

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Vivien O'Cuinneagain, Nursing Sister, Cape Town (left) and Liz Keth, Nursing Sister, Gauteng, at a Neurological Congress held in Johannesburg earlier this year

**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.

Our new ChairmanDr Peter Vurgarellis

was born in Pretoria and attended Langenhoven Hoer Skool and the University of Pretoria where he graduated in Medicine. (His wife Brenda was a classmate at the medical school). (They have two children, a son and a daughter). After qualifying they worked in Witbank and the Eastern Cape after which he came to UCT and specialised in Community Health. He worked in various managerial positions in the Health Services of the Eastern, Northern and Western Cape and retired in 1996 as the Regional Director for the Western Cape. He has been involved in the field of infectious diseases, chaired the co-ordinating committees for AIDS, Tuberculosis, Public Health Research, geriatric services and genetic diseases in the Western Cape. Has been involved with Rotary and was the District Governor for District 9350 (which incorporates the Western Cape, Namibia and Angola) in 2002-2003. His hobbies are gardening, Botanising, Orchid growing, Birdwatching, South African History and travelling, especially in South Africa.

From the Chair

Thank you for electing me as your new chairperson. I am looking forward to working with you all in the year ahead. I sincerely hope that I can do you and the association justice, and fill the gap left by Dr Krause who so ably chaired the committee. My thanks to him for all he has done. I am sure we will still be seeing much of him in the future, as he has agreed to continue assisting us on the clinical side of things. My background has been in the field of Health Management and I hope that I can bring some of this knowledge and networking to the Association.

Best regards to you all
Peter Vurgarellis



Dr Peter Vurgarellis, MNDA's new Chairman

NEWS

Kilimanjaro

(as mentioned in our previous Newsletter)

At the Annual General Meeting held at Pinewood Village, Pinelands, Cape, on 25 August 2004, we were treated to a slide presentation and shared in the experiences of the Kilimanjaro climb in June. This is Paul's story:

"On Wednesday 30 June 2004, 5 Cape Town climbers summited Mount Kilimanjaro in support of the Motor Neurone Disease Association.

The trip to Tanzania to climb the mountain was used to launch a fundraiser at Herzlia Constantia Primary School whereby the classes competed against each other to raise the most money in support of their teacher Paul Langeveldt, who was one of the five climbers which included Alan Verwey, Joanne Boswell, Wayne Shepperd and Colin Taylor.

"The adventure began on Friday 25 June 2004 with a 3-hour flight to Dar es Salaam. Accommodation was at the Springlands Hotel in Moshi. The first 3 days' hiking were characterized by cold, misty and wet weather. On day 4 we were greeted in the morning by our first view of the impressive Kilimanjaro massif. Our successful summit attempt was on the morning of day 5 with all our party managing to overcome the altitude, cold and gruelling 6-hour slog up to the peak with relative ease.

"The trip was a fantastic experience in spite of the inclement weather and my thanks go to my four friends for all their support on the mountain and for their willingness to be involved in this venture. My thanks also goes to the children and parents of Herzlia Constantia Primary School for their enthusiastic participation in this most

worthwhile cause. For us, the climbers, it was both an honour and an inspiration to be involved in this undertaking".

This was an extremely generous gesture on everyone's part and a letter of thanks and appreciation was sent to Paul, the school and the pupils, who donated R5.000 to the MNDA.

Office Bearers

At the AGM, 3 Committee Members resigned, 3 were re-elected and 2 new members were introduced. Dr Peter Kraus (Chairman) has stepped down due to work pressures and study commitments and Dr Peter Vurgarellis has agreed to take over as Chairperson. Bunty Money has vacated her post as Treasurer and introduced Enid Katz who will be taking over from her. Vivienne Zilberg, Secretary, who will still share her vast experience, general knowledge and background of the MNDA has handed over to Rina Myburgh. Aviva Pelham (Patron), Vivien O'Cuinneagain (Nursing Consultant and Vice Chairperson) and Elsabe Burger (Member) have agreed to stay on.

