

# Thumbs UP

The Newsletter of the  
Motor Neurone Disease /  
Amyotrophic Lateral Sclerosis  
Association of South Africa

February 2013



*Joining in the fun at the MNDA / Highway Hospice Fun Walk held at Lahee Park, Pinetown KZN. (more inside)*

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."

MNDA of South Africa is a member of the International Alliance

<b>PATRON</b> Aviva Pelham (M. Mus.)	<b>NATIONAL CHAIRPERSON</b> Dr. Franco Henning	<b>VICE CHAIRPERSON</b> Sheila Kendal
<b>SECRETARY</b> Rina Myburgh		

### ACKNOWLEDGEMENTS

John Hall for producing the design and DTP (desk top publishing) work.  
Logo Print (Maitland) for the printing of our magazine



### We are now on facebook!

motor neuron / als association of sa



The past year certainly flew past (time seems to be going by so quickly – it is not just an age thing – even the young ones seem to agree !) and 2013 is already well on it's way, but it is not too late to wish all our readers a happy and safe year ahead.

Like every year, 2012 had its ups and downs but we would like to focus on the positive. We had some wonderful people undertaking to raise awareness and funds for the Association. One likes to think that money is not everything but without it we would not be able to function and assist in the care, comfort and support of our patients, their carers and their families.

So:

**A REMINDER !**  
**Our R100 Membership Fee is due -**  
**Banking Details:**  
**MNDA of SA - Account No 27 062 913 0**  
**Standard Bank Rondebosch 025009**  
**(or whichever way is convenient for you)**  
**Please insert your name as reference**

## DONATIONS

The Association received donations from various sources since our last report - in memory of loved ones who had passed away, in lieu of gifts for special occasions, a little bit extra added to Christmas card orders and membership fees, annual donations from families of past patients, and of course the regular monthly donations from patients and their families. We say thank you to each and everyone for their kind gestures and ongoing support.

## FUNDRAISERS

### *Cape Town –*



Peggy Saxon, one of our Consultants in Cape Town, organised a **“Summer Evening Enchantment” cocktail event at Ottimo Cibo in Bishopscourt** on 17 October 2012 to raise awareness of MND/ALS, of people with the disease, as well as funds for the Association. The program of the evening included the very appropriate song “Some Enchanted Evening” by the duo, Aviva Pelham, well known singer (and patron of the MND/ALS Association of SA) and one of her protégées. An Auction of some of the generous donations received, such as weekends away, spa treatments, jewellery vouchers, sports bags, handbags and wine & whiskey hampers, and lucky draws of beauty & salon vouchers, dinners for two, etc, took place. The tickets at R300pp included a 3 course finger supper, and also wine, which was generously donated by patient Anthony Graham’s daughter, Janet Graham of Jaydex, Paarl.

The evening was well supported and raised R22,000 for the Association. A BIG thank you to Peggy, her friends who assisted with ticket sales, the guests, the sponsors of the prizes and everyone who contributed to making the evening the success it was.



Getting ready



Setting off

### Fun Walk/Run, Pretoria – *Fiona Keyter writes:*

My husband Leon Keyter was diagnosed with MND in February 2009, at the age of 57, and he sadly passed away on 20th September 2010. We had often taken part in the 10km walks on Saturday mornings in Pretoria which is often done to raise funds for various charities, like hospice, cancer and other organisations. Early this year I had a dream to celebrate Leon's 60th birthday by organising a fun run and walk. My main objective was to raise awareness and some funds for the MND Association. Leon and I had always found comfort from meeting other patients at Liz Keth's home. Liz organised talks from other therapists like physios, etc, which were both useful, and interesting. They were also there to lend us items like bath equipment, wheelchairs, cushions etc, which helped tremendously as the illness progressed. Now I also felt this would be my way to give back to the MND Association. I tried to find help to organise such an event, and after no luck with some people, I was given Daan Du Toit's name who is with Run/Walk for life, and he gave me a budget, and helped me to organise the event. My job was to look for sponsorship to cover the budget of flyers, t-shirts, medals, venue costs, water, and lots more.....

