

Thumbs UP

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

March 2014



Gaynor Bishop (3rd from right, back row) MND Consultant in the Eastern Cape, with her fellow graduates at a hospice palliative care course they successfully completed in November 2013.

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

PATRON Aviva Pelham (M. Mus.)	NATIONAL CHAIRPERSON Dr. Franco Henning	VICE CHAIRPERSON Sheila Kendal
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ACKNOWLEDGEMENTS

John Hall for producing the design and DTP (desk top publishing) work.
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**A REMINDER !
Annual Membership fee R200 -**

Banking Details:

Motor Neurone Disease Association of SA (or MNDA of SA)
Account No 27 062 913 0 at Standard Bank, Rondebosch
025009

(Please insert your name as reference)

With all the activities of the holiday season now well behind us, time again is marching on to other things but we would like to share with you some of the end of year get-togethers held at various support groups:



From KZN - Some patients enjoying the lunch at the end of year get-together organized by Kasturi Pillay (3rd from left) which was held at her home.



In PE Gaynor Bishop had a yearend party at a local coffee shop with gifts sponsored by a local pharmacy - Patients with their gifts, enjoying the outing.



Sheila Kendal (3rd from right, kneeling) with her Christmas hat and apron, and Peggy Saxon (3rd from right standing, back row) and some patients and carers in their support group having fun at the get-together in Cape Town.

A message from Sheila –

“After loads of thought and consideration, I have relocated to a quaint little town called Albertina. The Motor Neurone Disease Association has not been very active in the Southern Cape so I would like to get to know the patients, families and specialists in the area. My aim is to grow the area, by way of support. I will wholeheartedly miss the patients and

families whom I got to know throughout the years that I have been in the Western Cape, and would like to thank you all for putting your trust in me. I have introduced Joey Bayley into the area to assist MND patients in the northern suburbs and a volunteer Tracey Cuff, a psychologist, who will assist patients in the Helderberg area. She is also available for patients in other areas, where needed.

I am still just a phone call away should you need to chat.”

Sheila will be missed in the Western Cape, but will be a great asset in her new area where she will be setting up a support base for MND patients in the surrounding areas where we were not represented before. We know you join us in wishing her good luck and happiness in her new environment and with her friendly disposition, we are sure Sheila will soon settle in. We hope to have some feedback from her for our next newsletter.

Report Back

In our May 2013 issue we advised of a ****Golf Day** Mark Chapman of Hillcrest was organizing in memory of his late wife, Vereen. MNDA is very grateful and appreciative of all the effort put into that day - It was a big success and very well supported as is evidenced by the R40,602.39 deposited to our banking account.

Also in the May issue, we reported on the “No White Flags – Riding for MND”/Momentum 94.7

****Cycle Challenge (You and Me vs MND)** which Kevin Jordan of Wilgeheuwel had been organizing to raise awareness. This event was also very well supported and together with his wife, Karla, who organized a Women’s Day Brunch, they collected a sum of R100,000 which was deposited to our banking account.

****A really big big thank you to everyone involved, everyone who participated and everyone who supported these events – it is greatly valued and appreciated !**

We would like to mention that although the response to our Christmas card order in the September newsletter was not great, the card sales at Charity Kiosks in the Cape was a huge success and our whole stock was sold out!

DONATIONS

Thank you to each and every one for all donations received: whether it was in lieu of a gift, in memory of a friend or loved one, large or small, monthly or intermittent, or just a kind and generous gesture, all contributions in support of our Association are greatly appreciated and as you might be aware, make up the largest portion of our income. To mention but a few: Byron Athienidis, Ingrid Werth, Retha Nienaber, Family of the late Annemarie Barnard, R Maharage, Family & Friends of the late Mary Veale, Brian Davis, Greenkeepers Golf Society, R Els, Doreen Satusky, Hijl van Wymeersch, Grosvenor Bar (UK), E van Zyl, Rand Merchant Bank, L Chiappini, Family and Friends of the late James Maseko, Cash Focus, A Wienberg, Kurt & Joey Strauss Foundation, Masonic Bowling Association

MAIL BOX



Demisha Pillay, daughter of Kasturi (MNDA Consultant in KZN), read out her letter at their yearend function and we would like to share it with all our readers:

Let me start off my saying that I’m glad to have this opportunity to interact with you all today. As the daughter of a man who had MND, I had a few opportunities of being in the company of other Motor Neuron Disease patients: each facing their own struggles at different stages in their illness. However, it was always quite amazing to see the one thing nearly all of them had in common: a bright smile. And you know, that simple thing, spreads so much warmth amongst people. As a matter of fact, many people have once said that they remember my dad from his never fading smile.

