Thumbs UP

MNDA OF SOUTH AFRICA

The Newsletter of the
Motor Neurone Disease
Association of South Africa

May 2010

Aviva Pelham and her singers at the "Feast of Song" dinner

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."

ACKNOWLEDGEMENTS
John Hall for producing the design and DTP (desk top publishing) work.
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FROM THE OFFICE

We invite family and/or friends of MND patients, to consider giving some of their time to the MND Association, by serving as a committee member. It would basically mean giving input and attending a meeting for about 1 to 1,5 hours every 2nd month or so, at our offices in Pinelands.
Interested parties should please contact our office on 021 531 6130 to give details for consideration.

We endeavour to make equipment in good working order available to our patients and it is with regret that we must voice our disappointment regarding the condition/state (beyond normal wear and tear), in which some of these items are returned to us. In future, where repairs are due to the misuse of these items, or where items need to be scrapped, we would have no alternative but to look to the family for reimbursement of the cost of repairs or replacement of such items.

DONATIONS

Since our last report in "Thumbs Up" we received donations from:

R Kraut-Kramer, The Lemmer Family, Noeleen Thomas, Aerontec, WR Terry, Leisure View, NR Mercer, Masonic Bowling, Melanie Bold, Jean Gaiser, M Fermor, S Naidoo, Ray Whitmore, Tim Cowley, The Strauss Foundation, S van Zyl, L MacFarlane, RJ Labuschagne, AL Steyn, JJ Coertzer, GA Knight, GA Jordens, The Katzew Family, NM Macdonald (in memory of Di), NS Samols, Lesley Fisher. We also received contributions (deposited to our account) where names were not available. Thank you too, to our members who added that little bit extra to their subs !

And, of course, grateful thanks must again go to our regular and monthly donors for their ongoing support.

Ulla Stauch, daughter of Brenda and the late Joe Stauch (MND patient) married Jody Paulus on 9 April this year. The couple who live abroad, tied the knot in Cape Town. Ulla & Jody decided that in lieu of wedding gifts, they would request their guests to rather make a donation to the MND Association. Their family and friends came from all over and we received their gifts ! - a grand total of R11,780. This was a truly unselfish gesture on everyone's part and we are overwhelmed by their support. We wish Ulla and her husband a long and happy future together.

Ulla Stauch and husband Jody Paulus

FUNDRAISERS

The "Feast of Song" Dinner held at The Foodbarn, Noordhoek, on May 1st was such a great success and it may just be "served up" again next year ! We say a very big thank you to the de Bruyn family for organising this event, the sponsors who supplied the "fruits of the vine", Aviva Pelham (our Patron) and her singers, and of course the guests who attended the occasion and contributed to the enjoyable evening, which raised R24,045 for the MND Association. In fact, to everyone who had "a finger in the pie", your time, effort and wonderful support is very much appreciated.
Thank you.

Thus far we have unfortunately not been able to manage a fundraiser for 21 June which is International ALS/MND day, but hope to reserve a date in November for our annual fundraiser, being the musical "Annie" at the Artscape Theatre. Please look out for this !

MAIL BAG

Stan and Anne Butcher of Tzaneen, (seated) share with us their experiences of their holiday trip taken earlier this year, meeting up with family and friends along the way :

Stan was diagnosed on the 5th of Nov with Motor Neurone Disease, the progressive bulbar type. Realizing he would need a lot of care, I put time in for my retirement, which duly happened the end of January. We then embarked on a long country wide trip together, while we still could. A precious memory.

We left on the 6th Feb and spent a few days with the girls in Johannesburg. We then went to Stan's brother, Henry & Angela in the Drakensberg (Himeville) for 5 memorable days. They took us up Sani Pass, highest point in SA, which was an unforgettable experience. From there we went to a time share resort in Margate for 5 days. Stan's other brother, Charles, Brenda & family, live near there, plus several good friends who we managed to see and enjoy their company, the area and lovely resort.

On the 19th we went through to visit, Judy Butcher & family, (widow of Richard, Stan's other brother), in Pinetown. We had a great weekend with them. They even took us to U Zulu on the beach front.

