

Thumbs UP

MND/ALS
Association of South Africa
NPO 155-413

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

May/June 2023



Helene Hattingh (right), one of the MND/ALS's Gauteng patient advisors based in Pretoria, was delighted to be presented with two out-the-box BiPAP machines and a range of full-face masks to add to the Association's small stock of these costly but life-enhancing breathing aids loaned to our MND/ALS patients free of charge. The donation came from Gauteng medical equipment supplier Healthy Sleep MD Wessel Brits (centre) as part of an awareness- and fundraising campaign for the disease and for the Association's services to patients suffering from MND/ALS countrywide. With them is Zanie van Deventer (left), Healthy Sleep's Business Developer in Pretoria. [See page 3 for more on Wessel's Ironman exploits to].

MISSION STATEMENT of the MND/ALS 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.”

MND/ALS of South Africa is a member of the International Alliance

PATRON Aviva Pelham (MMus)	NATIONAL CHAIRPERSON Dr Franco Henning	VICE CHAIRPERSON Sheila Kendal Slabber
SECRETARY Wendy Toerien		

ACKNOWLEDGEMENTS

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FROM THE OFFICE



MNDA patients to benefit greatly from very generous donors

The Association has been on the receiving end of some incredible generosity this year. As a non-profit organisation (NPO 155-413) reliant on bequests and donations to continue providing patient support, free of charge – the annual membership fee we ask from patients is voluntary – we would like to express our deepest gratitude to a number of donors.

We'd like to remember Lavinia Brander (RIP 17/10/2019), whose grace, courage and selflessness was noted throughout her struggle with MND/ALS by her MNDA patient advisors (Peggy Saxon, then Kathy van Anandel, both of whom have since 'retired'). Having subsequently been informed that she had listed the MNDA as a beneficiary of her estate, the Association recently took receipt of her generous bequest: thank you, Lavinia.

In April the Association received a similarly generous donation from the Witkranz Trust, via an investment and fiduciary services company which seemed to indicate that anonymity was desired. All we could do was request that the facilitator express heartfelt thanks to our mystery benefactor on our behalf for the much-needed funds.

Someone we could thank personally was André Geldenhuys, whose wife Diana is bravely battling MND/ALS. On top of André's substantial donation upon registering Diana with the Association, came a generous deposit from son Jaco in the UK. Thank you both; please know that your contribution goes towards helping, not only Diana, but many others similarly afflicted; we are here for you at all times.

Louise van Zyl made another sizable donation in remembrance of her sister, one of our past patients, Hester Horne (RIP 8/3/2020). Thank you, Louise, for this, and for your message. Once again, the Kurt & Joey Strauss Foundation has come through for us, with what is a regular annual/bi-annual donation (facilitated through a trust management company) for which we are always so grateful.

We thank Wessel Brits, MD of Gauteng company HealthySleep and Ventco, for his donation of two brand-new BiPAP machines and a collection of masks, which extends our small stock of these pricey breathing aids available to our patients on loan, free of charge, to provide much-needed relief. Thanks also to his network of medical clients who responded to his on-line appeal for funds. [See page 3 for more on 'Ironman Wessel' who is, literally, putting his body on the line to create awareness and help raise funds for MND/ALS sufferers].

Thank you to Zelda Setzkorn and her family for donating a brand new CPAP breathing aid. As our patients derive greater benefit from a BiPAP than a CPAP, we are facilitating a 'swop' with one of our very generous breathing equipment suppliers. Also thanks to Letitia van der Merwe for kindly including a brand-new eye-gaze bar to attach to the monitor of the Tobii eye-tracker the Association loaned to her late husband Martin.

To Andrea Skeat, our appreciation for requesting donations to the Association in lieu of flowers at Peter's memorial service; we received several donations from family and friends, as well as business associates, expressing a sense of loss of a much-loved man and admired titan of industry. We'd like to thank Bill McBride and Angela Rademeyer for their regular-as-clockwork donations, and Elrida Botha whose ongoing generosity knows no bounds. Neil Bell, we thank you for your generous contribution in memory of Alison.