Dhevan Pillay, my father, was diagnosed in June 2006 with MND. He lived with it for 5yrs. And during those 5yrs I’ve learned a lot about life as a whole, and it certainly changed the way I viewed life. It was during that time that I finally understood the saying: **“Time has a wonderful way of showing us what really matters”**. I think it’s only after you have a time constraint put to a loved one’s life that you begin to live life to the fullest and appreciate the simplicity of certain moments that you once saw as “Insignificant”.

My father was a very hard working man - Forever busy and career driven. He was adventurous and took part in many

daring activities; he also loved spending time with family and friends. Hence the difficulty, he endured, in accepting his condition was extremely painful. "Acceptance" was the most difficult part of his journey. I mean, we can all relate to change, on a more subtle level of course. I'd say, 90% of us here today despise change, as we love to stay in our comfort zone and we expect life to remain unchanged and unhampered with. Simple things such as when we have to change our seating place at work or school can make us feel very uncomfortable and irritable for a while. Well imagine having to accept the fact that your whole body is changing rapidly and in turn your whole lifestyle.

For five years every single day my family and I fought the struggle with my father. Not only did this disease affect him, it affected my whole family in some way. We were a very closely bonded family and it felt as if we were enduring everything with him. As the years passed by, the four of us: my two siblings, mother and myself; developed specific duties in helping my dad with his daily activities.

My eldest sibling, **my sister**, was good at feeding him through his feeding tube. The feeding tube is a small rubber tube which is surgically inserted into the stomach via a small incision. The tube was a good aid in feeding him all the nutritional meals he needed in pureed form, as he was no longer able to swallow food due to the muscle loss in his esophagus. My sister was also the one who drove him around and took him out of the house frequently to enjoy the places he loved being at.

My youngest sibling, **my brother** Theo, is the replica sport fanatic of my dad. So the two of them always dominated the TV room. Theo was in charge of changing the television channels for him, feeding him snacks and just keeping him company while everyone else was busy.

And **me**? I was the communicator. As time went by, my dad could no longer speak, and the very few words he was able to say were always slurred and difficult to understand. It took a lot of patience to figure out the things he tried to say, as sometimes it would take about 45min to understand certain phrases and then put them together to convey the total message.

However being the one who understood him was a privilege to me, because he always had such valuable and wise things to say; his impeccable humor was also something no one wanted to miss out on!

Communication was one of the most challenging struggles we faced - and I'm sure that many MND patients would agree with me on this. It was frustrating, especially for my father, because it tired him out when he continuously had to repeat himself to make us understand what he was saying. One of his colleagues designed him communication charts. These charts helped us substantially with communication. Copies of the charts have been made and passed on to other patients.

Last but not least, **my mother** Kasturi Pillay, who took the bulk of the responsibility. From the preparation of soft meals, to the bathing and nurturing. Her responsibilities were very strenuous and tiring on her. Two years after my dad's passing she decided to be an active member of the MND association and Sherwood Highway Hospice in Durban. Since she learned how to care for an MND patient she wanted to share her knowledge and experience with other patients. My mother now runs the MND support group in Durban, and at present there are about 12 patients a part of it. She does home visits to at least two of these patients every week, to discuss the difficulties they are enduring and help find solutions to their problems. She gets great fulfillment and pleasure in trying to make a difference in people's lives.

The Motor Neuron Disease Association of SA is a nonprofit organization, of which the head branch is based in Cape Town and together with all MND Associations globally, strive to ensure continuous research is conducted to finding a cure, as well as help in empowering patients to live their dreams and lead as fulfilling a life as possible.

I guess I will never understand the full extent of the hardships and turmoil you may be facing as patients; however I do understand what it's like to live with someone who has MND. I have seen and lived through all the phases, and from that I can say that I have become stronger as a person. Although we saw my dad at his worst we viewed him as a man of much dignity and strength for how he carried himself and for the positivity that exuded from him. So I hope that you all will never lose hope, as hard as that may seem. I know that there will be times when you feel like you just cannot get through another day; and during those times I pray that there will be someone to remind you that there will always be people out there who are willing to carry you through those times. The positivity of your mind can shine through you, not always via spoken words but by your never fading smile.

