

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Anne Field (Centre), with her family who did the Pick'n'Pay/Argus Cycle Tour

**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

TREASURER
Bunty Money

SECRETARY
Vivienne Zilberg

INT. ALLIANCE REP.
Diane Heron

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.

Paul Langeveldt of Herzlia School, Constantia, and his team will be summiting Mount Kilimanjaro at the end of June. They will be climbing for MND awareness and sponsorship and will be wearing our aprons and vests during the 5 day climb. We hope to have a photograph of them on the summit and will report back in our next newsletter.

DONATIONS

All donations, big and small, are always gratefully received and we thank everyone for their share.

Pat Louw, in memory of her husband Melt Louw, donated a specialised piece of equipment.

Dr David Oliver of the Wisdom Hospice in the UK was selected for a Humanitarian Award of GBP 460. He is a great supporter of MNDA in South Africa and has very generously donated this award to us. The sum of R5,413 was received by us and will be used for the translation and printing of our "What is it?" brochure into Xhosa and/or Zulu and Afrikaans.

Last year we were given the opportunity to apply for a **Support Grant** from the International Alliance of ALS/MND Association in the UK and are happy to report that we were successful in being granted the sum of GBP 3000) R23,510 which will be used to assist us with the ever-increasing office running expenses.

"Party"

Jeremy Hindley, a patient, and his wife Vanessa, celebrated their 60th and 50th birthdays respectively, during April this year. They organised a formal dinner party for family and friends and requested that their guests give a donation to the MNDA in lieu of gifts. This generous gesture by all involved raised the fantastic sum of R14,450. A

big thank you to all who made this possible.

Quiz Evening

Report back - The quiz evening organised by the Union of Jewish Women – Constantia Branch, was a great success and the proceeds amounting to R4,184 has been used for the purchase of a new suction machine to replace equipment which had to be scrapped.



A cheque for R40,000 being the proceeds of the Golf Day was presented by the organisers. From left Jill Rabie, Roxy Levy, Aviva Pelham (Patron of MNDA), Enid Katz and Vivienne Zilberg (Secretary of MNDA) seated.

MND Global Awareness Day – 21 June

MAIL BAG

From Annatjie Schwartz of Somerset West

To all who take part in making MND so much easier on the patients, Thank You so very, very much.

But for the grace of God and the love of all the supporting people I certainly would not be sitting here writing this letter !! Vivien you are a star, running around the countryside lending a helping hand and a shoulder to cry on, and oh ! yes the happy smiles and little jokes that come so naturally when my tears are just about to overpower me Thank you every so much.

No, I have not forgotten Vivienne Zilberg who so religiously puts up with helping out in the office and getting sponsors when needed, your helping never goes unnoticed Vivienne. We all have come to love you and the effort you put into helping, and the friendly smile even when I know that smile costs you somewhat.

I have come a long way with MND. It would not be fair if I do not give all the credit for this to my Father in Heaven whom daily sustains and provides for me, yes I am very aware of the people working in the background. I know God will certainly bless them, their input does not go unnoticed by our Heavenly Father.

From the day I was diagnosed with MND it took me a while to come to terms with the disease. Again I can only thank God for the swift way He helped me to accept the prognosis and to live with a disease and not to die with the disease !

God also put it so plainly in His Word in the book of Deuteronomy 30-19;20. "This day I call heaven and earth as witnesses against you that I set before you life and death, blessings and curses. Now choose life, so that you and your children may

live, and that you may love your God, listen to His voice and hold fast to HIM. For the lord is your life and he will give you many years in the land He swore to give to your fathers Abraham, Isaac and Jacob."

God loves His children so that He actually gives them the hint of a lifetime, Choose Life ! and I want to add that from reading this scripture in the Word of God, it has set me free from the burden of MND, and gave me the victory ! He also promises in His Word that we must realise that the battle is not for us to battle, it is for Him to battle, so that we may receive the victory of His battle on your behalf !! Is that not great !!!!

I have come a long way with MND and I have been treated with so much compassion, love, kindness and care, and because of this I could work through many hills and valleys on the way. If you can get yourself involved with God, our Heavenly Father, things will definitely be easier to understand, trust Him in all your ways and lean not on your own understanding !

Stephen, my husband, was hanging on to a job that was costing us too much money, time and effort, and I just came to the understanding that he did not have to do that just so I could be on a medical aid scheme. I proposed to him to resign and for us to trust God for all we should need concerning MND ! From the very, very first day I was provided with an oxygen machine which the Rotary Club of Strand have sponsored, and service, for my free use. I needed a physio and the next day a trained therapist showed up free of charge. I need medicine and this I receive from the HH Hospital, and someone is even picking up the bill ! Now is that not simply the best provision from our Heavenly Father ?