Diane Heron who was the Chairperson of the International Alliance has withdrawn from office and will no longer be involved. MNDA of SA will however remain a member of the International Alliance.

Visiting Lecturer from UK

Dr David Oliver of Rochester Hospice in England, and who is an authority on palliative care in MND will be touring South Africa in March/April next year, visiting and lecturing to Carers and Hospice Staff. Details to be advised.



Annie and John Allies from Delft, Cape Town

Elsabie Burger writes:

A visit to Annie Allies and her carer, John, in their neat little 2-roomed home warms the heart. As we step into the house we are greeted by a welcoming smile from Annie, seated in her wheelchair, wearing a warm comfortable tracksuit given by Viv O'Cuinneagain and wrapped up cosily against the winter chill. John, her foster brother, is her constant companion, sensitive to her every need. Annie indicates that she wants to communicate by means of the alphabet board which John has stuck onto the wall opposite her. Donning the most ingenious headband and light beam, Annie is able to spell out her thoughts and feelings to us.

Annie so enjoys the MND A's newsletter and referred particularly to the very special letter in the last newsletter written by Annetjie Schwartz. Annie and John's Christian faith means a great deal to them and sustains them through the difficult and lonely times. Annie loves to attend the weekly prayer meeting in a home nearby and John very willingly pushes her there of an evening to share this special meeting with their friends.

For the first time, Annie's eyes welled with tears and sobs shook her frail body, overcome not by self pity but deep felt gratitude to Vivien and MND A for the love and care she receives. To Annie and Johan we say "God bless you both."

Pieter Scholtz, Vredeloof, Brackenfell

I would like to take this opportunity to thank Vivien O'Cuinneagain for her prompt action after we phoned to inform her that we now live in Cape Town after moving from Pretoria. Not only did she pay us a visit but also supplied my wife, Christine, with an electric wheelchair. Vivien, it is indeed of great help for Christine and for me.

Ek wil ook namens my en Christine vir Liz in Johannesburg kantoor bedank vir haar gereelde besoeke terwyl ons in Pretoria gewoon het. Ook die "Shoprider" wat sy aan Christine beskikbaar gestel het terwyl Christine dit kon gebruik. You can rest assured that we really appreciate the work that the MND A is doing for MND patients. Thanks and God bless.

Oh yes, regarding guesthouses that are wheelchair friendly. We spent a night at Anha Casa, a guesthouse at Hermanus. It was really the first guesthouse that we came across that was wheelchair friendly. A spacious bathroom, with a "drive in" shower and toilet. A very upmarket and highly recommended guesthouse. The telefax number is 028-3122841 and e-mail anhasaca@wam.co.za. www.hermanus.com/anhacasa.

Erica Sonnekus, Klerksdorp

I would like to share the next with you. We stay in Klerksdorp North West Province. My husband is 43 years old and has had MND for about 2 years. At this stage he is not yet totally dependent on a wheelchair but we are on our way there. He used to be very active and was getting very frustrated having limited movement or waiting for one of the family to push him where he wanted to go. My son Jaco decided to do something about it. Financially we could not afford to buy an electric wheelchair but he decided there must be a way. So he got businesses to sponsor us. We then decided to phone Liz of MND Johannesburg to see if there was any way to buy a chair with the money we collected. She went to a lot of trouble and put us into contact with Carel from CE Mobility. He was kind and very helpful and gave us very good advice which we appreciated as we knew nothing about purchasing a chair.

Well, my husband Anton got his new chair which also gave him a new lease on life. He goes just about anywhere on his own which means a lot to him to be independent again. It has been amazing to see the change in him. My family and I are very grateful to everyone who made this possible. We just wanted to share this amazing moment with everyone.