Well, with lots of help from friends, eg Laura Schultz who designed the flyers and shopped around for the best price for printers, and they subsequently did the T-shirts for a very good price too. We held the walk at the Pretoria Botanical Gardens, on the 17th November, there were 420 people taking part, and of that 63 were children under 12 which were not charged an entry fee for the race. We had the support of Joost Van der Westhuizen, who attended plus the J9 foundation, who also advertised the event on Joost's facebook, and twitter. We had good media coverage on 702 Radio, 94.7, and Tuks FM, and on the day the Rekord did a good report in the local newspaper, so I do feel we did achieve good awareness. I raised R17,952 in donations for the fun run, yet the total costs for the event was R23,642.

I would like to thank all the people who supported and helped me, there are many, even MND patients who helped, and hospice, especially Paul Kirby, who was incredible on the day, and at such short notice, and without whose help I could never have achieved my dream for Leon's 60th birthday!

People have now asked if I would like to make this an annual event, and I feel with more support, and sponsors, it can only become more successful, so it is not impossible.

If anyone is able to help and willing to repeat this fun run and walk in 2013, please let me know so we can start planning early in the New Year.

Thank you Fiona, and everyone involved with making her dream a reality, for your tremendous support for people with MND/ALS and the MND/ALS Association of SA.

*Fiona can be reached on 076 678 7691 or via email : [keyterlj@mweb.co.za](mailto:keyterlj@mweb.co.za)*

### Fun Walk in Lahee Park, Pinetown

MND/ALS Association & The Highway Hospice, KZN benefitted from a 5km Family Fun Walk and Aerobics Marathon organised by Kasturi Pillay, our colleague in Durban, in conjunction with the Highway Hospice, which was held at Lahee Park in Pinetown on 3 November. The day included live entertainment, Games & a Jumping Castle, Tea Garden, Raffles and Lucky Draws. Entry fees of R50 included a T-Shirt and a medal. Despite the weather, which was apparently not at its best behaviour, the event attracted a good crowd of participants and spectators and MNSA and Highway Hospice each received an amount of R11,595 !!

We would like to thank Kasturi and Hospice, their helpers, sponsors and participants for their enthusiasm, and for their support of people with MND/ALS.



*Linda & Gary Stewart supporting the MND/Hospice Fun Walk in Lahee Park*



*Natalie (left) with some of her "Iron (wo) Man" friends and participants*

**Natalie van Blek of Johannesburg**

bravely entered the Iron Man 70.3 Race, which she dedicated to a family friend, Sally Trollip who passed away in August 2012 from MND. Natalie approached family and friends to sponsor her by sending them a slideshow, in the hopes of raising funds for the MND/ALS Association in memory of Sally. Natalie received overwhelming support and to date deposits in varying amounts, totalling R5,593.70 have been made to the Association's account.

Natalie completed the race in 6 hours 30 minutes and 55 seconds and was placed 22 out of 136 in her category of ladies aged 35-39.

WELL DONE Natalie ! Thank you for your courageous effort and the generous support from family and friends.

**End of Year Get-togethers:**

In Cape Town Sheila Kendal and Peggy Saxon arranged an End of Year function for patients and a good time was had by all as can be seen in these photos:



*Sheila Kendal, Cape Town MNDA Consultant, in her "Mother Christmas outfit" (left) with standing: Japie de Goede, Anthony Graham, Ron Nosworthy, Eddie van Schalkwyk, Roshanna Langehoven seated: Richard van Zyl, Wilna du Bois, Sylvia Jager*



*Left: Joey Bayley (wife of a past patient Mike Bayley) Ron Nosworthy, Peggy Saxon (MNDA Consultant) and Anthony Graham*

Liz Keth, Gauteng MNDA Consultant, hosted a lunch at her home where members of the support group got together and contributed roast meats, salads, etc which turned the occasion into a real celebration lunch.

