

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



June 2007

Alfred Mzawupeli Mali happily smiling at the Support Group at St Luke's Hospice during his 2 week respite stay there

**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

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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

**In the previous issue of “Thumbs UP” we enclosed *Woolworths Supporters Card Applications* -
We are disappointed that so far we have not received the response we were hoping for.**

**We need 200 applications to start the ball rolling, so
PLEASE !**

**Return your signed application forms to our postal address: PO Box 789, Howard Place 7450
Remember every little bit helps - and we need help to keep our Association functioning !!**

Membership

Annual membership has fallen due and we enclose the forms for your convenience.
*To all of you who have already paid the new R75 annual subscription – many thanks !
(please then ignore this reminder)*

Our banking details !

Standard Bank Rondebosch Branch 025009 : Account No 27 062 913 0
*Please ensure correct account title: Motor Neurone Disease Association OR MNDA of SA
(Swift SBZAJJ 02500911 – for deposits from overseas)*

DONATIONS

Many thanks to:

JS Rossouw, PM Snyman, The Vineyard Hotel (Staff), Mathias family, MC Hood, N Pringle, Paul & Aviva Sulcas, Norman van Zyl, Knowles family, MA Longbeach, G Price, B Odendaal, T Katzew, JW Bell, HJ Veraar, A May, MM Fricker, Hilda van Zyl, SP Saayman, Peter & Rosemary Thorburn, M McLellan, Amanda Booyesen, Levitt & Aronoff family, Sue Lane, DY Scheepers, St Michael’s Church, M Wagenaar, Pamela Hobbs, WR Terry, RF Morris, Moira Essen, Rael Levitt, HA Wilson, S van Blerk, C Cabion, MG Norman, Janie Zaal, L Lemone-Ward, Kat Halpin, G Lord, JM Cope, EA Allright, D Serfontein, S Birkhead, R Els, Schewitz family, M Norman, J Gaiser, I Naik

- for monthly contributions, donations made in memory of loved ones, or in lieu of gifts to friends and family on various occasions, or simply because!!

MAIL BAG

The Reality of Living with MND

(By Jean Waters – taken from Thumbprint, Spring 2007)

“Whatever is ahead of me, is best not to dwell on and in the meantime, life is for living.”

I have Progressive Muscular Atrophy. It’s a rare form of MND with purely lower motor neurone (LMN) signs. It occurs in around 5-7% of all reported cases of MND. As it is five times more common in men than women it makes me one of a rare breed !

It took nearly eighteen months before I was diagnosed with MND, passing through the Orthopaedic Department before reaching the Neurologists. For a few months I lived with the possibility of having Multifocal Motor Neurophathy, until the inevitable diagnoses was reached.

The downside of the diagnosis of MND is self evident. The initial emotion was one of grief, inner turmoil and a complete sense of doom. After a few months when logic was restored,

it was obvious that I hadn’t the fastest progressing disease and the intense emotions lessened. I am now two years down the line, walking with difficulty, weak arms necessitating retirement, but still with purely LMN signs. Is there an upside to PMA? On reflection, I think there is. I am fortunate to have been given time, something so many people living with MND don’t have and I am grateful. It has enabled me to forge relationships which under normal circumstances, would never have happened.

A friend with secondary breast cancer and I formed “the small print survivors’ club” and met regularly, able to talk about common concerns and anxieties and spin humour into our predicament. Sadly, our little club is down to 50% of its original membership, but it was an experience I will never regret having and was so beneficial to us both.

Enforced retirement led to new doors opening. I have liaised with our local hospice and used my medical training to provide updates for the staff, including talking to them about

MND in all its forms. I have met other people living with MND, carers and professionals, forging new links, both locally and nationally.

I can empathise with other disabled people in a way that I could never have done without my first-hand experience. The support and practical help which I have received has been fantastic and has come from some of the most unexpected sources. Whatever is ahead of me, life is for living.

My family won't allow me to wallow. As my son said on learning of my encroaching disability: "Never mind Mum, just think, when you are in a wheelchair, we can set some blades beneath and it will save me mowing the lawn!"