The Association welcomed several donations of second-hand equipment. Thank you to the family of the late June Clark for a wheelchair, four-wheeler commode with buckets, toilet seat raiser, bedpan, mattress-supported body turner and sheepskins. We received two walkers with wheels and one without from the family of the late Elsabé Ungerer, and a wheelchair from the daughter of the late Lynette Gibb. Thanks to Cheryl Marais for a wheelchair, commode, walker, four-foot crutch and toilet seat raiser. Also to the family of the late Tokkie Strumpher, for a chair commode, walking sticks, a three-wheel walker, foldable walker and shower chair.

'Ironman' Wessel Brits puts body on line to raise awareness of MND/ALS

MD of Gauteng medical equipment supplier HealthySleep Wessel Brits literally put his body on the line to raise awareness of MND/ALS when he participated in South Africa's international Isuzu Ironman 70.3 event in Nelson Mandela Bay in March.

Decked out in kit he had specially made and branded #motorneuronedisease, Wessel completed the course (comprising a 1,9km swim, 90km cycle and 21,1km run equivalent to 70.3 miles) in 6 hours and 9 minutes, besting his previous Ironman time of 7 hours and 7 minutes. 'I can only say that having the #motorneurone-disease on my clothing gave me a lot more energy and motivation for the race!' He was enthusiastically and proudly supported by his family, also in #motorneuronedisease attire.

As a result of his efforts, which included an email appeal to the company's hospital and neurology network (through its aligned medical ventilator supply company VentCo) and social media postings pointing people to the MNDA's website (including a donation link), not only awareness of MND/ALS was raised (with social media postings during the event), but some R90 000 was channelled towards the Association. It came in the form of two BiPAPs, very costly breathing aids the Association keeps in stock to loan to patients, and a range of face masks, together with a small monetary sum. The Association would like to thank all those who donated.

Having decided to skip the June Ironman 70.3 event in Durban due to a busy work, travel and family schedule making inroads in his training, Wessel intends tackling the third/last international Ironman 70.3 event on the 2023 South African calendar in November in Mossel Bay [hopefully more on this in the next newsletter with links to social media platforms to follow his progress]. Thank you, Wessel, from all MNDA patients.



Wessel at Ironman finish line with race times



Wessel at Ironman finish line with family

FROM THE OFFICE

ANNUAL MEMBERSHIP / SUBSCRIPTION FEE CHANGE

A reminder: The MNDA's financial year begins on 1 April which is when the annual subscription fee becomes due.

This is irrespective of whether a joining fee was paid in the months preceding that. After several years pegged at a mere R200, we have increased it to a nominal (and still voluntary) R300.

We encourage patients / members to use electronic fund transfers (EFTs) if possible. This is to avoid the onerous bank charges on cash and cheque deposits which can subtract as much as R40 from the R200 deposit.

For patients without EFT facilities, a cash payment (via your patient advisor) is an option.

Banking details: MNDA of SA, Standard Bank, Rondebosch 025009, Current Account No 27 062 913 0.

MNDA/ALS GLOBAL AWARENESS DAY 21 JUNE

A reminder of MND/ALS Global Awareness Day on 21 June: a day, a week, a month in which to reflect on the effects of this debilitating condition on all who live with it and a time to hope for continuing strides in finding treatments to slow its progression and, eventually, one day, a cure.

During this time, the **Motor Neurone Disease Association of South Africa** tries to raise awareness of MND in South Africa and of the Association's role in supporting patients, families and caregivers through home visits, support groups, state hospital MND clinics, counselling and loan of mobility, breathing and communication devices free of charge to its registered members. The MNDA keeps records and statistics to assist with research.

As an official member of the International Alliance of ALS/MND Associations, the MNDA of SA encourages all to mark the date by spreading the word on MND (also known as amyotrophic lateral sclerosis) in their social circles and local communities while the spotlight falls on the condition worldwide on this day. MND/ALS is a rare, terminal disease that destroys neurones controlling the muscles, leaving sufferers progressively unable to move, speak, swallow and breathe. Intellect and awareness remain unimpaired.



