

# Thumbs UP

**MNDALS**  
Association of South Africa  
NPO 155-413

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

December 2023



*The MNDAs held its AGM in its central Pinelands office in November, a rare and rather special opportunity for our patient advisors from Gauteng, KZN and the Western Cape to get together and exchange news, views and ideas, and to get to know one another a little better: offering one another support to strengthen their capacity to offer their patients and patient-families support.*

*Seated from left: Kasturi Pillay (KZN), Esmé Paulsen (Cape), Helene Hattingh (Gauteng) and Romany Sutherland (Cape). Standing from left: Elizabeth Konstabel (Cape), Wilma Bezuidenhout (Cape), Daleen Bouwer (Gauteng), MNDAs vice-chair Sheila Slabber (Garden Route and Eastern Cape, outlying areas of SA), Louisa de Wet (Cape) and Chantelle Wynne (Cape).*

*[See pg 3 for why these ladies are so special.]*

## **MISSION STATEMENT of the MNDAs of SA**

“To provide and promote the best possible support for people living with Motor Neurone Disease, their families and carers and to raise public awareness.”

MNDAs of South Africa is a member of the International Alliance

**PATRON**  
Aviva Pelham (MMus)

**NATIONAL CHAIRPERSON**  
Prof Franco Henning

**VICE CHAIRPERSON**  
Sheila Kendal Slabber

**SECRETARY**  
Wendy Toerien

## **ACKNOWLEDGEMENTS**

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

## FROM THE OFFICE

### Section 18A certificate from the MNDA allows donors to claim a tax deduction

The Motor Neurone Disease Association, as a registered Public Benefit Organisation, is able to provide donors who are registered tax payers with a Section 18A certificate allowing them to claim a tax deduction on the amount donated to the Association.

To provide the Section 18A, the MNDA requires the following details of the donor: full name, physical address, ID number and tax number. The latter two requirements are a recent addition to the information that the MNDA needs to provide on the certificate. The certificate will also reflect the amount/s donated and the date on which the monies appeared in the Association's bank account.

Certificates can be requested annually via email to [mndaofsa@global.co.za](mailto:mndaofsa@global.co.za).

Donations to:

Motor Neurone Disease Association of SA  
Standard Bank Rondebosch  
Current/Cheque Account Number 27 062 9130  
Branch Number 025009  
Swift Code: SBZAZAJJ (for international donations)

### Equipment for sale

A Cape Town MNDA patient is offering an Acorn chair lift for sale that is no longer needed. It is as good as new, in full working order, but the rails obviously need readjusting to suit any new location. Please contact partner Tobias Linders on Cell 084 679 9829 or email [tdlinders@gmail.com](mailto:tdlinders@gmail.com) for more information.

A Durban patient is offering a brand new Bescare suction unit for sale. Costing around R7 500 new, the asking price is R3 000. Please contact MNDA KZN patient advisor Kasturi Pillay on Cell 083 777 2029 or email [kasturipillay0@gmail.com](mailto:kasturipillay0@gmail.com) who will put you in touch with the patient's family.

### We remember...



*The blue cornflower, which can withstand frost and drought, is the international flower of courage and hope for motor neurone disease.*

Our thoughts are with the families of Chris Hutchings (4/10); Elaine Heywood (19/11); Prof Rashid Bhikha (24/11); Paul Bannister (1/12); Sherry Dwyer (4/12); André Visser (5/12); Malcolm Lundy (6/12): may they rest in peace. The family of Diana Geldenhuys (9/3) also remain in our thoughts.

### **Gratitude to our donors and a desperate appeal for support**

The Motor Neurone Association of SA would like to express its heartfelt gratitude for the support of a few particularly special people in this edition of *Thumbs Up*.

Firstly, we received a very generous contribution from an unknown donor 'in memory of Diana'. We unfortunately cannot be more specific, although we think we know the Diana remembered, and hope our gratitude finds its way to the donor somehow.

To one of our new Gauteng members, Mr Kobie Botha of Pretoria: thank you for your unexpected and generous contribution. Also to daughter, Dr Lienka Botha, of Cape Town, for her kindness and expertise in offering help going forward in matters technological and general to broaden the MNDA's reach and raising of public awareness.

Our thanks go to the Jennings family for their donation and to Debbie Willis (in memory of her sister Veronica Oxche). Also, to Dan de Wet of Hermanus: Dan, thank you for your generosity in donating a particularly high-end, expensive walker and Aqua lift for use in the bath; our thoughts are with you and please know that the equipment will mean the world for the next person to whom it will go out on loan at no charge.

