer, here are some new Establishments to look at:

1. Eagles Nest House in popular *Plettenberg Bay* is ideal for a family holiday
2. Chalets No 408 in the *Pilanesberg* area is very close to *Sun City*
3. Cape Pillars Boutique Guest House is a place of elegance and style in *Durbanville*
4. Dolliwarie Guest House, *Panorama*, conveniently situated *near Canal Walk & Cape Town*
5. Nieuwehuyz Self-Catering Guesthouse – the first in *Prince Albert* !
6. Guest House No 411 in *Stellenbosch*
7. Oude Werf Hotel in *Stellenbosch*
8. Smirre self-catering House in *Stilbaai*



Condolences to the Family and Friends of:

Rika Hörstmann (3/5), Peter King (19/5), Susanna de Kock (1/6), Ruth Currie (5/6), Japie Schoeman (5/6), Ralph Satusky (14/6), Anna Marie Barnard (14/6), Lance Adonis (15/6), George Loverdos, Dorothy Veale (27/6), Sydney Schaefer (1/7), Jean Davis (5/7), Calvin van Wyk (12/7), Sylvia Jäger (21/7), Charles Riddles (22/7), Andalamma Chetty (24/7), Freddy Swart (24/7), Michael Barber (27/7), Ansa Bezuidenhout (28/7), John Parry (5/8), Hope Nysschens (9/8), Dennis Derbyshire, Anca Pelsler (12/8) Ansie Viljoen (13/8), James Thebus (23/8), Marie van Baalen (28/8), Sarah Jackson (30/8), Abdurraghiem Sallie (31/8), Pam Millard (7/9), David Mirman (12/9), Andre Behnm (16/9), Elsie Kotze (20/9)

**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.

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