

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



February 2004

Piet Oelofse of Paarl in his hoist which was invented by him and constructed with the assistance of his ex-employer

**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

PATRON
Aviva Pelham (M. Mus.)

NATIONAL CHAIRPERSON
Dr. Peter Kraus

VICE CHAIRPERSON
Vivien O’Cuinneagain

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Dear Friends

The festive season has come and gone, and we are already well into the new year. Hopefully you all had time to share special moments and memories with friends and family over this period.

It was indeed an honour and a privilege to have been invited to the "Steven Loeb" Golf Day. It has always been said that "work is for people who do not know how to play golf". As an organisation we are truly grateful for all the people who do not have to "work". The field was fully subscribed and patrons were also very generous come auction time.

A great day was had by all. It was amazing that there was a prize for every golfer. The sponsors were so generous. I would specially like to thank the organising committee for all their hard work, dedication and commitment.

More than all the fun had, was the importance of bringing about awareness of MND/ALS and the plight of patients and families who endure the illness.

"The greatest derangement of the mind is to believe in something because one wishes it to be so" – Rene J Dubos, 1876.

Stem cell technology is at an early state. In animal models of MND/ALS stem cells significantly slow progression of the disease and prolong survival. Further investigation has shown that transplantation into spinal cord of humans is safe and well tolerated by ALS patients but little benefit will be yielded if donor cells fail to integrate functionally into recipients' central nervous system circuitry.

We all agree that there is a pressing need for an effective treatment for ALS/MND. Such treatment may derive from a combination of therapeutic strategies aimed at different aspects of the disorder including drugs directed at events leading to cell death as well as the use of stem cells to replace dead motor neurons or to protect those that remain. There is no simple solution, at present stem cell transplant is no more than a light at the end of the tunnel.

Till next time.

NEWS

Year-end Get-togethers

- Gauteng : All Gifts sponsored by Lever-Ponds !

For the first time a patient get-together was organised in the Pretoria area and was held at the new Hospice Building in Centurion.

Both get-togethers were well attended by patients, family, friends and carers from as far a field as Bronkhorstspuit and even a family member from England ! Two friends, Tony and Dicken met again for the first time since leaving school.

- Cape Town : All our gifts were sponsored by Mr Price !

A patient, Connie Blyth, had this to report:

"There were balloons and crackers, Chocolate Cake and cooldrink, (and wine too, I think !)
And a delightful funny act, so slick and so quick, so lacking in tact,
That we laughed and chortled, our fears well away"

Another report from the daughter of a new patient –

"Just wanted to say a big thank you to all those involved in the wonderful get-together in Pinelands.
It was such a special day in many ways. It was our first encounter with others who had MND and I both dreaded and looked forward to this at the same time. My dad, Len Kilpatrick, was diagnosed in May. Both my sister and I were struck by the happy positive outlook of our new 'MND family' and especially apparent was the overwhelming love that surrounds them. What a privilege!"

Golf Day

A fundraising Golf Day was held on Thursday 29 January 2004 at King David Golf Club, Cape Town.

108 golfers teed off in a howling South Easter. An auction was held in the Club House after a Snack Supper. American Golfer, Tom Watson, had donated an autographed cap which fetched R2000. Final accounting is still being done and more details will

be available in our next newsletter. This event was organised by friends and family of Steven Loeb who has been diagnosed with MND at the age of 37.

Xmas Cards – were sold from Kiosks in Cape Town only as we did not have sufficient volunteers to man kiosks in Gauteng.

Open Garden Day

The Open Garden Day(s) on 25 and 26 October 2003, made possible by the generosity of Margot Gawith of Bishopscourt, was a resounding success despite the inclement weather. We had tremendous support from friends and the general public and we were fortunate to have an army of volunteers at the Gate and helping with the Tea Garden. Hopefully we will be able to do it again this year !