Ingrid Herholdt from Great Brak River whose husband Prof Wynand Herholdt, recently passed away, writes:

I would like to express my appreciation to the MND Association for all the support and help you have given us. It was such a relief to hear there was a MND Association after Wynand was diagnosed with ALS. You were a great help and a special thanks for all your visits, support and encouragement and always being there when I needed advice.

Wynand was diagnosed with ALS (Motor Neurone Disease) on October 5, 2001. His illness started in his one foot and gradually paralysed him until he was completely paralysed after 2 years. He could still speak and swallow up to the end. He believed that as long as he could still speak, he had work to do.

Five years and five months later, on 1 April 2007 Wynand died in my arms at the age of 66, two weeks before his birthday. It was an honour and a privilege to be his wife and to be able to care for him. We loved and cared for each other. We were happy like children. We held hands and it was important to us to share everything. Sometimes words were of little importance at coming to terms with reality. Being together was more important than anything else. There were times that emotions and frustrations took over but God took care of that. He made us strong and we had to come to terms with this illness and we did. We also have a lot of loving and caring people around us who visited Wynand on a regular basis. He enjoyed having people around him. He was never depressed and never complained.

Wynand believed he had 4 angels: his wife Ingrid, his nurse Helena, Spaas Floors who helped us in the house and his unknown angel who was always around us. He loved to do Bible study in the mornings and was always looking forward to do the Afrikaans cryptic crossword. Wynand was a remarkable and respected man. He was a professor at the University of Pretoria until his retirement in 2000. He was head of the

Psychology

Department and from 1985 became Director of the Human Resources Department until his retirement in 2000.

There is so much to say about Wynand and what he went through, but all I can say is this illness is difficult to come to terms with. Get help. Physically and mentally. These patients need a lot of love and attention but you as carer does to. If anyone who has ALS would like to talk to me please feel free to call me even if it is just for a chat. Remember, each patient is different. My number is 044-620 3221. I stay in Great Brak River (midway between George and Mossel Bay).

I will love and miss Wynand forever but I know he is whole again and playing "hop scotch" with the children in heaven. With love and best wishes, Ingrid Herholdt.

Shirley Levitt from Sea Point, who lost her husband to MND in February, sent us this e-mail recently:

I would like to thank everyone at the Motor Neuron offices, and in particular Vivien O'Cuinneagain, who went out of her way to be always on hand when needed, and contacted us even on Sundays and if necessary after hours, and always rendered exceptional assistance and help to me, my late husband Charles, and members of our family.

With grateful thanks, Shirley Levitt.

Francois Serfontein van Oudtshoorn, stuur hierdie briefie saam met sy geldelike bydrae:

My woorde is min maar my dankbaarheid groot teenoor julle vir al die goeie werk wat julle doen. Nogmaals baie dankie vir alles en baie groete aan suster Vivien.

Magre van Deventer, pasiënt van Uitenhage deel met ons:

Waarom gebeur slegte dinge met goeie mense?

Ek het toe die goeie verwag, maar rampe het my getref, ek het uitgesien na die lig, maar donker het my oorval. (Job 30:26). Lyding bring die beste in ons tevoorskyn. Paulus roem daarop dat, as hy swak is, hy dan sterk is. Liefde, geduld, medelye en deernis word dikwels uit lyding gebore.

...And believes in the following quotes:

- Once you choose hope, anything's possible.
- The best way to cheer yourself up is to try to cheer somebody else up.
- Never let your head hang down. Never give up and sit down and grieve. Find another way.
- Hope does not take away your problems. It can lift you above them.
- There are only two ways to live your life. One is as though nothing is a miracle.

The other is as though everything is a miracle.

- I believe in the sun even when it is not shining.
- I believe in love even when feeling it not.
- I believe in God even when he is silent.
- Prayer is the opening of the soul to God so that he can speak to us.
- The difference between the impossible and the possible lies in a person's **Determination**

To continue believing in yourself, believing in the doctors, believing in the treatment, believing in whatever I chose to believe in, that was the most important thing, I decided. It had to be.

A little girl (aged 4) was with her mother when they met an elderly, rather wrinkled woman her mom knew.