### In Port Elizabeth, Gaynor Bishop with her support group



*back row from left:  
Rob Pawson, Bunty Volk, a Volunteer; Dave Nichol, Jean Davis, John Parry, Hospice Volunteer. Front row from left: a Volunteer; Glyn Nichol, a Hospice Volunteer; Mandy Gurr-Snyman (seated), Gaynor Bishop and Joan Fowler (seated).*

## MAIL BAG

**Peter King of Joubertina (Langkloof)** has been living with MND for 2 years and his wife, Anita was recently asked by their congregation to tell them about it. Peter wanted to share this with our readers. (This is an edited version of her story)

Let me give you a little history about us. We first moved into the Langkloof more than 6 years ago, from Cape Town, and discovered this beautiful valley between the mountains. My husband and I love the peaceful valley with its friendly people and its natural setting; we are nature lovers at heart. And we have led a very active life here, we love to restore old buildings, furniture etc, so it was a shock to learn that Peter was diagnosed with MND in February 2011.

We had noticed in early 2010 that my husband was finding it difficult to write, then he started dragging his foot and would trip over things, eventually he had to walk with a stick, this was 6 months before he was diagnosed. He also had a bad fall down the stairs and injured his back, which we thought was the cause of these symptoms. But he put off going to the doctor as long as possible. Eventually he realized that he was not improving and went to see a doctor who recommended some tests in Port Elizabeth and to see a neurologist, who then confirmed that Peter had MND and that there is no cure. This was a shock, but we still could not really accept the diagnosis until he got progressively worse and he had to face the fact that he would have to use a wheelchair as he could not longer walk with a stick. This was about 6 – 8 months after diagnosis.

Now coming up to 2 years later Peter has lost the use of his arms, hands and legs and for almost a year now he has also lost his speech, and swallowing has become increasingly difficult. We have got an electric wheelchair which he uses every day and communicates with his cell phone as he can still move a few fingers to tap out letters and words. Through all of this we have been blessed with support and prayers from our family and friends in the valley and for this we are very grateful. It made me question the real understanding of “living for today”. Ask anyone what they would do if they knew that today was to be their last and many will respond with frivolous and self gratifying events. We only realize the futility of these things when we realize our loved ones will pass on and we should treat them with utmost kindness and love, each and every day. As if it were their last day.

A good life starts only when you stop wanting a better one and start living the one you have got to the fullest. Trusting God won't make the mountain smaller but will make climbing easier. I pray that we will climb all our mountains today and every day. Peter and I try to go out at least once a week for lunch or a drive to Eersterivier, although it takes a great

effort from his side and mine it is worth it, luckily he has a big strong wife!

We are also fortunate to have family from Cape Town, PE and Plettenberg Bay who visit regularly and lend an enormous amount of support, which we are very grateful for. So life can still be interesting and varied. Peter has accepted his illness with courage and determination. The condition of his body varies greatly from early morning when it is rested, warm and relatively comfortable to the evening when it can be tired, awkward and decidedly uncomfortable. His emotions can vary from complete anger and frustration to a serene calmness all in one day. Being in a state of enforced physical immobility yet with full intellect one can understand his frustrations. Still as his caregiver it has been a long difficult journey, both rewarding and frustrating at times.

I am far from “Mother Teresa” status, but I increasingly see my care giving activity as being a major part of selfless service and part of my own spiritual growth. Accepting life as it is and feeling connected with all beings who suffer, I find a more open sense of compassion, and a desire to help in any way that I can. My frustrations pale in comparison to Peter’s but are never the less real. Suddenly I am responsible for maintaining and running this property by myself, seeing to burst water pipes, electrical problems and storm damage just recently. And the huge problem of dealing on a daily basis with a husband who has restricted mobility and other frightening and alarming symptoms. When I find it gets too much to handle I sit in a quiet part of the garden and find the inner peace of realizing that neither taking control of our own lives, nor giving up on it is the answer. By offering control of our life to a loving maker, we can start dealing with our difficulties.