On the 22nd we travelled through the Transkei, through East London then slept that night in King Williams Town at a B&B. From there we left early and went into Addo Elephant park for the day, viewing a fair amount of game but unfortunately no cats. We then spent 2 nights with my brother, Lynton & Elise and managed to help them with last minute packing, as the removal truck suddenly notified them they were coming earlier. They have retired after 50 years in the ministry & moving to JHB.

The 25th saw us heading for Cape Town, but travelling inland through lots of quaint little farming towns. We slept in Ladismith at an interesting B&B. The folk who ran it had been in the area for 3 generations & had all the photos of the family up on the dining room wall, a family tree in photos.

We arrived in a "hot Cape Town" on the 26th for a full week. There is so much to see & do there that we were quite exhausted by the late afternoons. The highlight there was a helicopter trip over Cape Town, sponsored by our wonderful children. We even went in a "general taxi" to see the castle right in town. That was an interesting experience!! We stayed right on the beach front with a sea view. We also visited our niece Kate, Grant and their precious little girl, Taya for the first time), in Bloubergstrand, and they joined us at the aquarium a few days later. Of cause we did Table Mountain, Cape Point, Kirstenbosch gardens & travelled around quite a bit, as well as several walks along the esplanade. At times we really felt our age!!?? The temperature reached 38º. We had clear hot days the whole time we were there & the day we left Table Mountain had a table cloth of mist over it.
It was very distressing for us to see the drought in the Cape, especially in the country side. Dams so low & many empty.

On the 5th March we went to special Messina friends living in Stellenbosch and caught up with so much news. We all went to a farm stall together and bumped into the Afrikaans minister who was in Messina for years but now in Rustenburg. He was there to marry a Messina couple. Small world ???

Then it was on to Hermanus for 4 days where we stayed in such a friendly & comfortable B&B. One of the days we took a drive around False Bay past all the little coastal towns, seeing the most magnificent views. We stopped to see the penguins at Betty's Bay & went as far as the Strand & Somerset West, then back on the highway because we were *paah!!!!!*. We explored Hermanus & even went to a couple of Retirement centre's & realized how Blessed we are at Macadamia, from many aspects.

The 9th we were on the road again to Knysna, where we stayed for 2 wonderful weeks with my brother & wife, Nigel & Betty. Quietly I say that we often only arose between 8&9am. They have a beautiful holiday home there on a nature reserve. They were really good to us & showed us many places as well as taking us on some beautiful & sometimes strenuous walks. We often sat on their veranda having tea gazing across the lagoon at the beautiful view - it was really something to take in. Our entertainment also included watching a bulldozer busy recontouring the side of a mountain just across the lagoon. We took Nigel through to George on 18th to fly back to Jhb. That same day we visited Sandra Bull's mother in George, (our pastor's wife.) Betty, Stan & I left on 24th, sleeping over at another restful & interesting B&B on a farm near Springfontein in the Klein Karoo.

Stan had a bad day on our trip back to Jhb on 25th. Unfortunately with this disease, his voice and swallowing are affected. Fluid is the most difficult to swallow, so when we arrived in Jhb, I got hold of litre of ivi fluid & when we got to Gayle she put it up. He felt & looked better. We spent a quiet weekend with Gayle, Craig & Ruth, also visiting my brother Lynton who had several small strokes & was

in hospital.

So our holiday ended with Stan going to Hospital in Pretoria (arranged by our Doctor here) on the 29th for an insertion of a stomach peg tube. It was done at 9h00 but we were only discharged at 20h45. He had a really good sleep the whole day which was great. I give him all his fluid via that. He still managers to eat softer food very slowly, but when he can't, I can liquidize & feed him. Its amazing how our God times all things, this happening at the end of our wonderful and precious holiday. We took over 550 photos !

We had a safe trip home on the 30th. Our own beds and bath felt great. We were also so welcomed by all our friends and neighbours.

What a wonderful privilege, and we are so grateful to God, that he allowed us this time together. Stan even forgot all his spanners (something he has never done), but God was so Good, we never even had a puncture or any kind of problem with the car, or on the roads, after doing 7457 kms. All Praise to Him.