The MNDA is a registered non-profit organisation (NPO 155-413) relying on donations and bequests to sponsor its work. Please **DONATE** to: **MNDA of SA, Standard Bank Rondebosch Current Account No 27 062 9130**
Website: www.mnda.org.za Email: mndaofsa@global.co.za Tel: 021 531 6130

Looking back: YCARE youth manual training day in Gauteng

The MNDA has for several years been collaborating with University of Wisconsin-Milwaukee professor of social work Melinda Kavanaugh researching the needs of young caregivers in MND/ALS families in SA. As with many US households included in her study, Prof Kavanaugh has found SA families living in poor socio-economic conditions often involving children and teenagers in caring for an afflicted adult family member.

At the end of last year, Prof Kavanaugh, assisted by our patient advisors in the Cape and Gauteng, ran training sessions with local youth to trial her draft YCARE training manual. It features basic information on the disease and the various mobility, breathing, eating and communication challenges MND sufferers face, together with an introduction to the equipment and devices available to alleviate the disease's effects. In the December 2022 *Thumbs Up* newsletter article with photographs, we promised to follow up with a couple of Johannesburg shots:



Two of the MNDA's Gauteng patient advisors, Daleen Bower (standing third from left) and Carina Espag (standing far right), assisted US Prof Melinda Kavanaugh (standing second from right) in the Gauteng training sessions at Chris Hani Baragwanath Hospital. Also there were CHB consulting neurologist Prof Andre Mochan of Wits University (standing far left) and physical, occupational and speech therapists familiar with MND



MNDA Gauteng patient advisors Carina Espag (third left) and Daleen Bower (fourth left) prep for the YCARE youth manual training sessions at CBH.

FROM THE OFFICE

Spreading the word about MND/ALS at a VLV Overberg gathering

One of the MNDA's Cape patient advisors, Louisa de Wet, who supports patients in the Overberg and Walker Bay regions, was pleased to be invited by the Overberg circle of the Vroue Landbouvereniging (VLV) to share some of her knowledge of MND/ALS and the role the Association plays in helping patients, their families and carers living with the disease at the 89th annual conference of the Overberg circle held at the NG Church hall in Caledon in March.

Louisa, who manages the Gansbaai branch of the VLV, addressed some 95 ladies from the various other Overberg branches (including Villiersdorp, Kleinmond, Hermanus, Bredasdorp, Jongensklip and Caledon), with attendees also coming from Greyton and Napier. She said the response was heart warming, she fielded lots of questions and the ladies went home with pamphlets and fliers on MND and the Association's work. She expressed gratitude for the opportunity provided by the VLV to spread the word on the disease and what was being done in the way of support and research, here and overseas.



In remembrance of those who have found peace after passing in the past months



The MNDA extends condolences to the families of those who have passed in recent months and we remember: Masego Tsogolakgosi (21/11/2022); Ndumiso Loyi (8/12/2022); Yvonne Au (15/12/2022); Alison Bell (21/12/2022); Gadija Jones (22/12/2022); John Berling (28/12/2022); Pieter de Vos (3/1/2023); Wesley Mooi (22/1); Hazel Visser (23/1); Berdina Danielz (25/1); Renette Combrinck (28/1); Fanie Potgieter (31/1); Tertius Isaacs (14/2); Zayd Minty (22/2); Silvia Groenewald (1/3); Nonceba Tyatya (14/3); Carol Ann van Wyk (22/3); Jennifer Goliath (25/3); Peter Skeat (29/3); Gail Phillips (2/4); Mmama Paki (8/5); Jorge Faxelhas (10/5); Martin van der Merwe (12/5); Gert Venter (15/5); Pierre Heyns (20/5); Johann Olivier (22/5); Joseph Kleyn (22/5); Christa Rossouw (27/5); Darryl Jacobs (27/5); Tim Binder (27/5); Nesta Cohen (29/5); Sylvia Miles (2/6).

Our sympathies also go to the families of Goolam Amod, Andrew Adoons, Nhamoinesy Mayisela, Phaniel Mnkensani, Panwell Nzama, Carmella Seeff and Catharina Lewis.

'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 before being diagnosed with MND/ALS in 2020, has been documenting his 'Life Post-Diagnosis', sharing his poignant, philosophical, practical, honest and often humorous reflections with family and friends via periodic whatsapp postings. He is tackling living with MND head-on (see the December 2021 and May/June 2022 Thumbs Up) and hopes his thoughts, shared in this and following editions, will resonate, inform and (why not?) entertain.