The MNDA welcomes all equipment and devices, new and used, as well as any items not used (adult diapers, PEG food powders, feeding syringes etc) that we can pass on to other patients, free of charge, to help them in their day-to-day lives. Again, as always, we thank those extra special people who make regular/monthly monetary donations to the MNDA. We see you.

Finally: the MNDA, as an NPO (No155-413) with minimal and dwindling resources, is working hard to raise its visibility and redouble its efforts to find funds to continue its dedicated service of the past three decades, free of charge, to people living with MND/ALS, irrespective of ethnic or income group.

Several applications to the National Lotteries Commission over the past decade have failed: reasons given for rejection range from monies being unavailable, to the MNDA's service not fitting the stated 'theme' for that specific year. The increasing and well-documented reports of fraud and the National Prosecuting Authority's attempts to fight corruption and mismanagement surrounding the awarding of funds by the Commission are followed with some despair.

The MNDA will make another application early in 2024.

The MNDA is finally running out of funds as donations and bequests drop off: we have minimal overheads, maintaining a single office, a storage unit each in Pretoria and Cape Town for our equipment-for-loan free of charge, with our dedicated and compassionate patient advisors, retired or semi-retired ladies, earning a pittance (claiming an hourly and mileage amount each month as a small, supplementary income).

The days of volunteering are long gone: there are few with the necessary nursing/social work background and sheer compassion willing (and able) to do what these ladies do. They are to be lauded. The MNDA is lucky to have them. They 'are' the MNDA.

To end off, our gratitude to auditor David Cudlipp of Friedberg Miller Gruft Incorporated for his annual assistance (pro bono), and to long-time DTP designer John Hall for always being there to massage the newsletter into shape (also free of charge).

## FROM THE OFFICE

### **‘Diary Entries of Mark’ documents thoughts and experiences of Sea Point MND patient**

South African stage performer Mark Hoeben, one of South Africa’s leading tango dancers and teachers diagnosed with MND/ALS in December 2020, has been documenting his ‘Life Post-diagnosis’, sharing his poignant, philosophical, practical, honest, often outspoken and many times humorous reflections with family and friends via periodic Whatsapp postings. He is tackling life with MND head-on (see December 2021 and May/June 2022 Thumbs Up on our website [www.mnda.org.za](http://www.mnda.org.za)).

Mark hopes his thoughts, regularly included in our quarterly newsletters, will resonate, inform and entertain (why not!). His ruminations may also bring solace to MND sufferers in feeling less alone in their struggles with living with the disease, and help MND families and carers better understand the feelings and needs of their loved ones.

### **More Diary Entries of Mark: Up to 30 May 2023**

**Amid dealing with the practicalities of coping with living with increasing immobility during this time, Mark records how he has remained as active socially as possible, reflecting on ‘my joys, tears and wondrous events, achievements and people, family and friends, that have filled me with many feelings’:**

‘I attended a DES (Department of Emotional Support) dinner. The DES is a treasured group of early tango students who have buoyed me up over many years and who were pivotal in arranging and getting me to the hospital pre-diagnosis. They clubbed together with others to oversee and pay for the remodelling of my bathroom for this new challenge, and arrange wonderful, heartfelt dinners or lunches periodically.

‘I’ve gone on a few art dates and had many lunches and tea, coffee and cake dates at which I’ve shared my challenges and theirs, confirming my belief that we all have obstacles and triumphs and how we deal with them is what develops our characters.

‘I’ve seen some theatre – both inspiring and tedious. I’ve hosted monthly tango socials, planned and taught [with a colleague] exciting and challenging tango classes and workshops on dancing, connecting and musicality to a slowly growing group of enthusiastic and hugely attentive dancers. I’ve attended vital Pilates sessions with a master teacher who slowly and patiently has strengthened my core, chipping away at my fear and my body’s unwillingness to keep moving. I’ve persisted, mostly, in performing daily Pilates bed stretches and careful strengthening exercise; worked on vocal clarity and breath capacity building; had weekly acupuncture sessions.

‘My car is being readied for sale for as much as we can get for it. It’s been a wrench giving up my late-in-life choice car, “El Toro Rojo” (the Red Bull), but I’m OK with it; now. I said a fond farewell to it recently and I’ve moved on from it.

‘I’m so happy that I can still manage alone and live alone.’

### **Mark reflects on planning ahead for the challenges to come:**

‘I realised [in December 2022 – two years after diagnosis] the stress and worry that my family are feeling about being the end-stop for my full-time care eventually. Their concerns were that I seemed reluctant to face facts in the way they do and seemed to be floating blithely along, unconcerned [about the future] and only experiencing my day-to-day struggles, not facing up to the realities of my decline.