FEATURES

MAKING ADJUSTMENTS WITH MND

By Len Robinson

We find people extremely helpful

Before I was diagnosed with motor neurone disease [MND] I knew nothing about the affliction.
I was 75 years old and fit. I enjoyed fishing [surf and trout], climbing in the Drakensberg and a weekly 5 km brisk walk. Saturday mornings and most public holidays were usually devoted to gardening.
It was while gardening that I first experienced unsettling symptoms. I found that after spending a period sitting and weeding, planting or pruning it became more and more difficult to get back up on my feet. When it came to the point that I could only rise by grabbing a fence pole and pulling myself up I reckoned I had better consult my doctor. He did not know what the cause of the problem was and referred me to a neurologist. Here I had two or three appointments. These were pretty thorough, including receiving minor electric shocks, until finally I received the diagnosis. 'I am sorry to tell you, you have got Motor Neurone Disease,' he said. He did give me some background information, which I grappled to absorb. It is not easy to accept in a few minutes that you have a terminal disease, and that the prognosis is 2 to 10 years. [He was probably trying to be kind to me. Later I learned this is 2-5 years. Pity, at my age 10 years would be a bonus!] There was no treatment, he said, bar one medicine: Rilutek. It could perhaps add about 2 months to my life and was horrendously expensive. He recommended that I not take it.
The information he gave me was rather sketchy, so I sought more enlightenment from the internet. Here I read that degeneration of the motor neurones, which are situated near the brain, leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. It is not infectious or contagious. It can affect any adult at any age but mostly appears after age 40, with the highest incidence occurring between 50 and 70 years. An average of 2 people in every 100,000 contract the disease.
Armed with this information my wife, Helen, and I made what adjustments we could. We had been living in a sectional title unit with a lovely view but we were located very high up, on hilly ground. I was already having difficulty climbing the hills and the unit was not at all wheelchair friendly. This led to our first big adjustment, which was to sell our unit and move to a retirement centre, where we have stayed happily ever since.
The next adjustment was with driving. When I found I could not engage the clutch without lifting my left leg by hand, we sold our car and scraped together funds to buy a small one with an automatic clutch. This worked well for about a year but when I found I couldn't apply the foot brake without lifting my right leg by hand, I realised that the time had come to stop driving and leave that job to my wife.
I had my fair share of falls, which is a symptom of MND. Fortunately I did not break any bones, though we had to make a few calls to our clinic for help to lift me up again. At a slightly earlier stage we had worked for an organisation sorting and renovating donated toys to give to underprivileged children at Christmas time. I had a few falls there into cardboard boxes of toys and more than once ended up staring into the face of some startled soft toy or the other.
As my condition deteriorated I had to give up more and more of the things I had been doing. I was employed in a weekly half day administration job, but that had to go when I no longer had the strength to pick up the files. Similarly, a few charitable jobs fell by the wayside.
Walking became walking with a stick, then crutches, then with a walker and I finally ended up riding on a wheelchair. We now have a light weight wheelchair

which travels in the back of the car and I move between bed, wheelchair and car by sliding across on a transfer board.
Eventually an MND sufferer needs a carer and, as is often the case, my wife assumed these duties. This was quite a turnaround, as I had previously imagined I was getting to be her carer. She suffers quite badly from arthritis and sore feet so I had done what I could to help her over her worst attacks. Now we have a reverse situation where she somehow finds the strength to bed bath me, help me load on and off the wheelchair, transfer me in and out of the car and, not least, push me around in the wheelchair with its sometimes recalcitrant wheels.
We find people extremely helpful. When they see the wheelchair, strangers often offer to assist. Sometimes helpers get over enthusiastic, as when a well intentioned but misguided volunteer sent my transfer board flying and pulled me half off the wheelchair with my pants almost half way down to my knees!
Friends visit frequently and sometimes even bring meals or refreshments. We belong to the local Highway Hospice and have regular Thursday morning meetings for outpatients with a wonderful occupational therapist, Chantal Christopher, who alternates entertainment, education and promoting a positive outlook.
We are also registered with the MNDA of SA, KZN branch. They arrange regular get-togethers where both patients and carers can share problems and hopes. Esther Strydom was in charge here, and gave us enthusiastic and generous help until her husband's transfer to the USA. Minnie van Zyl is a worthy successor, who is both popular and helpful. We pick up tips at the meetings from chatting with others who are in the same boat. Valuable bonds of friendship form at these hospice and MND meetings.
How does it feel to have this disease? We each have to come to terms with it in our own way. It took me some time to clarify my own position on this. We are persons of faith so perhaps it was easier for me to formulate my thoughts. I will do everything I can to ameliorate my condition but, as there is no cure, I accept the illness as my cross to bear. How to explain it? I can't. But I do believe God knows what he is doing. I can't expect to understand the mind of God [otherwise I would know more than he!] but I can trust that he is doing the right thing for his own ineffable reasons.

