

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Mike Kellond (Left), Dr Francois Majoos (Right) in their Wheelchairs with their teams participating in the Cape Argus Gun Run on 26 September 2004 which started at the Green Point Lighthouse, going through the V&A Waterfront, then via the City Centre and passed the Green Point Stadium back to the lighthouse – 10km in all which they did in 1hr 20mins

**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 Vurgarellis

VICE CHAIRPERSON
Vivien O’Cuinneagain

TREASURER
Enid Katz

SECRETARY
Vivienne Zilberg/Rina Myburgh

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.

Hi there

Welcome to our first newsletter of the year. This is a bumper edition with

- Feedback from our successful Golf day Fundraiser, at the King David Golf Course. A big thank you to Enid Katz and her team of hard workers who made it the great success it was. It goes without saying, a big thank to the golfers who made it the fun day it was and of course our sponsors whose wonderful prizes added glamour to the occasion.
- We have news of Global Awareness Day, and your committee has put a lot of thought into it. We have managed to secure a performance at the Artscape Theatre on 21 June. See full details below. We need your help to sell the tickets to make it the success it deserves to be
- In this edition we have started by acknowledging all our donors, be it in money or kind. Without our volunteers and the financial contributions our organisation will not be able to support our members as it is borne out by the lovely letters of gratitude that we receive from our members
- We are fortunate to have access to the newsletters of our sister support groups around the world and to publish extracts from them in our newsletter. So doing, we can not only share in the experience of fellow patients, but also keep up to date with the research that is taking place around the world.
- The volume of research is astounding. Every day we hear of some new research that is taking place. I do realise that most of it at this stage is in the laboratory. With the speed of developing science, something unheard of twenty years ago, we will soon be seeing field trials that can only auger well for the future
- In closing let's always bear in mind the Decalogue of an MND patient.

Dr Peter Vurgarellis

NEWS

Global Awareness Day : 21 June is on a Tuesday and we have arranged
A charity performance of **Gilbert & Sullivan's**
"Pirates of Penzance"
at the
Artscape Theatre
on Tuesday 21 June 2005 at 20h15

Tickets @ R100 each includes Cheese & Wine served in the Foyer prior to the performance.
Tickets available from Roxy Levy at 082 468 8980 and/or 021-531 9744.

WE NEED YOUR SUPPORT – WE NEED "BUMS ON SEATS". PLEASE SELL TICKETS !

Golf Day

The golf day on 27 January 2005 at King David Golf Club was a huge success, well organized and raised a substantial sum for MNDA. In addition to their involvement with the Golf Day, a generous donation of R15.000 was received from Rabie Properties towards our Research Fund.

London Marathon

We are happy to report that Gordon Clarke has been accepted as a participant in the Flora London Marathon which takes place on Sunday 14 April 2005. He is running for MNDA of SA and sponsorship forms are obtainable from our office. (Please phone 021-531 9744) WE NEED YOU to help us by collecting funds which should then be returned to us together with the sponsorship form and/or copy bank deposit slip.

Fun Run

The Fun Run takes place on Good Friday, ie 25 March 2005. It starts and finishes at the Upper Campus of UCT and is a run up to the Two Oceans the next day. (Phone 021-6719407 or go to www.twooceansmarathon.org.za for more details)

Two of our patients, Mike Kellond and Francois Majoos, intend taking part in the 8kms run which starts at 15h00, in wheel chairs. We need volunteers to push a wheelchair on a relay basis, and/or to take part, raising awareness (and funds) for MND. How about it ?

Donations

We are extremely grateful for all donations received over the past year. Cash donations, from large to the very small add up to a meaningful amount and the equipment donated is so useful and appreciated.

Since last reporting, donations were received from: Kerchhoff, van Wyk, Gastrow, Adams & Adams, Evans, Farquar, Harms, Halstead, Booth, G van Zyl, E van Zyl, Buchanan, Stronin, J S Rabie, Pepler, Durman, Hancke, Potgieter, Hibbit, Pearce, J Kelly, P Watt, Alborough, van Blerk, Fourie, Fried, Pin, van Veen, Myburg, Masonic Bowling, Merdjam, Berold.