Helping a Colleague and Friend in need

When **Ralph Segers** was diagnosed with MND in July 2001 aged 36, he faced the prospect of possibly being boarded from the company where he was employed. As time passed, his employers accommodated him by finding the type of work to suit his circumstances. His colleagues became concerned for his comfort and well-being and decided to make his life a bit easier. They raised R1.500 to put towards a wheelchair to enable him to move around better. They even adapted the toilet seat to help with the call of nature! When getting to work and home again proved a problem, they put their heads together and arranged transport which now makes commuting a lot easier and more comfortable – rain or shine! A big thank you to all at Trax Interconnect (Pty) Limited who has made it possible for Ralph to continue working in a happy and comfortable environment.



Mike Kellond being taken for a ride!

Mike Kellond, a patient from Somerset West who is wheelchair bound, was asked by a friend what he really missed. He said that he wanted to get out of the house more often. His friend then proceeded to adapt his bakkie to accommodate a ramp so that Mike's wheelchair could easily be loaded.

Colly Fram who passed away recently was a respected businessman in Gauteng and well known in racing circles. He was supportive of MNDA and instigated a donation from a local insurance company. His family have donated an electric bed which is presently being used by another patient in Gauteng and will be used in perpetuity by many MND patients. His carer, Robert, spoke of his boss and best friend – and how much he would miss him. He said he had bought a car that needed fixing and Colly helped him pay for repairs. “I never thought I would ever meet anyone like him, or his family, in my life. Everybody has been so kind and I will miss them a lot.” He added he would take some time off to mourn the loss of his friend before embarking on a new job. Ruth, Colly’s wife said: “Robert has been wonderful. Colly became very close to him and I don’t know how we would have coped without him. He helped in every way imaginable”.

From Stephen Loeb, Plettenberg Bay

I AM THAT I AM.

Exactly one year ago I was diagnosed with ALS. I was 37 yrs young and healthy, or so I thought. I was very active and loved the outdoors. I loved sport from a young age played as much as I could, you name it, and I played it. I became obsessed with the martial arts and practiced many different styles from about the age of 11. At 28 I got married, at 30 had my first child; a boy and 2 years later, along came my daughter. Life was good and I could not have asked for more, and like all of us thought nothing could possibly go wrong. I thought I would continue riding my wave of life well into my 80’s and then move on to greener pastures as we all eventually do. I would get to see my beautiful children Gabriel and Jessica grow up (now 7 and 5 yrs old), finish school, be at their weddings and maybe even have grandchildren. I imagined my beautiful wife (Darice) and I would enjoy our retirement years with strolls on the beach and enjoying each other till the end of time – how true the saying “Man plans and God laughs”.

Having MND has taught me to understand the meaning of “Be in the moment” and “live in the now, as tomorrow may never come.” We have all heard these words at some stage of our lives but not too many people get to live it. The present moment is all there is, there is no other reality, the past and the future do not exist don’t waste your energy delving in them there is only now.

All of you out there with MND probably felt the same as me when diagnosed, that the world had come to an end. At that moment, I thought my life was over but a year later I am still here. I have learnt to live in the moment, my moment. I cannot talk as well or walk as well or do anything as well as I used to and physically am not the same as anyone else, but so what, we are all on our own journey, we are all very special and we carry on in our own special way and be the best we can be in our own unique way. We are all winners. Life is all about perception and how we perceive it, so it is. We create our own reality. TRUST THE PROCESS, THINGS ARE EXACTLY AS THEY SHOULD BE. Don’t fight it just BE.

We are all on a train ride and this train has no brakes, nothing you or I do will stop the train and it may be a very long ride or maybe a short ride we don’t know only God knows, trust Him. He knows exactly what is happening to us and we are all a piece of Him. He wont let you fall harder than He thinks you can handle. Trust and faith are the best brakes you could have on this ride with them you hold the power to stop that train right now. We have been chosen to have MND because we are all special. Enjoy this ride of your life and turn that obstacle into an opportunity. At times I feel grateful to be where I am in my life. My journey has brought me so much love so much wisdom and so much spiritual growth that I know I would never had attained if I were healthy and able bodied. After all what is the meaning of life, what is our purpose down here? Surely it is to achieve a state of beingness, of Godliness and this can only be achieved

