

Thumbs UP

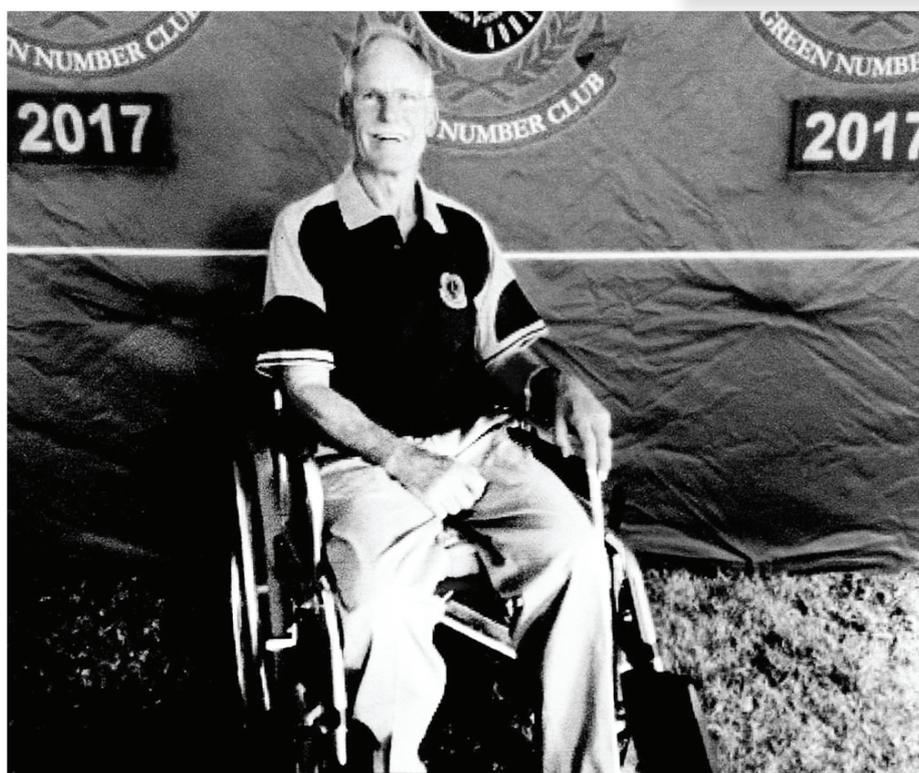
MNDALS

Association of South Africa

NPO 155-413

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

September/October 2017



*Piet Vorster :
Guest of honour and member of the "Green Number Club" at Comrades 2017*

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

SECRETARY

Rina Myburgh

ACKNOWLEDGEMENTS

John Hall for producing the design and DTP (desk top publishing) work.

Logo Print (Maitland) for the printing of our magazine



NOTICE IS HEREBY GIVEN
OF THE
24TH ANNUAL GENERAL MEETING
OF THE
MOTOR NEURONE DISEASE ASSOCIATION OF SA
TO BE HELD ON
FRIDAY 20 OCTOBER 2017 AT 11.00 am
GROUND FLOOR, WBHO HOUSE, GLEN ROY,
PINELANDS

TO FACILITATE SEATING AND CATERING ARRANGEMENTS

PLEASE R.S.V.P.

BY PHONING THE OFFICE ON 021 531 6130

OR E-MAIL ON mndaofsa@global.co.za

BY LATEST FRIDAY 13TH OCTOBER 2017

Global Awareness Day

As mentioned in our previous Newsletter, “MND Global Awareness Day” was on 21 June and the call was “cheers” and “raise a glass” ! To end off a committee meeting held at the time, our Patron, Aviva Pelham truly answered the call by presenting a bottle of sparkling wine, which was served in beautiful little glasses which belonged to her late mother, Santa of “Santa’s Story” fame.



*Back row from left : Rina Myburgh, Sheila Kendal Slabber, Elsabe Burger, Aviva Pelham (Patron)
Front row from left: Joey Bayley, Peggy Saxon, Tracey Cuff*



Edith Potgieter (left and seated left in the 2nd photo) Consultant in the Gauteng area, and with a group of family and friends “raising their glass” for MND Global Awareness Day



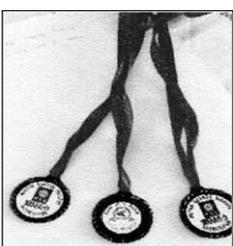
Victoria Goodstein, also a Consultant in the Gauteng area (seated centre) at a MND support group meeting where members wrote notes of “cheers and salutes” to people and things they care about.