We are grateful for the continued support from the Kurt & Joey Strauss Foundation as well as the Philip Schock Charitable and Educational Foundation and District Grand Lodge SA North.

Mr Malcolm Dunn of Johannesburg recently celebrated his birthday and requested his friends and family to donate funds to MNDA instead of buying gifts. This was a great gesture and raised the grand sum of R9,300.

The voluntary support received from everyone is also much appreciated and without which we would not be able to function and provide the patient care required.

After the passing of Nico Visser of Heidelberg CP in September 2004, his wife Jackie wrote:

Firstly I want to thank you all from the bottom of my heart for the wonderful support that you gave Nethanjah and me in this extremely painful time. Every prayer, visit, phone call, card, e-mail, flower and sms helped me through yet another day. Without the strength of our Heavenly Father and your love I would certainly not have been able to carry on. But Nico was to me, and I am sure to all who knew him, a very good example of how we could and should go on even if the flesh is unwilling. I want to ask everyone who is able, to put pen to paper when the time presents itself and write from your personal experience something about Nico and send it to me. I want to put together a file to give to Nethanjah when she is older and asks about her dad. To all who invited us to come and visit, I shall, when it is in the Will of our Father and I feel a bit stronger, try and get to each of you. Thank you so much for your thoughtfulness.

From : Winnie Pepler and her family from the Strand CP thanked Vivien O'Cuinneagain:

How will I ever be able to thank you and the MND Association for your wonderful technical, practical and emotional support and for all your kindness and loving care ? Words cannot express our heartfelt thanks and the admiration we have for the way you all supported and helped our family cope with the difficulties we experienced during the illness of our loved one. It was the most trying time of my life and not one of us realized what all of us would have to endure while this terrible disease took its course. Only by the grace of our loving Heavenly Father and His faithful care which He bestowed on us through the willing hearts and hands of family, friends and all the wonderful people of the MND A, the Hospice and Serenitas, could we survive. We are glad to say that even though David's illness and death caused us all intense pain and grief, we also experienced many blessings which enriched our lives and for which we are humbly thankful. May Gold bless you and use all of you to lighten the burden of patients to come. I'm not worth anything, but I am here if ever you may need me.

Another "Thank you" to Vivien O'Cuinneagain from Peter and Marion Marx of Somerset West CP:

Our recent transfer to Somerset West was made even more traumatic with the diagnosis of Marion's disease shortly after our arrival here. We were very tempted to move back to Johannesburg where we imagined our old circle of friends would make things more pleasant for Marion. With hindsight we now both realize that going back would have been a grave error, as some friends have moved away and one could not have better support and medical facilities than what we have in S/W anywhere. When Marion first mentioned that she was thinking of going to a support group for MND I wondered what such a group could do that a medical practitioner could not. I have quickly come to the realization that the doctors can do very little, and that the MND support group is a wonderful organization that has such excellent personnel representing it. The care, advice, and introduction to equipment is really invaluable. I often wonder how a MND patient would cope without such professional support and caring people. Both Marion and I would like to express our sincere gratitude for the way that you conduct the

meetings and for all the attention you give to individual patients in the form of visits, providing equipment and expert advice. It is great to know that there is someone like you around, who keeps in touch with the latest developments in the handling and treatment of MND, something that perhaps cannot be expected from a neurologist due to the rareness of the disease. We also appreciate the fact that you allow each patient the freedom to choose whether they wish to pursue a certain course of action like having a peg fitted for example, whilst at the same time giving all the options and guidance one could possibly desire. Above all we feel very privileged that we have met someone like you with what I can only describe as the human touch. We both thank you for the wonderful work you do.

