

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 2023



*The vibrant figure depicted above is that of one of the Motor Neurone Disease Association's patients, the late Jennifer Murray. Jennifer was recording her thoughts and experiences about living with MND/ALS up until her death in November 2022. Her family had her writings bound and printed and would like to encourage all touched by the disease to acquire a copy of the book, **Smeltkroes van my lewe**. Proceeds of the sale have most generously been pledged to the MNDA to help others still battling the disease. Please contact Jennifer's sister Joy Powrie on Cell: 079 765 7077. [See page 3 for Jennifer's story].*

MISSION STATEMENT of the MNDA 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.”

MNDA of South Africa is a member of the International Alliance

PATRON Aviva Pelham (MMus)	NATIONAL CHAIRPERSON Dr Francko 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



NOTICE IS HEREBY GIVEN
OF THE
30th ANNUAL GENERAL MEETING
OF THE
MOTOR NEURONE DISEASE ASSOCIATION OF SA
TO BE HELD ON
FRIDAY 17 NOVEMBER 2023 AT 11 am
MNSA OFFICE, GROUND FLOOR, WBHO HOUSE,
GLEN ROY ROAD,
PINELANDS

.....
*Attendees please to confirm by phoning the office on **021 531 6130***

Or emailing mndaofsa@global.co.za

BY LATEST MONDAY 13 NOVEMBER 2023

Section 18A certificate from the MNSA 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 MNSA 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 MNSA 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

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)

Jennifer Murray's story about living with MND/ALS, the 'crucible of my life'

Jennifer Murray of Cape Town was diagnosed with MND/ALS in 2020 two days before her 65th birthday.

Mother of four grown children, she had lost her own mother to the condition some 15 years earlier. Primarily afflicted by bulbar onset-ALS (the 'new' term for what was previously known as progressive bulbar palsy), which affects speech, swallowing, eating and ultimately breathing, Jennifer continued to communicate by writing, which included putting down her thoughts on and experiences of living with MND/ALS, up until her death on 20 November 2022.

Jennifer came to the MNDA in October 2020, contacting us via email, and was subsequently registered with the Association and supported by members of our Western and Southern Cape team of patient advisors, most latterly Chantelle Wynne and Sheila Slabber. Jennifer's sister Joy Powrie eventually became an additional and invaluable point of contact, especially when the need arose for equipment, available from the MNDA free of charge (stocks permitting). This included mobility equipment, a suction machine and BiPAP to help Jennifer breathe, as well as advice and contact details for carers and care agencies to help the family help Jennifer.

It was Joy who recently contacted the Association to say that her sister's writings had been bound and printed in book form. Titled *Smeltkroes van my lewe (Crucible of my life)* – a *smeltkroes*/crucible being a situation or severe trial (in this case living with MND/ALS) in which different elements interact, leading to something new – the book is available at R150 a copy (see cover photograph on front page of this newsletter). Joy has with great generosity pledged to donate proceeds from the sale of the book to the Association, for which we thank her most sincerely; a heart-warming example of paying it forward...

To order: please contact Joy Powrie on Cell: 079 765 7077 or via Email: joypowrie@gmail.com

It is written in Afrikaans. But should those not able to read Afrikaans wish to see an English version, please speak to Joy; and perhaps, should there be one of our bilingual patients, family members or 'friends of' the MNDA who would be interested in translating it (pro bono), speak to Joy about that too; ultimately these decisions rest with her and the family.

The Association wishes to thank Joy, Grant, Creighton, Amy-Joy and Jenilee for being willing and open-hearted enough to share Jennifer's story with others: patients and their families, donors and supporters of the Association, leading to a greater understanding of and compassion for a life lived with MND/ALS.

Speaking of books...

Cork University Press in collaboration with the Irish Motor Neurone Disease Association has published *Living with Motor Neurone Disease: A Complete Guide*.

It's edited by Dr Marie Murray, a clinical psychologist, systemic family psychotherapist, author and editor on several similar books, with articles by 'many of the most distinguished Irish experts on MND', from doctors and neurologists to MND outreach nurses and community care workers. It is described as a step-by-step guide for everyone: it explains what MND is; how it's diagnosed; how it affects individuals and families; how to talk about it to children, adolescents, family, friends and work colleagues; and how to adapt home life and the work environment.

Bear in mind, it's written in an Irish context, but promises to be universally helpful and informative. For more, see the link: <https://www.book2look.com/book/1TyHlxsdhf> or email Mike.Collins@ucc.ie

FROM THE OFFICE

Grateful thanks to the kind-hearted for all donations, whether large or small

It was a wonderful surprise to hear from one, Robert Burke, all the way from Canada, whose charitable foundation The People Bridge, raised funds in memory of a friend of one of their board members from South Africa. The funds arrived safely in our account in September and we have emailed Robert to find out more and to thank him personally, and included a copy of our previous newsletter. We're hoping to hear from him and have added him to our donor's mailing list, so here's hoping he receives this newsletter too.

A heart-warming response was received from friends of the late Joan Philp to remember her life and thank the MNDA for supporting her and her family by donating to the Association. A steady stream of contributions followed her memorial service in Fish Hoek in July, testament to the affection and regard in which she clearly was held by so many. Thank you to all, and also to husband Garrick and sons Jason and Bruce: given that deposits do not always reference the name of those remembered, we can confirm that at least R10 000 came in in memory of Joan, including a particularly generous donation from J.Seaman.

Others we'd like to thank for their generosity include African Impact; Judith Bethan Burton (from overseas); Callie Smit; and a mystery donor for their R4 000 contribution in memory of Denise Scholtz, who passed in July. Denise's father Brian Lennox was also a donor during Denise's time with the MNDA.