Kasturi Pillay, (2nd from left in first photo and 2nd from right in last photo) MNDA Consultant in KZN with patients, family and friends at Global Awareness Day

In Kasturi’s words:

“Our Global Awareness Day was acknowledged at the Highway Hospice in Durban, with all patients with terminal illnesses coming together. I gave a talk on this special day and brought awareness to all. Lots of questions were asked. A Social Worker at Highway Hospice also spoke about the aim of Hospice, especially to our MND patients and mentioned that their sole aim was to bring comfort and offer support to people with incurable diseases, and the high standard of palliative care that is offered free of charge. MND patients were heartened and felt they had a second home to turn to when they needed to give their families a rest and misconceptions of Hospice were now cleared up after some discussion.



Each patient was given a medal to motivate them on the road they are now on and to show they are coping on this hard and tough journey with MND and Cancer. They were very chuffed and it brought smiles to their faces. It was a lovely day and all patients had a hot meal and refreshments before they left.”

Giant Leap Workspace Specialists, combined goodwill and charity by donating 6 commodes and a wheelchair to MNDA as a token of their support for Mandela Day.

Patient Kevin Jordan, who has his own website www.YOUandMEvsMND.co.za and is a good “ambassador” for MNDA with all the awareness and fundraising events he organizes, took delivery and duly had a “test drive” in the wheelchair, below.



We are very appreciative of Giant Leap’s generous gesture which certainly boosts our stock of equipment we have available for loan to our patients.

..... We would like to thank all our donors, benefactors, family and friends for their support over the past year – please be assured that your contributions are greatly appreciated. Without your loyalty, generosity and kind gestures we no doubt would have more stressful times !

Thanks also go to

John Hall who takes care of the layout of “Thumbs Up”, Logo Print who does the printing, Peter Rosmarin who checks our books before it goes to the auditors, and David Cudlipp of FMG Inc, who conducts the audit. Many thanks to you all for your time and for supporting us again this past year.

We wish you a peaceful and prosperous 2018 !

*Coming together is a beginning
Keeping together is progress
Working together is success*

~ Henry Ford ~

NEWS

Dave Jack writes a blog titled “**the marathon.co**” which deals with his experiences and the people he had met and things he had done and seen in his relationship with the Comrades Marathon which goes back to 1956 when he was only 9 years old.

His blog of 28 June 2017, is about the winner of the Comrades Marathon in 1979, Piet Vorster, who not only won the race but broke the record while doing so.

These photos of Piet in action comes courtesy of Dave’s blog, and we urge you to go to “the marathon.co” to read about the interview Dave recently had with Piet.



Piet Vorster : 1979 Comrades winner

Piet Vorster was diagnosed with MND some three years ago and is today in a wheelchair and in need of constant care.

Dave has known Piet since the days when he won Comrades and when approached, Piet had no hesitation in agreeing to the story of his win featuring in the blog. Dave comments: "I have had a couple of very nice comments from people who knew Piet in his running days saying what a really great guy he was and I can assure you that as someone who visits him regularly, and who knew him years ago, he is still a great guy who is not allowing MND to affect his outlook on life."

Dave Jack in his blog, suggests to readers that if they wished to make donations to MNDA of SA to do so with the reference : *Piet Vorster – Comrades Marathon*

RESEARCH

In our May/June 2017 issue of Thumbs Up, we advised of the drug Radicava (also known as edaravone), as treatment for MND.

The following articles are excerpts from the Summer 2017 issue of "Thumb Print" - Magazine of the MND Association of UK:

"New MND drug licenced in USA to mixed reviews:

At the beginning of May, the Food and Drug Administration (FDA) in USA announced that they had licenced a drug called Radicava (also known as edaravone) for the treatment of MND. This is the second drug that alters disease progression the FDA have licenced (riluzole being the first drug more than 20 years ago).

The drug was given to 69 people with ALS (the most common form of MND) by intra-venous infusion, another 68 people received a saline intra-venous infusion instead, as a comparison group. People were given six cycles of the drug. In each cycle they received the infusion every day for nearly two weeks, and then a two week break. In total, people were on the drug for around six months. The people who took part in the study were very carefully selected based on their early MND symptoms. It is estimated that this would be equivalent to approximately 7% of people with MND in Europe. The effects of the drug were measured by a comparison of any changes in symptoms between those who received the drug and those who didn't. A small but statistically significant beneficial effect of edaravone was seen.