through working on our spirituality and not our physicality, so maybe it’s a blessing we have received. We have been forced to work on ourselves to attain greater heights. Our physicality has been taken away leaving us only with our spirituality. We may not understand our process but that does not mean its wrong. Maybe we need to change our perception and truly trust our creator. He does not make mistakes. Let your faith carry you. Remember everything in life is based on either love or fear and there is NOTHING to fear except fear itself. Love yourself and love life. Just be, and try and discover the beauty of the inner you, the bigger you, the real you, the person within, which is perfect and has no flaws. You do not need any part of your physicality to be truly happy. Your beauty and happiness are within yourself. You don’t need anybody to make you feel special. You are all special. You are all a spark of the divine. Use this time to ignite this spark and discover the light within you and you will find out that life is beautiful. Let your light burn brighter now than ever and I pray that we may all experience God’s Grace. If you don’t go within, you go without.

Strength to you all

Until we meet

Shalom



Ken Shuter completing the Comrades in March

This photo of **Ken Shuter** was taken last March after his completion of the Comrades Marathon route in a wheelchair. Ken passed away on 14 September. A memorial service will be held at the Michaelhouse Chapel on 27 September. Ken taught English, Art and Physical Training at many schools in KZN and lastly in Haenertsburg. He was well known in educational circles and will be sorely missed by colleagues and past pupils.

DONATIONS

Apart from a number of smaller donations which all added up to give our coffers a boost and for which we are very grateful, and those mentioned earlier in this Newsletter, we also received the following:
 R 4.500 from the Philip Shock Foundation
 R 5.500 from the Kurt & Joey Strauss Foundation
 R 1.500 in memory of Jessica Kercchoff
 R25.000 in memory of Margaret Meredith

INFO

In need of a Carer ?

CareBase is a Division of Caregivers International, who has established an internet database (Carebase) and which aims to provide associations and their members with trained home based carers as and when required. The introduction service is free and members will pay the carers as and when they work.

For further information contact Keith or Phoebe on 0861 22737, or Website www.carebase.org, e-mail: carebase@cgi.co.za or telephone 021-782 0153.

Rilutek

With the new legislation for medication, patients are advised to shop around and/or negotiate with their Pharmacists for the best deal for Rilutek, as prices vary greatly.

RESEARCH

Scientists may have developed a gene therapy treatment for the most common form of motor neurone disease (MND):

In lab tests on mice the therapy slowed onset and progression of Amyotrophic Lateral Sclerosis (ALS). It also extended life expectancy by 30%.

Writing in the journal Nature, the research team at biopharmaceutical firm Oxford BioMedica stressed the work is at an early stage.

MND affects about 5,000 people in the UK and there are 1,000 new cases a year.

The disease is caused by the death of cells – called motor neurones – that control movement in the brain and spinal cord. There is currently no known cure.

ALS is a form of the disease which affects adults, leading to paralysis and death within five years for most patients.

Key gene: The new treatment – called MoNuDin – essentially consists of a gene which triggers production of a chemical called a vascular endothelial growth factor (VEGF). The gene is injected into the muscles, but stimulates VEGF production in the nerve cells of the spine. ALS is linked to reduced levels of VEGF in both mice and humans. It is thought that the chemical plays a key role in protecting nerve cells from damage. Tests on mice showed that a single shot of the new therapy was enough to produce a significant beneficial effect.

Prof Alan Kingsman, Oxford BioMedica chief executive said: "Although these results published in Nature are still at a preclinical stage, the data suggests that VEGF gene therapy could provide an effective treatment for ALS".

Dr Brian Dickie of the MND Association, welcomed the findings. He said: "These findings reflect current optimism amongst researchers that gene therapy represents a viable strategy for the treatment of ALS and other neurodegenerative diseases, overcoming problems of access of drugs to the central nervous system, which can occur with more conventional approaches to treatment."