Peter has always had a good sense of humour so when there is a stressful event such as a fall or accident we both look at each other and laugh. Just recently he fell in his bedroom and was trapped between his wheelchair and the cupboard, I had to make a quick decision how best to lift him and put him back in the chair, as I was lifting him he started laughing, saliva was dripping on my head. We both laughed till we cried. After a few hilarious attempts I managed to get him back in his chair.

This spiritual journey that Peter and I share has brought us closer to Jesus Christ. He has shown us the strength to give up all control of our lives, acceptance of the circumstances we find ourselves in, and the maturity to handle it all with serenity.

*Anita King*

## RESEARCH



*\*Article in Thumb Print, magazine of MND Association, UK, Autumn 2012 issue:*

### **Banking on DNA to unlock MND secrets:**

The MND DNA bank is the largest running research project that MND UK has ever funded. Nine years into its conception, it’s seen by researchers as a vital resource to help them unravel the many mysteries of MND.

Kelly Edwards from the research team explains:

“The DNA bank offered an important opportunity for people living with, and affected by MND, to take part in research. By donating a simple blood sample to the DNA bank between 2003 and 2011, individuals have given the research community a valuable tool to understand more about the causes of MND. This is enabling researchers to lead the way to develop new and better treatments. Because of the large size of the DNA bank they have ready access to a significant number of samples from patients with the C9orf72 mistake.”

Although participants knew the research might not help them, they hoped that it would help people diagnosed in the future. After samples were collected, they were stored as both DNA and the cells within the blood that contain the DNA (lymphocytes). Researchers can then use these samples as an invaluable resource to find out more about the causes of MND. Each precious sample is accompanied by supporting data such as the person’s age when the sample was taken, their gender and connection to MND. For participants with MND, extra information was gathered, including their symptoms at the time of giving their sample. Although the samples will remain anonymous, the screen will enable researchers to identify the extent to which known gene factors cause or contribute to each case of MND – C0orf72 for example, or one of the other genes already identified – and which of them still have no known cause, increasing the speed at which the remaining, unknown causes of MND are found. Over 3,000 people took part in the DNS bank study including 1,800 people with MND as well as family members and carers/spouses. Without the participation of patients and their families MND research will get nowhere.

*Also from Thumb Print, MNDA UK magazine:*

### **Championing the rights of People with MND worldwide –**

The Charter sets out the natural rights and the respect, care and support we believe those affected by MND deserve and

should expect. The campaign is winning support at the highest levels. The support is sending a strong message to influential individuals and organisations that people with MND and their carers must have their rights respected and ensure they are given the best opportunity to access the care they need to live the highest quality of life possible, and achieve dignity in death.

#### *Taking the Charter world wide -*

The MND Charter has been developed to champion the rights of those living with MND and their carers to support all levels of campaigning and influencing.

#### *Internationally-*

The vision is 'a world free of MND'. Until this has been achieved we must fight the challenges people living with MND face in accessing good care and support every day. By joining forces with the international MND community it can be tackled worldwide.

The aim is to receive support for Charter statements worldwide, in order for ALL people with MND, no matter which village, town, city of country they live in, to have their rights respected.

### **Excerpt from Winter 2013 edition of Thumb Print:**

#### *Joining the debate on new medicines –*

There is a growing debate about when and how people with rare and terminal illnesses should be allowed access to new medicines. Developing new drugs is a slow process, and they don't come along very often, so it is a challenge to get them through rigorous licensing processes to the people that need them quickly enough.

MNDA of UK have joined the debate by calling for the European Medical Agency (EMA) and policy-makers in the UK to put more effort into developing a model of 'adaptive licensing'. This means giving people new drugs earlier and monitoring their effects closely as part of the licensing process, rather than restricting their availability until the process is complete.

It's a complicated issue. Undoubtedly, any drugs given to someone with MND should be both safe and effective. That said, assessing what levels of safety and efficacy are appropriate can be difficult matters of judgement. We know from the feedback we receive, that some people with MND may make a different judgement to a person in full health.