The little girl looked at her for a while and asked "why doesn't your skin fit your face?"

How to stay young ...

(Taken from Publiser's Desk of Village Ads – May 2007)

- (i) Throw out nonessential numbers. This includes age, weight and height.
Let the doctors worry about them – That is why you pay them.
- (ii) Keep only cheerful friends. The grouches will pull you

down.

- (iii) Keep learning. Learn more about the computer, crafts, gardening, whatever.
Never let the brain idle. "An idle mind is the devil's workshop and the devil's name is Alzheimer's"
- (iv) Enjoy the simple things
- (v) Laugh often, long and loud. Laugh until you gasp for breath
- (vi) The tears happen. Endure, grieve, and move on. The only person who is with us our entire life, is ourselves. Be alive while you are alive
- (vii) Surround yourself with what you love, whether it's family, pets, keepsakes, music, plants, hobbies, whatever.
Your home is your refuge.
- (viii) Cherish your health: If it is good, preserve it. If it is unstable, improve it.
If it is beyond what you can improve, get help
- (ix) Don't take guilt trips
- (x) Tell the people you love that you love them, at every opportunity.

And REMEMBER,

**Life is not measured by the number of breaths we take,
But by the moments that take our breath away.
We all need to live life to it's fullest each day !**



Patient June Long (of Mowbray, Cape) and her husband Des, gaining knowledge at a Support Group Meeting at St Luke's Hospice recently

Carers' Assessments

You have a legal right to an assessment of your own needs if you are looking after someone who cannot manage without your help. You also have a right to an assessment if you intend to look after someone.

You may want to consider some of the following points:

- Do you get enough sleep? Is your health affected in other ways?
- Are you able to get out and about? Do you get time for yourself?
- Are your other relationships affected?
- Is the person you care for getting enough help?

Also think about what might help you cope:

- services that give you a break
- emotional support from other carers or people who understand
- help with household tasks
- help with caring tasks during the day/night
- activities for the person you care for

Make sure the person you are caring for isn't present when the assessment is carried out. This way you can talk more openly, without feeling inhibited or guilty.

Looking after Yourself

Carers aren't really very good at considering their own needs. How can I think of myself, you might say, when my partner or relative is seriously ill? But it is vital to understand your own requirements too. By doing this, you will be better equipped to maintain your own emotional, mental and physical strength to cope with all that is required of you.

- Eat Well

It may sound blatantly obvious, but in order to be able to do everything you need as a carer, you need to ensure that you are eating a well-balanced diet. If you need help, your doctor will be able to point you in the right direction. And don't forget to treat yourself once in a while!

- Keep Fit

If you have to do a lot of physical caring for your partner, you may feel this is enough. But it is important to get some regular exercise, such as walking or swimming. If you like exercise and gym work, that might be worth a try too. Just remember, if you are new to exercise, take relevant advice. Exercise releases endorphins into the blood stream, giving you that feel-good factor. It can be an excellent way of combating stress too.

- Time for You

Everyone deserves a bit of space, some 'me' time when they can focus on their own needs for a while. This can be as simple as listening to that new CD you bought ages ago, settling

down with a good book, or relaxing in the bath. It's about what you enjoy. Be selfish for once – you deserve it!

- Training

Looking after someone's every need can pose new strains and stresses on the body.

For instance learning the correct techniques for lifting and handling can be a really positive step and prevent injuries.

- Taking a Break

Often carers balk at the idea of taking a break away from the person they care for, but the benefits can outweigh any worries. Getting away can offer the opportunity to try new things, see new areas and meet new people. It also gives you a talking point for when you return and share details of your experience. Breaks can be anything you like – maybe you've always wanted to visit a particular city, or try a course in watercolour painting. It doesn't matter what it is, so long as you get the opportunity for 'time off' to recharge your batteries.

- Holidays

Some carers think a 'proper' holiday is impossible, or even selfish. But it can make a real difference to our ability to cope. You could go alone, or with a group of likeminded people.

(Thumbprint – Spring 2007)

Life is too short to wake up in the morning with regrets.

So love the people who treat you right.