### 'Diary Entries of Mark' contd...

'Quite the reverse: I had been presenting a calm exterior as I dealt and deal with the day-to-day challenges; but from mid-December [2022] I made plans quietly to begin making my end-of-life decisions. At first I decided to use no life-prolonging interventions such as a feeding and liquid medication tube [percutaneous endoscopic gastroscopy (PEG)], in order to hasten my end and be no cost and trouble for my family. However, once my GP shared how painful and awful a death it would be once unable to swallow and drink, I pulled myself together and began setting down my wishes and made plans that are necessary and will free my family from that stress.

'I have been assisted by someone who had walked this path with her late husband and pointed me in directions to make these decisions without emotion and without burdening my family who have and will have enough grief at the end. I was pointed to and had a few face-to-face meetings with a financial advisor who will charge very little to access a life policy I had taken out years ago and consolidate my money into a separate account for the payment of full-time care when it's needed. I've updated my will and appointed an executor of my "vast" estate.

'I have met a few times with a former theatre colleague who is now a palliative care worker to make my end-of-life decisions and put my medical, funeral and memorial wishes down. I've appointed medical proxies who will speak for me and share my decisions and wishes when I can't anymore. As a dance teacher, I'm sharing my insights and experiences while I still can. I'm not panicking, but am aware that time is fleeting and limited.

'I've made inroads in packing up and donating my precious theatre, dance and art books, of which there are many. I've been identifying people and institutions who will treasure them as much as I do. Clothes, jackets and shoes are being given away to needy people as so many are good quality but can never again be worn by me.

'I also met another new friend living with MND who left it too late to save her voice for future use, a process called Voice Banking\*. You use your own voice to record text-to-voice or eye-to-text-to-voice communication when you can no longer speak intelligibly. This voice-banking process will begin soon. It also allows for "double dipping": using a number of voice notes from before to save your voice from when it was more flexible, able. Your voice is "banked" with the company and you only pay an annual fee when your speech is finally unintelligible. Again, an emotionally draining process as I don't want to believe I'll lose my voice but have to accept it will happen.' \* [Contact Inclusive Solutions: [www.inclusivesolutions.co.za](http://www.inclusivesolutions.co.za); [info@inclusivesolutions.co.za](mailto:info@inclusivesolutions.co.za); Tel 0860 888 121]

**#Musings 2:** Some people have commented that I need to accept and give up control and I retort that I'm losing so much control that the little autonomy I still have is essential for me. And I need to be specific and painfully pedantic about my surroundings and things in it to avoid the fumbles and mishaps that seem to happen always when things are out of place, however frustrating it is for others.

"AAA" is the mantra of friends with MND/ALS overseas and I've adopted it:

'ACCEPT – the disease which you cannot change, but not so blindly that you don't try to keep everything firing and working for as long as you can; accept your limitations.

'ADJUST – your actions, your practice, your environment, so that you avoid inevitable setbacks (falls); adjust your clothing, eating and other implements; adjust your horizons.

'ADAPT – make adaptations and find a new reality, but explore how much you can still do.

[More in the next edition of *Thumbs Up*]

## FROM THE OFFICE

### MNDA office closes for holiday season, patient advisors taking a respite period

The MNDA office in Pinelands will be closed from Friday 15 December 2023, re-opening on Monday 8 January 2024.

This also allows our dedicated, hard-working and compassionate team of patient advisors, who work from home, to have a well-deserved respite period. Individual patient advisors will be conveying this to their patients, families and carers, and we ask that their time off, to recharge the batteries, be respected.

For any emergencies during this period, please contact your GP, nearest clinic or hospital. The MNDA looks forward to resuming its service in 2024. And on that note...



*We wish you and yours a very blessed Christmas,  
And to all a holiday season that is safe and peaceful.  
We look forward with hope to 2024.*



**CONTRIBUTE** to *Thumbs Up*:  
news, pics, letters, thoughts...  
let's hear from you!

**LEAVE A LEGACY:** Help others with a gift of lasting value in your will. Many support the work of the MNDA through bequests from their deceased estate.

MOTOR NEURONE DISEASE / AMYOTROPHIC LATERAL SCLEROSIS ASSOCIATION OF SOUTH AFRICA

**Physical Address:**

WBHO House Office G02  
Glen Roy Rd  
Pinelands 7405  
Tel: 021 531 6130

**Postal Address:**

PO Box 789  
Howard Place  
7450  
Email: [mndaofsa@global.co.za](mailto:mndaofsa@global.co.za)

**Banking details:**

MNDA of SA  
Standard Bank Rondebosch 025009  
Current Account No 27 062 913 0  
Swift code: SBZAJJ