Aviva Pelham (our Patron) expressed her admiration for Vivienne Zilberg (herself a Patient from whose home the MND A "office" in Cape Town operates) to whom everyone speaks who phones the office, and who, with assistance, still runs the office:



Vivienne Zilberg at work in her office

When I try to think of all you have done for MND, all those hundreds of hours of commitment, those weeks and months and so many years of loyalty, it leaves me speechless. And more important, YOU've been the driving force from the start. You are the one who reminds us of what's going on, what's got to be attended to, what we should be doing, thinking, reading, etc. You keep us on the straight and narrow. I seriously doubt if MND A would be functioning now in Cape Town if it hadn't been for you and all your input. You are our glue. You are our inspiration. Thank you again and again, You are just so exceptionally special and I'm proud to know you !

From : Warren Waterston

The most meaningful and enriching time of my 53 years was the past 2 years of caring for my wife. The path of self discovery, of the realization of what compassion and emotional intimacy truly are, of communicating silently through spiritual sharing and the presence of an unknown dimension in humanness, was astounding. It was a time for pure honesty between us, like the innocence of two children, and a complete realization of the mortality of each other. It was a humbling experience that we could

share together. Words were often of little importance in our efforts at coming to terms with reality. Holding hands was worth more than the warmth of the mid morning sun in winter. Just being ... having still some time together ... knowing the hour glass was running out, gave an urgency to living, a reason for being there for each other, and a deep sense of appreciation of God's continued caring. Yes of course one feels weary at times, emotionally drained and burdened by a sense of helplessness and frustration at being able to do so little. If I could – I would do it all again, only with more love, more passion and a greater sense of what a privilege it is to care for your loved one.

Extracts from the Australian Newsletter – "Ask the Expert"

Q. "I was diagnosed with MND 18 months ago and am being looked after at home, with regular visits to my GP. He mentioned that a new treatment called Rilutek is now available in Australia. Will it help me and how can I get it?"*

A. Rilutek (riluzole) has been used worldwide for a number of years in the treatment of MND, but was only listed by the Pharmaceutical Benefits Scheme (PBS) in Australia in June 2003. In clinical trials Rilutek increased life expectancy by up to 9 months, although more recent analyses suggest perhaps greater benefit. Rilutek is generally well tolerated by MND patients and can be taken in combination with other treatments. It is probably best used in the early stage of the disease in the expectation that it will delay the onset of further symptoms. Rilutek is an 'Authority' medication, meaning that it is generally prescribed by a neurologist or other specialist and is reserved for MND patients under 75 years. There are a few further criteria that need to be satisfied, including an assessment of respiratory function. These issues are best addressed through further discussion with your neurologist.

(* Rilutek is available in South Africa – 1 months' supply (58 tablets) @ ±R2.854,29 excl VAT)

Q. "I am having problems swallowing my saliva. Sometimes I can't stop dribbling which is embarrassing when I am out. Also, my voice is becoming weaker. Is there anything I can do?"

A. Problems with saliva are common for people with MND. Either they seem to have too much or not enough! It is generally not that the saliva production is increased but rather that there has been deterioration of the actual swallowing mechanism, as muscles become weaker. The problem may be worse if you have difficulty keeping your head upright. There are no easy answers but here are a few options:

- As a first step, consciously remember to swallow and try to keep your lips closed as much as possible to prevent the saliva escaping

- Use head supports and collars to prevent the head falling forward

- Try medications that can reduce salivary production (eg. Atrobel, amitriptyline). But be aware that they may cause "dry mouth" and saliva substitutes are sometimes required.

- Suction equipment may be useful

- Some people with MND have trialled injections of botulinum toxin (Botox) into their salivary glands to reduce secretions, with variable effect.

Regarding changes in your voice, most people with MND develop weakness in the tongue, face, throat and larynx at some stage, and as respirator function becomes affected, may notice difficulties in loudness of their voice. You could try voice therapy, although this often results in fatigue. A simple voice amplifier is often a good substitute. Ask your Speech Pathologist for the best options for you.

Q. "I am having problems with cramps in my legs, which are very painful, particularly at night time. Can I take anything to reduce them?"