Forget the ones who don't, and believe that everything happens for a reason. Know a good thing when you see it, and don't let it slip away. If you get a chance, take it.

If it changes your life, let it. Nobody said it would be easy, they just said it would be worth it.

"Life may not be the party we expected but we might as well dance while we are here"

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.

.... Using human stem cells in the news

(*From Thumbprint Magazine – Spring 2007)

Stem cell research has hit the headlines recently, with the Government (*UK*) examining the pros and cons of encouraging altruistic donors of human eggs and also considering the potential use of animal eggs as an alternative, to create cybrids (sometimes known as chimeras). Both approaches have been proposed as a means of generating human embryonic stem cells for research.

At present, there is no viable way of studying living human motor neurones in the laboratory, which is greatly inhibiting understanding of MND and the search for more effective treatments. Stem cells offer a potential source of motor neurones for research, but progress in this area is hampered by a lack of human eggs.

We appreciate the issue of stem cell research raises ethical and practical concerns. But as long as the process is legal, involves informed consent, and the research itself has a sound scientific rationale, we support any such advances that bring us closer to a world free of MND.

Motor Neurone ...Neighbourhood Watch

(*From Thumbprint Magazine - Spring 2007)

For many years, researchers have almost exclusively looked at motor neurones when studying MND. However, over the last five years, the topics studied have broadened to include a group of cells called 'glia'. Researchers have shown that these cells, that surround motor neurones, are involved in Motor Neurone Disease. We now know more about them and are beginning to target drug treatments specifically to alter their function.

There are many different types of glial cells including microglia and astrocytes. Their role is to support the function of motor neurones. They outnumber motor neurones in the brain by five to ten times. When the function of the brain is imbalanced, the glial cells move from a resting state to an activated state.

Astrocytes got their name from their star shape. In normal conditions they provide nutrients for neurones and also ensure that messages between neurones are efficiently and correctly passed on.

Microglia act as sensors for nerve cell damage in the brain and spinal cord, and help clear away any damaged or dying cells. Their role in MND is not very well understood; to date researchers are perplexed by the balance of protective and toxic properties of microglia in MND.

In 2003 MND researchers' attention was drawn to the role of both types of glial cell in motor neurones. Prof Don Cleveland's research group at the Ludwig Institute, University

of California used the SOD1 mouse model of MND to illustrate the importance of glia in MND. 'SOD1' is an abbreviation of the gene that is damaged in a rare, inherited form of MND. Incorporating a mutant (damaged) copy of this gene into mice causes them to develop MND, thus allowing researchers to model the disease.

In this mouse model of MND, the mutant SOD1 (mtSOD1) gene is incorporated into both the motor neurones and the glial cells surrounding them. Dr Cleveland altered this balance, breeding mice with a mixture of the normal SOD1 and mtSOD1 in motor neurones. Some mice had mtSOD1 in the motor neurones and not the glia and vice versa. What he found was surprising. The glial cells containing the normal SOD1 gene appeared to protect the neighbouring motor neurones with the mutated gene. However, there was a negative effect: the presence of a few glial cells containing the damaged SOD1 gene can cause their healthy neighbouring motor neurones to degenerate.

These experiments were a clear demonstration that glial cells contribute to motor neurone death. Thus Prof Cleveland commented at that year's International Symposium on ALS/MND in Milan, "having good neighbours matters!"

The Clinical Potential of Minocycline in Amyotrophic Lateral Sclerosis

(An extract of a report published by Allitia B DiBernardo MD and Merit E Cudkowicz MD MSc, of the Department of Neurology, Massachusetts General Hospital):

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive, adult-onset neurodegenerative disease characterized by selective dysfunction and death of motor neurones in the brain and spinal cord. The disease is typically fatal within three to five years of symptom onset. There is no known cure and only riluzole, which was approved by the US Food and Drug Administration (FDA) in 1996 for the treatment of ALS, has shown some efficacy in humans. There remains a crucial unmet need for effective neuro-protective strategies in ALS. Recently, experimental data have highlighted the beneficial properties of the antibiotic minocycline in models of neurodegeneration. This article reviews the clinical potential of minocycline for the treatment of ALS.