While it is exciting news that a second drug has been licenced to treat MND after two decades of trials, it is currently uncertain what this means for people with MND. Questions remain about how much difference it would actually make and how many people with MND would see an effect. There are also question marks over whether there is enough evidence to licence the drug in Europe (according to regulatory requirements). These are questions that are actively discussed with neurologists at the moment.

Updates on edaravone will be provided in future editions of Thumb Print. Edaravone articles will be posted on the research blog (www.research.wordpress.com search 'edaravone').

Any questions about this can be directed to the UK Research Development team on research@mndassociation.org

“How do they choose what research projects to fund ?

In order to find effective treatments for MND, researchers first have to understand exactly what causes the disease. Every year a large number of funding requests are received from MND researchers for their specific projects. Each application is carefully considered by the Research Grants team and specialized Research Advisory Panels, made up of 10 MND scientists and clinicians. The applications are scored at the end of the meeting and the highest-scoring projects are given to the MND Association's Board of Trustees for final approval. (Abridged)

“Projects that are being funded:

- *Dr Manolis Fanto (Senior Lecturer at King's College London)*
- *Fruit fly model for Annexin gene causing ALS*

Mutations in a gene called ANXA 11 are associated with about 1% of MND cases. In order to understand why mutations of this gene affect the functionality of motor neurones, we first need to understand its normal function. Dr Fanto and his team will study the fruit fly equivalent of the ANXA11 gene and investigate how mutations may damage the neurones. Findings from other studies show that mutations of this gene are likely to lead to defects in autophagy, a process by which a cell gets rid of its waste. If successful, the project may lead to ways of testing potential therapies.

- *Dr Tennore Ramesh (Lecturer at the University of Sheffield)*
- *Zebrafish model to identify novel therapy*

Mutations in the C9ORF72 gene are known to lead to death of motor neurones. One of the reasons that this might be happening is because RNA, a structure important for translating our genetic information into proteins, is created with toxic properties. Dr Ramesh and his team will use zebrafish with the C9ORF72 form of MND to test a new therapeutic molecule that is thought to reduce the toxicity associated with C9ORF72 mutations. Using zebrafish is an efficient and inexpensive way to test potential therapeutic compounds.

- *Dr Chris Sibley (Safra Research Fellow at Imperial College, London)*
- *Identifying new TDP-43 associated RNAs in ALS*

Finding MND biomarkers (ie fingerprints) is crucial to diagnose a patient faster and to reliably track MND progression over time. By establishing a measure that would reliably inform us about the presence of MND and its current stage, researchers can use it in clinical trials to observe improvements after taking a specific drug. Dr Sibley and colleagues identified a specific molecule that they believe is present at abnormal levels in about 98% of people with ALS, the most common form of MND. This project will focus on further investigation of this molecule, which could eventually lead to a development of a new biomarker.

- *Dr Alexander Whitworth (MRC Programme leader at the mitochondrial biology unit, Cambridge)*
- *The role of axonal RNA transport in MND*

Correct functioning of RNA, a template crucial for creating new proteins, is important for survival of all cells. However, in MND, mistakes in handling RNA can lead to the death of motor neurones. Dr Whitworth will use microscopic techniques to investigate how RNA moves along motor nerves, as it has been suggested that their excessive length can affect the way RNA is transported along these nerves. These analyses will be first done in laboratory dishes with individual cells, and followed up by investigations of the affected mechanisms in fruit flies. Findings from this study can increase our understanding of what goes wrong in motor neurones and create a platform for new, more effective therapies.

- *Dr Jean-Marc Gallo (Reader at King's College London)*
- *Identification of pathogenic mechanisms of C9ORF72*

Mutations in the C9ORF72 gene have a negative effect on many normal functions within a cell, leading to development of MND. The aim of Dr Gallo's project is to investigate which mechanisms cause disruptions in the cells as a result of the Mutation. Dr Gallo will recruit a specialist to use mathematical and computational analyses to work

out the most likely mechanisms that are altered in MND as a result of the mutation. Findings from this project will provide more information on the toxic mechanisms involved in MND and could identify new targets for potential treatments.

- Dr Han-Jou Chen (Postdoctoral researcher at King's College London)
- Heat shock response pathway for ALS therapy

Dr Chen's previous work has shown that by increasing levels of the heat shock protein (HSF1), the tendency of the TDP-43 protein to clump together, accumulate and cause death of motor neurones, decreases. HSF1 was already found to be reduced in spinal cords of people with MND, suggesting that lack of HSF1 contributes to accumulation of TDP-43. In the current project, Dr Chen will apply a specialized gene therapy technique in a mouse model to investigate the effectiveness of increasing HSF1 levels on reducing disease symptoms. The findings could lead to identification of new drugs that might act on HSF1, giving rise to a potential treatment."