Raffle

Our raffle was well supported countrywide in spite of the fact that the reverse side of the form was incomplete. Our prizes were sponsored by Relais Hotels, Protea Hotels, GrandWest Casino, Galaxy Jewellers, Ramsay Son & Parker, Traumerei Coffee Shops and The Mugg & Bean.



Esma Claassen and her daughter at a recent Patient/Carer get-together in Somerset West.

A baby in the family



Patient Nico Visser and his wife Jackie's baby girl, Nethanjah, was born on 7 January 2004 and we wish them well with their bundle of joy.

International Alliance Symposium in Milan

in November 2003 was attended by Sisters Vivien O'Cuinneagain and Liz Keth.

* A report is included for patients.

Internet Communication

Through our "Mouseketeers" patients have been able to make contact with each other to chat and compare notes.

Internet Info :

The ALS Association www.alsa.org

<<http://www.alsa.org/>>

The ALS Survival Guide <http://www.lougehrigsdisease.net>

The Primary Lateral Sclerosis Site

<http://members.home.net/freyerse/welcome.html>

Note from Ted & Rina Evans, Suider Paarl

Dear Friends at MND Association

This is just to sent you a Christmas greeting and trust that you will spend happy times with family and friends. May we realise afresh what Christmas is really all about and be thankful that Jesus did come as a baby, lived a sinless life as a man so that He could take the punishment for our sins in His own body on the Cross. He died so that we may live, also eternally with Him in glory one day. What a privilege and what love ! May the new year also be a good year in the service of MND. Go on being there as a wonderful support for the patients as well as the carers. Thank you SO much for all your support during this past year for us. May the Lord bless you richly.

With our love from Rina Evans (also for Ted).

Letter from Janita van Rooyen (daughter of patient Susie Wilken) - Pretoria

Thank you for the wonderful support that we received from the MND Association of SA. Liz has received a great gift from God to help and support people in difficult times and in the short time I have known her, she really went out of her way to make difference in the life of my mother, who suffers from MND.

The Christmas Cards are really beautiful and in future years I will help you distribute them, because all my friends said they would love to buy some.

Please keep up the good work and be certain that you unselfish devotion to this good cause is truly appreciated.

Seasons greetings and good wishes for the new year. Kind regards

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.

Note from Ishwair Naik – Killarney

I just want to let you know we – Gautengers – had our first get-together on Saturday 8th November.

I couldn't help admiring how Ms Liz Keth and her daughter Karin organised it so well. The success and credit of it definitely goes to the dynamic pair. In Ms Liz you have a very caring and dedicated individual who has her patients' wellbeing at heart. Despite her crowded schedule she paid me a courtesy call before jetting off to Milan to the MND Symposium.

Incidentally we bought our Xmas cards at the meeting, though rest assured I'm busy with the raffle form sent by you.

I am a long surviving MND patient – 13 years – I was saddened to see no old faces at the meet on Saturday. Regards.

Ken Shuter of Magoebaskloof:

By voicemail – we recently had a conversation with Ken. He is on a cell phone with a connected earpiece. He remains cheerful and positive even though he has no use of his arms but he still puffs a cigarette 3 times a day (!) by way of a mechanical device which was invented by a friend. Ken has moved from his cottage and is staying in the home of friends. He has an electrically operated Lazy Boy chair in which he spends most of his day. He recently made a trip in a Micro Light in tandem with a crash landing ! What fun !!

Although Ken can no longer type he would like to keep in contact and compare notes. So call him on his cell at 082 7731 373. He would love to hear from you.

From Connie Blyth of Cape Town

I don't know what I would have done without the Motor Neurone Disease Association and their nurse, Vivien, who is an amazing person. I repaid their support by dyeing my hair bright pink for the Christmas party to cheer everyone up. I decided to go for temporary blonde after that, but bought permanent tobacco blonde instead – don't see why I should be white haired As a result I am now strawberry blonde.