The Oxford BioMedica team worked on the treatment in collaboration with the Centre for Transgene Technology and Gene Therapy in Belgium.

Story from BBC News: <http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/3750125.stm>

(Published 27 May 2004)

Internet Info

The ALS Association

www.alsa.org

The ALS Survival Guide

www.lougehrigsdisease.net

The Primary Lateral Sclerosis Site

<http://members.home.net/frey-erse/welcome.html>

BOOKS of Interest and which chronicle the lives and struggles of families living with ALS/MND.

Caddy for Life : The Bruce Edwards Story (by John Feinstein)

His Brother's Keeper : A Story from the Edge of Medicine (by Jonathan Weiner)

Tales from the Bed : On Living, Dying and Having It All (by Jenifer Estess)

Learning to Fall : Blessings of an Imperfect Life (by Phil Simmons)

They paint intimate portraits of those involved as they bravely face their battle with ALS/MND.

www.exclusivebooks.com

www.amazon.com

www.bn.com

HINTS**MAKING EATING EASIER**

Eating can be a dangerous activity for people with M.N.D with weakened throat muscles. Don't take risks. Learn as much as you can about your own swallowing limitations from a speech and language therapist and dietician and other health care professionals. Become aware of swallowing changes as they occur in your throat muscles, and ensure that your diet is adapted to your changing abilities.

Take more time

Eating and drinking may be a slow and labour intensive process. Allow more time to eat meals and never rush or speak with your mouth full.

Be relaxed when eating

Eating is a social event and a person experiencing difficulty with eating and drinking may feel acute embarrassment. Anxiety and distress may accompany embarrassment, and anxiety itself impairs the ability to relax. Being relaxed and feeling confident is of tremendous assistance.

Some people find it easier to relax if there are no distractions. For example, they may turn off the T.V. or radio, and discourage visitors from calling at meal times. Others find the distractions helpful in allowing them to relax and feel less anxious.

Concentrate on eating

Eating in a group may result in not being able to concentrate on swallowing or feeling that you cannot take your time, resulting in an inadequate meal not being eaten or being rushed, causing coughing and distress. Eating alone may make it easier, though it may also be important to have at least one other person nearby should you encounter problems.

Focus on eating position

With chewing and swallowing problems you should try eating in an upright position, with the chin tucked towards the chest to close off the airway to the lungs when swallowing and to prevent coughing. Drinking may be easier with the use of straws, sports water bottles, babies' feeding cups etc. seek advice. Thicker liquids rather than thin ones for some.

Take small bites

With weakened tongue and lip muscles, smaller bites are easier to handle in your mouth and will reduce the chances of choking if the food falls into the throat before being chewed.

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 !

Be prepared

Learn what to do before an emergency happens. When the throat gets irritated or blocked, it can close around the irritant making it difficult to breathe. Even your saliva can cause coughing and choking. This may also happen when a few small particles from a previous meal are still stuck in the throat. Practice the following so that you will be prepared if this should happen.

Try to relax

Lean forward, the further the better, depending on the seriousness of the problem. If possible stand up and bend over as if to touch your toes. Try to take small breathes through the nose. Expel the food by breathing in slowly, and exhaling or coughing quickly. For more force "splint" your abdomen by crossing your arms over your lower abdomen and pressing firmly in and down as you cough out. A caregiver can also do this by standing behind you and pressing their hands into your abdomen as you cough. Ask a nurse or someone to show you this technique. Never hit a choking person on the back. When a person is choking from food, hitting on the back can cause the food to jam tighter in the throat. If you feel food sticking in the throat try swallowing two or three times to clear it, before taking in more.

Take food and drink separately

It may be difficult for the throat muscles to switch between eating and drinking, which require slightly different muscle activity. It may help to eat food separately from drinking rather than switching back and forth. If food is stuck in the throat and liquid is added, the liquid can very easily be channelled into the airway leading to your chest, and causing more problems.