Condolences to Family and Friends of:

Bev Vermeulen (7/5), Farried Williams (25/5), Sakunthala Chinnappa (28/5), Jeanette Sapsford (29/5), Stuart Owen (31/5), Turlough Kordom (5/6), Susanne Taylor (12/6), Ralph Bender (25/6), Clive Naidoo (29/6), Vivienne Welcome (8/7), Priscilla Hall (11/7), Ilse Westphal (17/7), Joyce Leseane (6/8), Lynne Manderson (12/8)

End of Year

Although it was a good way of spreading awareness, we have opted not to order any new Christmas Cards this year. As mentioned before card sales were dwindling and last year's sales did not cover the costs incurred. Should any of our readers wish to order cards, we do have some left over from last year and an order form is attached. Thank you to our loyal "buyers" who have supported us over the years.



JOYOUS CHRISTMAS WISHES TO OUR PATIENTS AND READERS
WHO CELEBRATE THIS HOLIDAY
AND
A HAPPY AND PEACEFUL 2018 TO ALL !

~~~~~  
*A student at a Management School came up to a pretty girl and hugged her without any warning  
The surprised girl said : "What was that ?"  
The guy smiled at her and said : "Direct Marketing"  
The girl slapped him soundly  
"What was that?" asked the boy, holding his cheek  
"Customer Feedback"  
(Real Deal June 2017)*

**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**

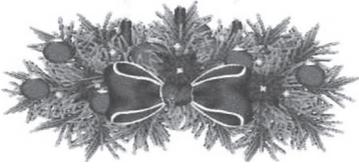
*Your Will can be a convenient vehicle for making a charitable gift of a lasting value. Please consider MND Association as a living memorial for a loved one. Many people support the work of the MND Association of South Africa through bequests from their Estates.*

MOTOR NEURONE DISEASE / AMYOTROPHIC LATERAL SCLEROSIS ASSOCIATION OF SOUTH AFRICA

MND Association of SA  
P.O.Box 789 Howard Place 7450  
Tel: 021 531 6130 or 072 326 4477  
Fax: 021 531 6131  
E-mail: mndaofsa@global.co.za  
www.mnda.org.za

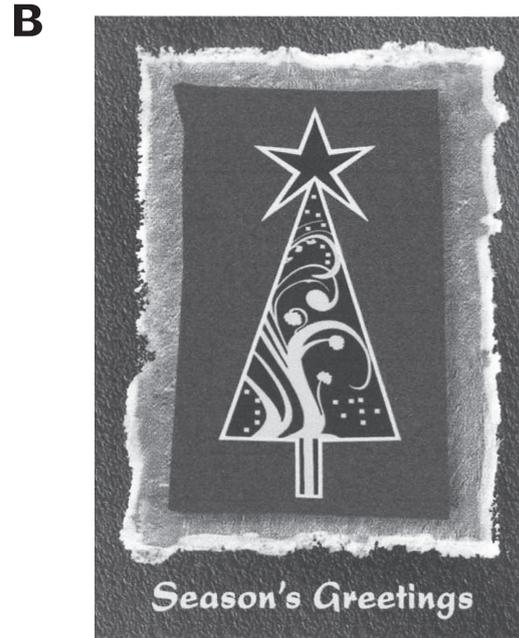
**Banking Details:**  
MND of SA  
Account No 27 062 913 0  
Standard Bank Rondebosch 025009  
Swift Code : SBZAJJ 025009

# ORDER YOUR CHRISTMAS CARDS NOW



**A**  
White background, with blue and silver tree and silver stars.

**B**  
Shades of Blue background with outline of tree, decorations and wording in silver.



*These images of Christmas cards are not to scale*

## ORDER FORM

Please complete this order form and return (via post, fax or email) with cheque or proof of payment to:  
 MND/ALS Association of SA, PO Box 789, Howard Place 7450.  
 Internet Payments: Account No 27 062 9130 at Standard Bank Rondebosch 025009  
 with name and "cards" as reference.  
*All cards require standard postage.*

Name ..... Telephone No .....

Postal Address .....

..... Postal Code .....

..... Pkts A Blue and silver tree and silver stars on white background  
 (5 cards & envelopes) @ R25 per packet R .....

..... Pkts B Silver Tree on shades of blue  
 (5 cards & envelopes) @ R22 per packet R .....

Cost of Cards R .....

Add postage 1 pkt: R4; 2-5 pkts: R8; 6-10 pkts : R10 R .....

**Total Payment** R .....