A. Muscle cramps, spasms and stiffness are common symptoms of MND, particularly early in the course of the disease. In fact. Cramps are present in about 10% of patients at the time of their initial consultation. The causes of cramp are varied in MND, some related to muscle breakdown, others possibly to over-activity or over-excitation of the nerves supplying the symptomatic muscles. In terms of treatment, physical therapies including massage may be of benefit. Some people with MND have also reported benefits with calcium, magnesium and manganese supplements. A number of medications can also help. Quinine sulphate is a common over-the-counter preparation that can be trialled. Tonic water contains small amounts of quinine, which may be a more pleasant and equally effective way of preventing or reducing cramp. Medications used for epilepsy are also effective, particularly carbamazepine and gabapentin. If stiffness is also an issue, baclofen may be effective. These latter medications require prescription and should be discussed with your physician.



Annatjie Schwartz of The Strand, using her Bi-Pap machine

Dr Roger Chung, NeuroRepair Group, School of Medicine, University of Tasmania:

“Excitotoxicity and Cytoskeletal alterations in the pathogenesis of Motor Neurone Disease”

Glutamate is the key chemical involved in transmitting signals between nerve cells within the brain. Changes caused by injury or disease lead to abnormal cell functions and ultimately to death of neurons. The sustained exposure to glutamate which leads to death of neurons is termed excitotoxicity. Excitotoxicity is thought to be involved in the development of MND, but it is not clear if over-activation of glutamate receptors leads to be specific patterns of nerve cell changes that are seen in MND, and in particular the changes involving neuronal cytoskeletal proteins (proteins responsible for maintaining the structure and shape of neurons). Furthermore, it is not entirely clear why motor neurones are particularly susceptible to excitotoxicity.

This project will determine whether excitotoxicity can directly or indirectly cause the changes in cytoskeletal proteins that are seen in MND, and whether the specific cytoskeletal composition of motor neurons contributes to their selective vulnerability. Finally we will explore whether a protein that we have developed that promotes brain healing may also have a neuroprotective role in MND.

This project will be undertaken primarily by Dr Roger Chung, supported by the Bill Gole MND Research Fellowship, under the supervision of Professor James Vickers, who has world-renowned expertise in the study of neurodegenerative disease.

Dr Chung completed his PhD in Biochemistry & Molecular Biology at the University of Tasmania in 2003. His primary research focus is understanding how the brain responds to injury or disease. He has a great interest in promoting medical science research to the local community. In recognition of his efforts, Dr Chung has been nominated as a Tasmanian finalist in the Young Australian of the Year Awards for 2004. He was the winner of the Tasmanian Premier’s Young Achiever of the Year Award for 2004.

An article in the Cape Times of 9 February 2005 reads:

London:

The scientist who created Dolly the sheep, the world’s first cloned mammal, was granted a licence yesterday to clone human embryos for medical research.

Professor Ian Wilmut, of the Roslin Institute in Edinburgh, plans to obtain stem cells for research into Motor Neurone Disease (MND), a procedure that divides the medical world along ethical lines.

Britain’s cloning watchdog, the Human Fertilisation and Embryology Authority (HFEA), granted the licence to Wilmut, Dr Paul de Sousa of Edinburgh and Professor Christopher Shaw of King’s College London.

“Our aim will be to generate stem cells purely for research purposes”, Wilmut said. “This is not reproductive cloning”.

Human reproductive cloning is illegal in Britain but therapeutic cloning, creating embryos as a source of stem cells to cure diseases, is allowed on an approved basis.

Stem cells are the body’s master cells. Those from days-old embryos have the ability to form any kind of tissue and scientists are working to learn how to manipulate them for transplants from diabetes to cancer and MND.

The practice has divided the medical world. Opponents argue the use of a human embryo for medical research or even treatment is unethical.

But the British group said the stem cell technique would greatly assist research and treatment.

Reuters

HINTS and TRAVEL TIPS

Powered Wheelchairs – Special Care Needed !

The majority of electrically powered wheelchairs and scooters have a freewheel device to allow them to be manoeuvred in confined spaces and to be pushed in an emergency without using the control system fitted to it. In most cases this action disengages the only effective braking system available to the user. If a unit were left at the top of or adjacent to a slight incline with the drive disengaged, then the effect of the user boarding it might be sufficient to start to roll. The user would have no means of slowing or stopping the wheelchair. Users and carers should use the freewheel device only when it is essential and it should always be re-engaged as soon as the manoeuvre is complete.