Thank You.

Demisha Pillay

Do not educate your child to be rich
Educate him to be happy so when he grows up
He'll know the value of things, not the price

An encouraging and inspirational story which featured in the February 2014 issue of "Muse" Pinelands (Cape Town) Community Magazine:

51 years ago, a baby girl born with her internal organs being misplaced because of a hole in her diaphragm, underwent emergency corrective surgery, but complications during the life saving operation resulted in brain damage affecting the motor neurones. She remained in hospital for five months and her family was told that she probably would not live long and would never be able to walk. In spite of the medical team not holding out much hope, the love, dedication and support of her family encouraged her. Although confined to a wheelchair she keeps herself busy typing old-fashioned love stories and is a great believer in love that comes from the heart. An *inspirational poem from a St Giles booklet is a favourite with her and she feels we should accept one another, without judgement, just as she has accepted her physical disability and the pain that comes with it.

*The poem -

It was but a Friendly Smile
And little it cost in the giving
But it shattered the night like the morning light
And made tomorrow worth living

It was a Kindly Word
A word that was lightly spoken
Yet not in vain
For it chilled the pain
Of a heart that was nearly broken

It was but a Helping Hand
And it seemed of little availing
But its clasp was warm
So it saved from harm
A brother whose strength was failing

RESEARCH



Inherited MND – To test or not to test ?

*(Taken from the Autumn 2013 issue of "Thumb Print", magazine of MNDA, UK)**

A small portion of people living with MND (5-10%) have a family history of the disease. This rare form of MND is sometimes known as familial, or inherited, MND.

Information has recently been reviewed and updated, to include genetic testing. Samantha Price from the research team* explains:

When a neurologist diagnoses MND, they ask a number of questions about family members to find out whether there is a family history of the disease, including any sign of speech or mobility issues. In most cases of MND, the direct cause is not known and is thought to be a combination of subtle genetic, lifestyle and environmental factors.

In a small number of cases (5-10%) there is a strong family history of MND. This is known as inherited MND, in which genes play more of a crucial role in the disease.

Our genes are made up of thousands of DNA 'recipes' that translate into proteins. These proteins determine everything from the colour of our eyes to how motor neurons grow. Sometimes we inherit a mistake in our DNA that damages the final protein. This mistake can, in the case of inherited MND, be harmful to motor neurons and may be passed down from one generation to the next. While inherited MND is extremely rare, it understandably creates concern for family members.

A genetic test may enable family members to find out whether you carry one of the MND causing genes and are therefore at increased risk of developing the disease. Choosing whether or not to have a genetic test is a very personal decision.

A neurologist or genetic counsellor will fully explain the possible results and their implications. This is known as genetic counselling and, although sensitive to the emotional aspects of the situation, is not a form of psychotherapy. A genetic counsellor will state the facts clearly, and give accurate information on the implications for the family. This includes drawing up a family tree, providing information, discussing any questions or concerns and available options.

Genetic Testing

Some people living with inherited MND, who do not know which gene has caused them to develop this disease, may not wish to have a genetic test as it would not open up any new treatment options. However, others living with the disease choose to have a test so that family members can then be tested for the gene and discover whether they have an increased risk of developing inherited MND.

A genetic test consists of taking a blood sample, which is then sent off to a genetic laboratory. The blood sample is then screened for MND-causing genes that have been identified through research. An individual is only put forward for genetic testing if there is a strong family history of MND and they wish to be tested. Genetic testing is accompanied by genetic counselling through a genetics service.

Consultant clinical geneticist, Dr Pradeep Vasudevan, Leicester Genetics Service, explained the process: "If you have a family history of MND you can discuss this with your GP or specialist consultant who will then refer you to the regional Clinical Genetics department. Following referral to a consultant, a genetic counsellor or nurse may contact the family to collect background information and in some circumstances will also provide genetic counselling at the hospital or in the home. This is where patients or relatives at risk of an inherited condition are advised of the consequences (eg other family members that the result may affect).

For most individuals, a clinic appointment with a clinical geneticist is then organized (and any follow up appointments as necessary) to allow examination, investigations and further management. A detailed summary letter is also sent to the family, the referring clinician and or GP".

To test or not to test ?