RESEARCH

(We received this report from the International Alliance of ALS/MND Associations in the UK)

Researchers discover genetic link between both types of ALS
Finding could ultimately lead to therapy for ALS

CHICAGO --- Researchers from Northwestern University Feinberg School of Medicine have discovered a link between sporadic and familial forms of amyotrophic lateral sclerosis (ALS), a neurodegenerative disease also known as Lou Gehrig's disease.

Researchers found that a protein called FUS forms characteristic skein-like cytoplasmic inclusions in spinal motor neurons in most cases of ALS. Mutations in this gene have been previously linked to a small subset of familial ALS cases. Researchers thus linked a rare genetic cause to most cases of ALS, clearing the way for rational therapy based on a known molecular target.

The study was recently published online in the Annals of Neurology.

ALS is a disease in which muscle-controlling nerve cells in the brain and spinal cord (motor neurones) die, resulting in rapidly progressive paralysis and death usually within three to five years of the onset of symptoms. Most cases of ALS are of unknown etiology and appear as sporadic ALS. About 5 to 10 percent of ALS cases are familial. Some forms of familial ALS are caused by genetic mutations in specific genes. Mutations in the Cu/Zn superoxide dismutase gene (SOD1) account for approximately 20 percent of familial ALS cases. Mutations in the TAR DNA-binding protein gene (TDP43) and FUS gene occur in about 4 to 5 percent of the familial ALS cases. Altogether, mutations in specific genes have been identified in about 30 percent of familial ALS cases.
In contrast to familial ALS, the etiology and the pathogenic mechanisms underlying sporadic ALS -- 90 percent of all ALS -- has remained largely unknown. Understanding the causes and pathogenic mechanisms of sporadic ALS is the major challenge in this disease.

For this study, researchers examined the post-mortem spinal cords and brains of 100 cases, 78 with ALS and 22 in a control group. They found FUS pathology in the spinal cords of all the ALS cases, except for a few cases with SOD1 mutations. But FUS pathology was not present in control cases without ALS.

"This is a game changer because it establishes a connection in the development of sporadic ALS with a known cause of familial ALS," said senior author Teepu Siddique, M.D., the Les Turner ALS Foundation/ Herbert C. Wenske Professor of the Davee Department of Neurology and Clinical Neurosciences at Feinberg and a neurologist at Northwestern Memorial Hospital.

"Our finding opens up a new field of investigation for rational therapy for all of ALS," Siddique added. "This is the holy grail of researchers in this field."

"There hasn't been a therapy for most of ALS, because the cause was unknown," Siddique said. "Three genes have been identified in ALS, but the problem has been connecting inherited ALS to sporadic ALS."

"We identified the FUS pathology in sporadic ALS and most familial ALS cases," said Han-Xiang Deng, M.D., associate professor of neurology at Feinberg and lead author of the paper. "The patients with the FUS pathology may account for about 90 percent of all ALS cases. Our findings suggest that pathological interaction of FUS with other proteins is a common theme in motor neuron degeneration in the vast majority of the ALS cases. We believe that this is a major step forward in formulating a common pathogenic pathway for motor neuron degeneration. Importantly, it may offer a novel avenue for developing therapies through targeting these FUS-containing inclusions."