I was determined to make my 80th birthday in July, but I'm delighted to have found out that I am actually in my 80th year, so if I don't make my birthday, it doesn't matter. I've reached my goal anyway. I'm planning to throw a "wake party" during the next couple of months. I don't see the point of people saying nice things about me after I'm gone – I'd much rather hear them myself. Overall, I've had a good life, and I'd like a chance to celebrate that with some of the people I care about.

Donations

A big thank you to all who donated funds in the past year.

Another thank you goes to the family of Minnie Alexander who donated an electrically-operated Lazy Boy chair which is an ideal piece of equipment for a MND patient.

A Lightweight Wheelchair was purchased with money collected by the Interactors of Plumstead High School, in memory of Gregory Magiera. This is a terrific effort by the young people and an inscription to this effect will be attached to the chair.

CARERS – Keeping Positive

Pauline's husband Alan (73) was diagnosed with MND three years ago and is now confined to a wheelchair. The couple, who celebrated their golden wedding anniversary this year (2003), had always done everything together – and living with MND is no different.

"I am a fairly resilient sort of person, which helps, I'm sure", says Pauline. "I've found that keeping positive does make a difference, especially for Alan. It would be very easy to give up, but I won't let him. Getting dressed is becoming difficult for him now but I try and think up ways so that he can still do it for himself. That way it gives him a sense of achievement. He can't do much around the house any more, but he can perch on a stool and dry the pots for me. It sounds like a small thing but it's very important.

She admits that there have been tough times since Alan's diagnosis.

"I've had teary patches like anyone else, days when you feel you can't cope. I've cried many a time. You do have to be very patient and you do need a sense of humour" says Pauline. "Some of the hardest things are when you need help now, not after you've filled in several forms and told someone how much money you've got. The other day I just couldn't get Alan out of the bathroom – he was too heavy and couldn't help me. We struggled and managed it in the end. They are moments when you want someone to appear on the doorstep".

Pauline admits that Alan's one-day a week at a hospice is her lifeline. "It gives me a breather, a few hours when I don't have to think about any one else, don't have to worry. Knowing he's having a nice time helps too".

She's also in touch with her local Branch and has telephone contact with her Visitor. "We've only got a small flat and Alan finds it hard having too many people coming in and out. But knowing the Visitor is on the end of a phone is reassuring".

Becoming a carer to someone you love can be very hard. "It does change your relationship, because you're suddenly not only their wife, but also the person doing everything for them. That can be frustrating for both of you, but you just have to keep that sense of humour", adds Pauline.

HINTS

Ensuring that MND patients eat enough, especially in the latter stages, is vital. It is known that people with MND didn't eat enough to meet their nutritional requirements and this led to weight loss and a low BMI (Body Mass Index). Documentation shows that weight loss carried an adverse prognosis in this condition.

* We enclose an Ensure Recipe Page for patients.

Car Kit converted to Self-Answering Phone by Piet Oelofse



The car kit is a normal hands free answering system which is used in cars while driving. The whole unit consists of the holder for the cell phone; the speaker with the aerial mounted on the speaker and the voice pick-up is next to the holder of the phone as seen on the photo. Inside the black box in which the above mentioned items are mounted is a transformer which converts 220-volt power into 12-volt power to charge the phone. The cell phone can be set to answer automatically after two rings and can also

hang up after the other person has hung up. Instead of using a transformer a 12-volt battery can also be used for the operation of the unit.

Tip

A patient who has had MND for 5 years has found that by having up to four pairs of socks under the chin stops the jaw opening and getting a dry mouth.

Condolences to the family and friends of

Norman Nel, Beatrice Kaburu, Nigel Fitzgerald, Brian Sherratt, Daphne Russell, Minnie Alexander, Issie van Wyk, Andre Fourie, A Myburgh, G Gosling, Joe Stauch, Pam Lewis.

Attending a wedding for the first time, a little girl whispered to her mother,

"Why is the bride dressed in white ?"

"Because white is the color of happiness. And today is the happiest day of her life" said the mother.

The child thought about this for a moment, then said, "So why is the groom wearing black ?"

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