Diary Entries of Mark: From 1 Feb to 28 Feb (Tuesday 2 March: 2 years and 2 months since diagnosis)

'What have I discovered and learned since my diagnosis? Who knew this disease would progress this slowly for me? My conduct and reaction to my diagnosis was/is unexpected and markedly different from my long-held beliefs about myself and my reaction to adversity.

'Firstly, it came after a protracted period of years of body parts inexplicably letting me down (acutely noticeable to me because I worked with and in my body so much in my acting, teaching of acting and examination of students, and dancing and teaching of the tango), and my energy lessening (so much so that I only longed to rest on my bed and eventually lost all hope in my survival with this ageing malarkey and ability to sustain myself financially as an artist, acting teacher or dancing teacher). I seemed unable to turn my hands and feet to those other strings to my bow.

'So the diagnosis, facilitated by a few friends and my GP in a month only, after the lengthy Covid lockdowns and weakening due to inactivity and sparse nutrition was a shock, but also a relief. That I wasn't malingering, I wasn't growing old disgracefully and going to become a dishevelled disappointment to myself, and others. And it wasn't and isn't my fault.

'And then, in that dark, lonely night between the initial diagnosis on 21 December 2020 and the confirmation at midday on 22 December, I had a stark choice to make: either to curl up and wait passively in fear and silence for death to take me, or to embrace what life I had left, living it with passion and grace, elegance and humour and gratitude. There was no choice, actually.

'And the rewards have been plentiful, surprisingly. The connections with friends, family and colleagues have been deep and rich. The willingness to help and generosity of time, efforts, lifts and even financial assistance has been immeasurable.

'One of the struggles in my new reality is 'balance', and finding balance is hard.

*Physical balance: in standing and walking and leaning down. And of course, avoiding falling or at least mitigating the effects thereof: using a cane, then a rollator or four-wheel walker; slow, deliberate action especially when turning in a hard-surfaced area, on an incline or when windy; weekly Pilates sessions and daily stretching exercises; walking as much as I can; wearing a ribcap or soft protective headwear to reduce the severity of injury when falling; carpets in my flat for softer landings; the resolve to be careful.

*Mental balance: between 'living in the now' and 'planning for the future' (which is unknown). The planning for the later stages and the end has been so difficult to focus on with the daily struggles taking so much energy and attention, and with the subject of my death in practical terms being a fearful prospect. But I'm addressing it and my end-of-life plans slowly but surely.

'Also, finding a balance between living joyfully and accepting death as inevitable, and leaving nothing unsaid or unexplored.'

[Next time, Mark highlights some practical, medical insights into the effects of MND on the body and mind.]

FROM THE OFFICE

MNDA vice-chair's flying visit to Johannesburg to support the supporters

Earlier this year, MNDA vice-chairperson Sheila Slabber, based in the Western Cape and the patient advisor for the Garden Route, Southern and Eastern Cape, spent a week with the Association's Gauteng patient advisors, familiarising herself with working conditions in that neck of the woods (particularly hard hit by Eskom's load shedding and failing health and road infrastructure), running information sessions and providing a morale boost.

She lauded Helene Hattingh, Daleen Bouwer and Carina Espag for their hard work, dedication, compassion and care in supporting MND patients in Gauteng, and further afield in North West, Mpumalanga and Limpopo when needed (by advising patients via email, whatsapp and telephone calls). All three joined the MNDA in their part-time positions as patient advisors early in 2022, after the loss of two long-time advisors and the tragic passing of a third. Carina has sadly since left the MNDA – gratitude to her for her commitment and efforts. Pretoria-based Daleen and Helene have picked up her patients while the Association looks for someone to cover Johannesburg Central, South and the East Rand. Daleen has also taken on Carina's responsibilities registering new and attending to existing MNDA patients at the monthly MND clinic at Chris Hani Baragwanath Hospital.

The Association has been invigorated by Helene and Daleen's enthusiasm, efficiency and growing knowledge of how the Gauteng health system and allied medical businesses can be managed and harnessed in the service of MND patients. Helene is a retired professional nurse still active in the hospital environment and Daleen has experience and qualification in the education, pharmaceutical and counselling fields



MNDA vice-chair Sheila Slabber (right) with (from left) Helene Hattingh, Daleen Bouwer and Carina Espag.

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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

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