Presentation of Wheel Chair by Interactors of Plumstead High School (as reported in our February Newsletter) Ms Magiera (teacher), Terri Jackson, Lee Mars, Stephanie van Heerden, Roseanne Cox

I have to tell you that from my side I also had to do my part: I had to have Hope, and I had to have Faith. I know our Heavenly Father gives to each of us the measure of faith he/she needs for a specific need. I never, since the day of my prognosis, felt sorry for myself. I never asked "Why me Lord?" He could answer "Why not you My child?" I only would have stood with a mouth full of teeth with no answer! For what in heaven or earth qualifies you or me not to have to carry the burden of this disease? God will always give you and me the grace and the hope and the faith, we will ever need to hold our heads up high.

I made it a rule not to leave my house without make-up, and my hair done in some kind of fashion. I never went to the shopping malls while I was not feeling at my best. I never wanted anyone to say "Gee but you aren't looking so great. You must be ill." It has absolutely nothing to do with any person what is wrong with me. As long as God knows and I know and the people close to us helping us to cope have to know, I am as happy as a pig in mud!

I have had another setback, but again God was ready and able to do more than I could ever hope or ask for. The machine I needed to assist me with my breathing was delivered at my doorstep by Vivien and the doctor standing by in full force to make it as comfortable as possible for me!

I thank all who are always there for me - to guide, help and pray for me!

I would like to leave you with this verse of hope and love to experience the way God loves us and provides for us. Proverbs 3 v 5&6: "Trust in the Lord with all your heart and lean not on your own understanding. In all your way acknowledge Him, and He will make your path straight".

Never ever look at the circumstances. Look up, look to Jesus and not to the stormy water around us trying to engulf us with all its might!! God will never forsake you.

Love, Annetje Schwartz

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.

From Australia:

My dad has slowly progressive MND and my mom has been his carer for many years. Sometimes mum has had to call for assistance because she was having difficulty in getting dad out of bed or from his chair, and of course she always knew if it was an emergency, she could call an ambulance. What we didn't think about was the possibility of dad having to access emergency assistance if mum became sick or had a fall.

It's for this reason that I am sharing with you the situation mum and dad faced when mum was hanging curtains up and fell and broke her hip. Mum was in her bedroom, dad was in the lounge and food was cooking on the stove. The kitchen is at the other end of the house from the bedroom. The telephone is in the lounge opposite the wall where dad sits so its useless to him. Mum had to get herself from her bedroom to the kitchen for fear that a fire would start. It took her about half an hour to drag herself along the floor to the kitchen. She managed to pull herself up and was able to turn the stove off. She was in a lot of pain after having to move with a broken hip and felt like she was going to faint, so couldn't attempt to move again to reach the phone. Luckily dad was able to lean over from his chair and managed to reach the power point to turn his computer on. Also very lucky that dad did not fall out of his chair attempting to do this. He connected the internet and entered the MND chat room (www.mnd.sa.au/ <<http://www.mnd.sa.au/>> then clicked on the chat room link). Fortunately someone was in the chat room at the time, as dad was able to type his message. Then they called my sister to let her know that mum needed an ambulance. One and a half hours after mum broke her hip, an ambulance arrived at her house. She is now recovering well after a hip replacement and dad is being cared for by my brother.

It's very upsetting to know that Mum and Dad needed help urgently and it was unavailable to them. The truth is, we didn't imagine such a situation, but we should have had something set up for dad to be able to get help if mum needed it. I think my dad is a very strong person. He has a lot of determination and will-power to not let MND beat him, but I think my mum is the most caring, loving, devoted person I know. She has cared for dad for years, and it's so important that we also care for her and think of her needs. I think all carers are very special people. They are always there when their loved one needs assistance and we need to make sure, someone will be there for them, if they too need assistance. There are a few different devices a person with MND could have access to if they found themselves in a situation such as my parents were in. I'm sure many of you already have such access devices in place, but for any of you who might not have, I hope that my parents' story will make you aware of the importance of the person with MND also being able to get help if needed.

If they are able to use a telephone, make sure that it is in reach to call emergency services.

(Editor: It is advisable to always have some means of emergency contact - ie. Neighbour, ADT Response, Emergency Panic Button, etc)

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>

HINTS From Birmingham

After refusing surgery to slow down salivation, (I dribble a lot), my doctor prescribed 1 to 3 drops of Atropine eye drops on the tongue when needed. This amazingly has worked great. The thought of Botox injections or radiotherapy on my saliva glands did not appeal, this is only a short term approach but it suits me.

Walk in Bath - The bath that's a shower that's a bath !

Features which guarantee the ultimate in safe, dignified, independent and luxurious bathing. For more details contact "Walk in Bath" at Tel No 0860 102 999 or visit their Website www.walkinbath.co.za <<http://www.walkinbath.co.za>> or e-mail walkinbath@telkomsa.net or write to PO Box 175, Hunters Retreat 6017.