Brian Dickie, Director Research Development explained: "There are further, more practical, questions about how a new model of licensing would work. How should the process for making drugs available be managed? Who should be responsible for it? At what stage should drugs be made available?. These questions are particularly pertinent to neurodegenerative diseases, where the symptoms may vary widely from one person to the next and drugs being tested may have relatively subtle effects".

The topic has gained new profile following the launch by Les Halpin of the Empower: Access to Medicine campaign, which is calling for easier access to drugs for people with MND and other serious illnesses. Les, who is living with MND, has impressed many people with his determination and passionate commitment to the cause.

Brian added "The time seems ripe to push for adaptive licensing, with a growing debate around the issue and the buoyant state of MND research giving a growing understanding of MND that could lead to easier testing of drugs in the laboratory, and possibly the new biological 'targets' for future drugs".

### **Something of Interest**

Most people in "the world of MND" have heard of renowned scientist, Prof Stephen Hawking who is living with MND. He celebrated his 70th birthday last year but was diagnosed with MND in his early twenties while studying at Cambridge University and has lived with the disease for close to 50 years. He is also a patron of the MND Association in the UK and took centre stage at the Olympic Stadium to launch the spectacular opening ceremony of the Paralympic Games last year. Prof Hawking has signed the MND Charter and said : "People with MND are just normal people with an abnormal condition".

### **Disabled Travel**

- *On the Wheel Guest House, Pretoria*  
has a ramped heated swimming pool and Jacuzzi and day visitors are welcome
- *Au Pear Guest House Newlands, Cape Town*  
is near the home of the Currie Cup Champions !
- *Blackheath Lodge in Sea Point – near the V & A Waterfront*
- *Wind-Rose Guest House, Gordon's Bay*  
is situated on a beautiful farm, overlooking the sea and mountains
- *Pip's Place in the Strand – across the street from the ocean*
- *Baleens Hotel, Hermanus – where you can use the beach wheelchair and swim*
- *Wild @ Heart, Hermanus – self-catering flat for a family holiday*



**Condolences to the family and friends of:**

Kentso Pheko (5/9), Winston Samuel (17/9), Mike Bailey (23/9),  
 Debbie Beytel (6/10), Alpha Meiring (11/10), John Mamabolo (16/10), Molly Tagg (20/10), Trix Thompson (26/10),  
 David Lourens (27/10),  
 Yasmine Salie (2/11), Ives Visagie (11/11), Jean Bricknell (16/11),  
 Erina Koelman (23/11),  
 Jeanette Posthumus (30/11), Gadija Isaacs (3/12),  
 Martin Ferreira (12/12), Hilary Benningfield (15/12),  
 Gary Gray (15/12), Jeremy Hindley (7/1),  
 Jan Janse van Rensburg (9/1), Neville Barnard (12/1)  
 Gustav Jephtha (3/2)

The Kenguru car was designed by a Hungarian company and is still in its final stages of development. Motorcycle type handlebar controls and classified as a scooter. Will we see this car in SA ? [www.kengurucars.com](http://www.kengurucars.com)

**Ben Viljoen, a patient from Pretoria, sent us this snippet of advice in September:**

Each morning I wake up and say to myself:  
 You have two choices today –  
 You can choose to be in a good mood or you can choose to be in a bad mood  
 I choose to be in a good mood.  
 Each time something bad happens,  
 I can choose to be a victim or I can choose to learn from it,  
 I choose to learn from it.  
 Every time someone comes to me complaining,  
 I can choose to accept their complaining or I can point out the positive side of life,  
 I choose the positive side of life.

“Life is all about choices –  
 When you cut away all the junk, every situation is a choice  
 You choose how you react to situations  
 You choose how people will affect your mood  
 You choose to be in a good mood or bad mood  
 The bottom line is : It’s your choice how you live life”.

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

***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.*

**MOTOR NEURONE DISEASE ASSOCIATION of South Africa**

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