Next time we will discuss diet changes and feeding options along with utensils that can be used.

Dying to Live !

First I was dying to finish my high school and start college, and then I was dying to finish college and start working. Then I was dying to marry and have children, and then I was dying for my children to grow old enough so I could go back to work. But then I was dying to retire. And now I am dying, and suddenly I realise that I forgot to live.

Please don't let this happen to you. Appreciate your current situation and enjoy each day !

(Taken from Village Ads' Publisher's Desk)

Remember

There is only one way to happiness and that is to cease worrying about the things which are beyond the power of our will. (Epictus) Happiness is not something you postpone for the future. It is something you design for the present. (Jim Rohn)

FUNDRAISING

Christmas is around the corner and what better way to remember family and friends than with a Christmas greeting ! We enclose order forms for Christmas Cards and request that you send your orders in early and make this a fundraiser wherein we can all participate.

There will be no raffle this year. However, we have something very different and will be looking for sponsors – **The Flora London Marathon in April 2005 !** We have been fortunate in that Gordon Clarke of Gauteng, and a team of his friends are trying to secure a ballot to enter the race to raise funds for MNDA in South Africa. We

should know by December this year whether they have been successful. Anyone able to support this effort should please contact us for further details.

Golf Day

On 27 January 2005 the King David Golf Club in Cape Town will be hosting the 2nd Drive or Life Golf Day, after a highly successful inaugural event in 2004. Proceeds of the day will go to the Stephen Loeb Trust and the MNDA (NPO 003-462). The format will be a 4-ball alliance, 2 scores to count on each hole, except the short holes where 1 score will count. This is a shotgun start (12.30 for 13.00) and prize-giving will be held in the clubhouse at approximately 18.30.

Anyone wishing to find out more about the golf or to sponsor a hole/prize, may contact either Enid Katz (021-7153308 / 083 269 8248) or Jeff and Roxy Levy (021-683 1145 / 082 444 5667).

A thought to share with a Helper / Carer

A friend gives hope when life is low

A friend is a place when there's nowhere to go

A friend is honest, A friend is true

A friend is precious, a friend is u !

Blondes might be

A blonde was driving home after work and got caught in a really bad hailstorm. Her car was covered with dents, so the next day she took it to the repair shop.

The shop owner saw that she was a blonde, so he decided to have some fun. He told her just to go home and blow into the exhaust really hard, and all the dents would pop out.

So, the blonde went home, got down on her hands and knees and started blowing into her car's tailpipe. Nothing happened. She blew a little harder, and still nothing happened.

Her roommate, another blonde, came home and asked "What are you doing ?". The first blonde told her how the repairman had instructed her to blow into the tailpipe in order to get all the dents to pop out. Her roommate rolled her eyes and said HEL-LOOOOYou gotta close the windows !"

BUT

A young man found out he was going to inherit a fortune when his sickly, widower father died, so he decided he needed a woman to enjoy it with. So one evening he goes to a singles bar, where he spots the most beautiful woman he's ever seen. Her natural beauty takes his breath away.

"I may look just like an ordinary man" he says as he walks up to her, "but in just a week or two, my father will die, and I'll inherit 20 million dollars". The woman went home with the young man that evening and the next day she became his stepmother ! **when will men ever learn ?**

PLEASE inform us of your change of address, telephone number and/or any other contact details as we would like to stay in touch and ensure that our Newsletter and any other communication reaches you!

Condolences to the family and friends of:

Connie Blyth, Dennis Harmsworth, Soon van Loggenberg, Pieter Maassen, Annette Lombard, Margaret Meredith, Susan Bekker, Colly Fram, Ann Field, John-Leonard Kilpatrick, Jessica Kerchhoff, Boet van der Walt, Mervyn Hendricks, Abraham Rabie, Willem Geldenhuys, Nathan Fried, Frank Moody, Nico Visser, Pam Holman, Hester van Niekerk, Kathy Schuitema, Ruth Gaberone, Ken Shuter

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