TRAVEL TIPS

Wheelchair Friendly Winetasting !

Graham Beck Winery (Ph: 023-626 1214)

The Graham Beck Winery just outside Robertson, is a strikingly modern structure in an industry crowded with history. Situated

on a hill overlooking the vineyards its huge curved roof, boldly coloured walls, and modern interior décor are unique, even to this day. But therein used to lie the catch. The building’s design only provided for access to the tasting area and cellar via two long staircases, a “no-go” for any disabled visitor.

“I have enjoyed the Graham Beck wines, particularly their chardonnays and brut’s, since the early 1990’s when I first “discovered” the Robertson Wine Route. Sadly, for the past twelve years I have never been able to reach the tasting area. The staff have always been very obliging, bringing wines down into the gardens alongside the koi pond without hesitation, but the lure of the tasting room, and the views it obviously had to offer, was always there.

Graham Beck was concerned that although his wines were being rated five out of five for awards, the Robertson winery was receiving a zero for accessibility. Well, that has certainly changed, and if one could award them a six out of five for access it would be deserved. Last year the estate adopted a no holes barred approach to changing its access for disabled visitors.

Under cover disabled parking bays have been created, a state-of-the-art lift installed, and a fully accessible bathroom facility constructed. To smooth things off all floors and decking were leveled so that one can easily roll from the tasting area to the restaurant, to the outside veranda, and even into the 900 barrel cellar.

So often the provision of wheelchair access appears as a cosmetic afterthought. This is not the case here. A lot of money, time, and effort has gone into creating the finest facilities available. In one move the estate has gone from being inaccessible, to being an example for all others to follow. An outstanding effort indeed"

writes a wheelchair-bound wine lover !

Decalogue of the MND patient

- I. Do not ever try do so something you know you cannot, nor permit anyone to do something for you which you know you can do yourself
- II. Adapt your surroundings to your situation by using orthopaedic aids to substitute your damaged muscles
- III. Organise yourself with those who have problems similar to yours. This way your efficiency will increase
- IV. Select emotional and intellectual activities which are not limited to your illness. Keep your physical activity to the maximum, without tiring yourself
- V. Find a way of being useful to all those who surround you. Collaboration reduces the effort.
- VI. Do not allow depression, dejection nor loss of interest to take a hold of you. This makes your condition worse and does not lead to anything
- VII. Make your imagination a tool which allows you to escape from the isolation which is provoked by MND and allows you to join others
- VIII. Do not feel inferior because you are different; assert your right to be happy, just as any other human being
- IX. In your own beliefs, look for the necessary strength to carry one and you will find that the best in you cannot be affected by MND, if you don't want it to
- X. Never lose your hope. No-one has ever found a remedy but some day someone will – why not you ?

True Story !

A man came home from work one day to find his wife on the front porch with her bags packed. "Just where the heck do you think you're going ?" said the man. "I'm going to Las Vegas" said the wife, "I just found out that I can get \$400 a night for what I give you for free!" The man said, "Wait a minute!" and then ran inside the house only to come back a few minutes later with his suitcases in hand. "Where the heck are you going ?" said his wife. The man said, "I want to see how you're gonna live on \$800 a year !"

Condolences to the family and friends of:

Kevin Thoresson, Fritz Fritz, David Pepler, Bill Bond, Natalie Stanlake, Chris Jonker, Colin Waterston, Neil Sauer, Claude Smith, Aida Perry, Annie Allies, Dennis McGee, Johan Nortje, Jan Lloyd, Peter Human, Nico Jordaan, Christine Scholtz.

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.

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

MOTOR NEURONE DISEASE ASSOCIATION of South Africa

P.O.Box 191, MILNERTON, 7435,
TEL: (021) 531-9744
FAX: (021) 531-6222
E-mail: mndaofsa@global.co.za

JOHANNESBURG
TEL: (011) 791-4739
CELL: 082-878-3716
E-mail: keth@futurejhb.co.za