The one exception to the new finding is when familial ALS is associated with a mutation on the SOD1 gene. In those patients and in the mutant SOD1 transgenic mouse models, researchers did not find evidence of FUS pathology.

"This tells us that it follows a different pathway of pathogenesis, so treatment for this form of the disease would have to be different," Deng said.

The study is supported by the National Institutes of Health, the Les Turner ALS Foundation, the Vena E. Schaff ALS Research Fund, the Harold Post Research Professorship, the Herbert and Florence C. Wenske Foundation, the David C. Asselin MD Memorial Fund and the Les Turner ALS Foundation/ Herbert and Florence C. Wenske Professorship.

HINTS & ADVICE

Simple Guidelines for Happiness

Free your heart from hate, Free your mind from worry

Live Simple, Give More, Expect Less

(1) Renee Pelser & husband Elwyn (MND patient) of Bryanston, gives this advice on "Vocalization"

I think this might be of interest to MND sufferers, especially those who cannot speak but have use of their fingers. iPhones have a program called iTunes. You register (free) and then look up education – speak it! Cost $1.99, and you can download it onto a computer or iPhone. There is a choice of voices. Hope it helps.
Regards, Renee. (My husband has bulbar palsy and has not been able to speak for quite a while.)
(ii) Peter & Marion Marx sent this mail received from their nephew in the thought that it will assist them and possibly other patients with a communication problem:
Did a bit of digging around and found these downloads on the web and wondered whether either would benefit Marion.
There are two different methods here of moving the cursor on the screen and being able to use the computer by:
a) moving one's head and b) moving one's eyes.

Cameramouse uses one's head movement and could be used (in the case of Marion) in conjunction with canassist (keyboard), which is a predictive keyboard on the screen.
Downloaded both of these and had no problem spelling words on the pop up keyboard. This was of course with good head control.
Once you run Cameramouse (with your webcam connected) you just move the cursor to say your nose - press control and then the cursor will be controlled by the position of your nose. Under "setting" you can

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

control the sensitivity of the "mouse" and also initiate the "click" feature. This too can be set to the sensitivity you want. The click works by pointing on a letter and then not moving the cursor for the time you set - say .5sec. All this will be self explanatory once you download the files.

The second option is also really neat - the eye control method - see The-EyeWriter pdf.
Andrew in a few minutes took my old web cam and connected it to a pair of old glasses and managed to control a dot on the screen very easily. He said it was more intuitive than the head method. Once again self explanatory once you look at it. We have not yet found out how to control the cursor, but Andrew doesn't think that would be a problem, but we didn't want to go too far till we got your feedback.

From what I have seen, it would be better for the user to be lying in a bed with an elevated back rest or adjustable bed so that the head remains still and thus allows for better control of the eyes and maybe head as well.
Alternatively, tilting the wheel chair back may also work.
Your spare computer/monitor could also be elevated so that Marion's head wouldn't fall forward.

Anyway, please give this some thought, speak to Marion, and let me know what you think.
Making the camera glasses is no problem and we could make it here, and also any software installation/tweaking could be done from here. Andrew does this for Brian - takes control of his computer and sorts out his problems for him.
If you decide on any of these routes, it would take some effort on Marion's part and yours and could be quite challenging, but who knows!!
Lots to think about!!

It is fantastic that this type of "stuff" is now freely available - buying a commercial set up would cost a fortune. With this set up anyone with reasonable head/eye movement could once again have full control of the computer - powerful stuff.

Disabled Travel

New additions:

1. **Quarters Hotel** in Hermanus, W-Cape
2. **Misty Waves Boutique Hotel** in Hermanus, W-Cape
3. **Sugar Valley Guest House** in Durban, KZN
4. **Coral International Hotel,** Cape Town,W-Cape
5. **Hyatt Regency Oubaai Golf Resort & Spa** in Herolds Bay, W-Cape

Condolences to the Family & Friends of

Kenneth Phalo, Eddie Marsh, Eric Poonyane, Skatana Pebe, John Tiffin, Roland Jolink, August Lemmer, Brian Stanley, Wolfgang Henrich, Willie Basson, Elsa Hoffmann

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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