A patient who has inherited MND, recently decided to have a genetic test to find out which gene causes the disease : "My father died of MND around 25 years ago and his brother died two months after of MND. When this happened I didn't know much about what MND was and I was told it wasn't inherited. Due to this I wasn't worried and didn't imagine it would happen to me in the future, or even think about it again until it 'hit me'. Now that I know MND can be inherited I have chosen to have a genetic test to find out what gene could be responsible for causing my MND. When I get the result I can then decide whether to tell my family and it is then up to them if they wish get tested. My sons who are both in their thirties, do not wish to know or have a genetic test but are prepared to help out in any research".

Important things to know:

Inherited MND is rare (5-10% of total MND cases).

A diagnosis of inherited MND is only given if there is a strong family history of MND.

Genetic Testing

Genetic testing is only available at present for the MND-causing genes SOD1, C9ORF72, FUS and TARD-BP.

Genetic testing is only available for unaffected family members over the age of 18 years.

Clinical Genetics provide a diagnostic service and genetic counselling for individuals or families with, or at risk of, genetic conditions.

What are genes and proteins ?

All cells in our bodies, including motor neurons, contains 23 pairs of chromosomes that hold all our genetic material in the form of genes. Everybody inherits two copies of each gene from their parents. These genes provide the 'recipe' to make proteins. These proteins can then perform functions within our cells such as getting rid of waste materials from inside the cell. If we inherit a mistake in a gene, this can cause the resulting protein to be damaged and unable to perform its role within the cell. This is what happens in inherited MND."

*MNDA of SA would like to point out that currently the testing cannot be done in South Africa,
but testing is possible by sending the blood overseas.
Cost is ±360 – 900 GBP, depending on which mutation is present*

(From a "ALS Worldwide" Booklet : A Paradigm Shift in ALS/MND Clinic Care: The Best Practices from the Patient Perspective)

Symptom Relief : Alternative Opportunities

The lack of successful research on behalf of the ALS community is daunting. Nothing close to a cure exists at this time because the disease itself is not fully understood. Amyotrophic Lateral Sclerosis and Motor Neurone Disease are umbrella names that are suspected to encompass many different diseases. Today, more than eighteen different genes have been identified as being involved in ALS/MND. As a result, the variations in gene involvement are limitless. Symptoms vary from patient to patient. A particular drug being clinically tested may have benefit for one out of five subjects but it is nearly impossible to detect which patient will experience benefit before taking the medication.

For all of these reasons and more, genetic testing of patients has become essential before the clinical trial of a drug. It may be years before genetic testing is refined and fully relevant for the ALS/MND patients alive today, although efforts are already underway to code RNA/DNA and genetic profiles into individual patient histories. These can be matched with individual responses to medications and other treatments.

Until research efforts are able to fully embrace genetic testing, a new approach for medications needs to be developed to generate a sense of hopefulness for the ALS/MND patient community. If an FDA approved drug exists for other conditions that has the potential for minimizing symptoms or providing other support, particularly if little or no adverse reactions are anticipated, it should be prescribed. If there is a reasonable consensus by the medical community that a particular medication can potentially extend the length and quality of life, it should be offered to patients. If empirical evidence exists from patients or practitioners, then a reasonable consensus by the medical community should be enough to provide patients the opportunity to try what is currently available to them.

"While we await the results of scientific endeavor to deliver better neuroprotective therapies for slowing the disease course in ALS, much can be done to improve troublesome symptoms".

Pamela Shaw, MD, PhD

Sheffield Care and Research Center for Motor Neurone Disease (SITraN, Sheffield, UK)

Condolences to the Family and Friends of:



Willem Kriel (20/9), Yvonne Roberts (22/9), Daniel Kok (24/9), Henk Boshoff (30/9), Valerie Roman (4/10), Aubrey Burger (4/10), Silvy Beukes (4/10), Willie Cornelius (7/10), Yvonne Reid (30/10), Dehlia Rezek (3/11), Marion Marx (5/11), Monnie Rowjee (8/11), Sandy van Gysen (28/11), Alpheus Motsepe (3/12), Lourens Badenhorst (12/12), Katherine Langford (19/12), Johannes Heunis (28/12), Franna Coetzee (29/12), James Maseko (12/1), Peter Emslie (16/1), Marian Jack (21/1), Jess Lambert (27/1), Mandy Barrington (6/2), Arlindo Esteves (6/2)

**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.

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