RESEARCH Update

Following the recent publication of her paper on a study to investigate the feasibility and safety of administering stem cells to people with MND, Dr Mazzini of Milan gave an update on her research. From the 7 patients that have received stem cells to date Mazzini and colleagues concluded that results appear to demonstrate that transplantation of these stem cells into the spinal cord of humans is safe and well tolerated by MND patients. As in clinical studies of potential drugs, Dr Mazzini used several standard tests for muscle strength and respiratory function to monitor progress during the study. Data from these measures up to 21 months after and six months prior to receiving additional stem cells were presented. All the patients are still alive, although both muscle strength and respiratory functions are declining. One interpretation is that the patients are declining at a slower rate after receiving the additional stem cells. In such a small group of patients, with no controls, it is difficult to say whether any differences in the rate of decline of muscle strength or in respiratory function would be due to the stem cell treatment or to the natural progression of the disease in these individuals. In addition to the clinical study, Dr Mazzini briefly mentioned a study in progress in animal models of MND. Dr Mazzini's presentation evoked some robust debate on both the methodology and ethics of conducting such controversial studies. Several eminent clinicians voiced strong concerns about Dr Mazzini's clinical stem cell studies. In an editorial of the medical journal in which this study was published it was cautioned that "it is inappropriate, in the present state of knowledge, to use stem cells as a therapy in MND".

Comments

In the past year, a number of unlicensed "clinics" have suddenly appeared, overseas, offering various forms of treatment, usually in the form of umbilical cord blood cells, at costs that can run to tens of thousands of dollars. In the USA, the Food & Drugs Administration has taken a dim view of the activities of these centres, effectively forcing them to move to countries beyond their jurisdiction. The Association shares concerns of the FDA and American patient associations that laboratory studies do not support some of the claims being made, that the dangers of this sort of treatment are unknown, that the standards of follow up care and monitoring are poor and that the clinicians involved have little or no experience in treating neurological conditions. Anyone with MND considering taking any such treatment should discuss the issue in detail with their neurologist before making any decision.

Food for Thought

Good nutrition is important for everyone with MND. There is evi-

dence that the energy needs of the body increase as it tries to compensate for the loss of motor neurones. Some people with MND can experience particular difficulties with eating and drinking. There are also the pleasurable and social aspects of eating as well as nutritional needs. Gastrostomy feeding (known as "PEG") with data presented on when it should be introduced, its beneficial effects and the quality of life for people with gastrostomies.

For further information on "PEG" placement, contact your GP or MND office.

Setting new trends

Neurones can be exceptionally long cells – in some the start of the cell, known as the "Cell body" is found in the spinal cord and the end is in a toe. The majority of studies investigating how motor neurones die in MND examine what is happening in the spinal cord, at the start of the cell only. In a thought-provoking presentation, Dr Jonathan Glass (Atlanta, USA) showed that motor neurones were damaged at the end of the cell (where they connect to the muscle) before they were damaged at the beginning. The data suggested that scientists might have been looking in the wrong place (the wrong end of the neurone) to find the earliest stages of the nerve damage. Dr Glass observed this type of damage in both mice and humans. He said that these results could have implications when studying why motor neurones die, and how to prevent or protect them.

Holiday Updates

We have read in the Thumbprint Magazine from England about holiday destinations which are wheelchair friendly.

We invite you to give us feedback on holiday venues/establishments, locally, which are REALLY wheelchair friendly and would be suitable for MND patients. They are so far and few between, so if you know about such "special places" please let us know. It could be holiday cottages, guest houses, etc.

Membership

Annual membership forms are enclosed. However, if you have paid your membership within the last 2 months, it would be considered as 2004.

Condolences to the Family and friends of:

Antonie Roux, Ernst Meier, Aletta Maritz, Esma Claassen, Melt Louw, Kate van der Westhuizen, Ted Evans, Pat Wisdom, Vanod Bhoola

"A True Story"

A passenger in a taxi tapped the driver on the shoulder to ask him something. The driver screamed, lost control of the cab, nearly hit a bus, drove up over the curb, and stopped just inches from a large plate glass window. For a few moments everything was silent in the cab, then the driver said "Please, don't ever do that again, you scared the daylights out of me". The passenger, who was also frightened, apologised and said he didn't realise that a tap on the shoulder could frighten him so much, to which the driver replied, "I'm sorry, it's really not your fault at all. Today is my first day driving a cab. I have been driving a hearse for the last 25 years".

Rejection ?

A father was at the beach with his children when the 4 year old son ran up to him, grabbed his hand, and led him to the shore where a seagull lay dead in the sand. "Daddy, what happened to him ?" the son asked. "He died and went to Heaven", the Dad replied. The boy thought for a moment and then said, "Did God throw him back down?"

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