Minocycline is a semi-synthetic tetracycline derivative that has been in clinical use for more than 30 years. The drug, which has broad-spectrum antimicrobial activity, is commonly used for the long-term treatment of chronic conditions such as acne vulgaris and rosacea at doses of 100-200mg/day. Drug-induced autoimmune syndromes have been reported rarely, in the order of one per million individuals treated. Minocycline therefore has an established record of clinical safety with long-term administration. Its small size (496kDa) and high lipophilicity confer advantageous bio-availability

and blood-brain barrier permeability. Its cerebrospinal fluid (CSF) penetration surpasses that of other tetracyclines.

Minocycline exerts anti-inflammatory effects separate and distinct from its antibiotic activity. Neurological interest in minocycline was piqued by its effects in the setting of non-infectious injury, specifically by the finding that the drug reduced neuronal loss after hypoxic injury. In animal models of ischemia, final infarct volume was reduced both with acute administration and with drug delivery up to four hours after ischemic onset. Subsequent work confirmed minocycline's neuroprotective effect in several models of acute and chronic neurodegeneration, including hemorrhagic and ischemic stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, Parkinson's disease (PD), Huntington's disease (HD), ALS and epilepsy. Contrary to numerous reports of the potential benefits of minocycline in neurological disease is data suggesting that the drug may have no effect, or may even exacerbate disease in models of HD, PD and stroke. On balance, pre-clinical evidence favouring the neuroprotective potential of minocycline, in combination with its excellent central nervous system (CNS) penetration and well-established clinical safety, make the drug a viable candidate therapy for ALS and other neurodegenerative diseases. Whether minocycline will prove effective against neurodegeneration in humans is not yet known. Jankovic and colleagues at Baylor

University are currently using 200mg/day of minocycline in an on-going study of 30 patients with HD whom they will follow for three years; Cudkovic and colleagues at Harvard also have an HD trial underway. Minocycline is under consideration for phase III testing in PD based on encouraging results of a recent phase II trial. The first large efficacy trial of minocycline in humans is currently being conducted in patients with ALS.

***The Star Newspaper – 9 May 2007**

Ottawa

Researchers have developed the first antibody that detects the only known cause of the fatal nervous disorder ALS, or Lou Gehrig's disease. It identifies "misfolded" mutations in the enzyme superoxide dismutase-1 (SOD1), which cause about one to 2% of all cases of ALS. The antibody could eventually help to diagnose the disease earlier and find ways to immunise against it, researchers at the University of Toronto's Faculty of Medicine said.

ALS is a progressive disorder that attacks the nerves and muscles causing complete paralysis and death usually within two to five years. There is currently no known cure or effective treatment. (Sapa-AFP).



Patient Peter Thorburn (of Bergvliet, Cape) and his wife Rosemary at a Support Group get-together in Somerset West

Condolences to the Family and friends of:

Marjorie Calitz, Prof David Erasmus, Margaret Prins, Jean Moll (Fullalove),
Prof Wynand Herholdt, A van Graan, Leo Nel, Anna Foggitt, Dorothea Meyer

*A little boy (aged 3) hugged and kissed his Mom goodnight –
“I love you so much,
That when you die I’m going to bury you outside my bedroom window”*

Instead of flowers Another way to honour your loved one:

When someone close to us dies, we experience grief, sadness and, ultimately, an appreciation of all the memories we have of that special person. In our sadness, we look for a way to express our feelings, to let close ones know our feelings.

There is another way that is far more lasting to show we care. It’s a way of expressing hope that one day a cure for motor neurone disease will be found, a way in which we can offer a continuing and meaningful tribute.

Support to people living with MND and their families, is provided through telephone contact, information, personal visits, practical help and the loan of necessary equipment.

When you make an “In Memoriam” donation to MNDA we will send the bereaved family a card acknowledging your gift. The card identifies you but does not mention the amount given. (Please let us have all relevant details and remember when sending a cheque, to correctly insert the Payee’s name).



Patient Kenneth Rhode of Eerste River and his wife Estelle

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

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