Thanks also go to Monique Stanton, who lost her mother Lynette Bonafini, one of our past patients, in December 2021 and, to celebrate her own birthday recently, asked for donations in lieu of gifts to be sent to the MNDA; so thank you, Denise Armstrong, for your generous 'birthday' gift to us. Thank you, Carel du Preez, remembering your colleague and friend Deblèssé Smit.

Once again, we'd like to express our gratitude for the kindness shown by those who donate regularly; we are so grateful to see those regular monthly contributions. Thanks especially to Bill and Sheila McBride and Debbie de Jager; also Elrida Botha.

We are grateful to those patients and their families (current and past), as well as 'friends' of the MNDA, for renewing their annual membership fee (just R300), due in April each year (but welcome at any time).

Donation of new or second-hand equipment and device always very welcome!

Sadly, we cannot afford to keep buying new mobility and breathing equipment and other devices, and are therefore indebted to those for donations to shore up our stocks of second-hand equipment to loan to patients free of charge. Sometimes items donated and loaned out to patients are returned in poor repair, scuffed and dirty. If irreparable, they need to be written off.

Therefore special thanks to those who donate equipment, whether it's a BiPAP or eye tracker; wheelchair or walker; commode or shower chair; suction machine or nebuliser; or anything handy in helping a family member cope with living with MND, so long as it's in good condition.

Thank you, Letitia van der Merwe, Di Davis, Sarah Steele, Beverley Ayre and Lorna Spires.

Condolences for the loss of loved ones; we know they are now at peace



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

The MNDA would like to express sympathy with those who have loved ones.

We remember: Jill Neto (16/3); Bruce Murray (16/3); Michael Wilson (13/5);

Marinus Calitz (12/6); Amanda Campbell (13/6); Karen Heydenrych (23/6);

Zubair Mohamed (23/6); Rikus Potgieter (24/6); Joan Philp (25/6);

Beverley Johnstone (30/6); Pureza Goncalves (3/7); Denise Scholtz (15/7); Elizabeth Rafopoulos (17/7);

James Manditereza (20/7); Hennie Coetzee (2/8); Roxy Lee August (12/8); Pieter du Toit (18/8);

Tom Strauss (24/8); Marilyn de Vries (28/8); Ray Bowes (29/8); Deblèssé Smit (6/9); John Hendricks (8/9);

Sarasvatha Naidoo (27/9); Yvonne Gerner (29/9); Joey van Eeden (30/9); Peter Noble (2/10);

Hilda Pretorius (10/10); Nonasile Mnukuana (12/10); Raymond Carr (14/10); Liz Kruger (15/10);

Wesley Tiedt (18/10); Annette Myburgh (21/10); and Karen Hounsom (29/10).

Condolences to the families of Eugene Saffy; Gert 'Ollie' Olivier, Werner van Zweel and Mathys van Eeden.

'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 before being diagnosed with MND/ALS in 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 living with MND head-on (see the December 2021 and May/June 2022 *Thumbs Up*) and hopes his thoughts, shared in extracts in the May/June 2023 and in this and following editions of our newsletter, will resonate, inform and (why not?) entertain. It may also bring solace to MND sufferers to feel 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 one.

Diary Entries of Mark: From 1 Feb to 28 Feb & 1 March – 30 May 2023

In these extracts, Mark describes some physical effects of the disease and how he copes.

'One of the features of this disease for me is a 'very high metabolism' and constant adrenaline rushing through the body. I accept that my body's system is in 'fight or flight mode' always, which affects my reactions and drains me. Hence my need for regular grazing (high-protein intake) and efforts to maintain constant calm (avoiding surprises, shocks, sounds, situations, people that jangle the nerves), maintaining a stability, not only physically and mentally, but of mood. This 'startle reflex' is something I have to adapt to and take anti-anxiety pills to calm me when having to face crowded, noisy, bright and jangly environments.

'Stoicism has been an outcome of the disease for me; I found it's no use crying and wailing; this is my new reality or situation and when something happens, like an unexpected fall (of which there have been many), I focus on finding ways of trying to conquer, surmount this unexpected, unwelcome obstacle.

'For instance, load shedding happened at 6pm one Monday evening and we got home to my block of flats after a good and thorough Pilates session at 6.05pm because of increased traffic. So the lift to my 5th floor flat had stopped working. My neighbours helped me climb the stairs by carrying my rollator up and giving it to me to navigate each landing. It took nearly 15 minutes of dogged and slow climbing up the 10 flights of stairs to reach my front door.

FROM THE OFFICE

‘Luckily, I don’t cry or laugh inappropriately or involuntarily so that feature of the disease has hopefully passed me by. But the ‘invisible aura’ around my body is very sensitive and has expanded so people stepping too close when walking or sitting near me can inhibit my movement, and jangles my nerves.

‘What has also been a source of learning has been discovering how uncomfortable so many people are around people with disabilities and how many tend to avoid addressing and questioning me directly. Once I show them that I’m not drunk or mentally challenged, they relax. What I’ve also found is how few people ‘helping’ me actually listen to me and ask me what I need from them. They assume that they, as able-bodied people, know better than me what I need or how they can help me. Which leads to some fractious encounters when eventually I snap at them for twittering or insisting, while I try to explain, or justify that what I’m doing and how I’m doing it is slow and laborious because my speech is worse when I’m walking, planning or anxious... and they explain that my snapping demonstrates to them how ungrateful I am, when they were just trying to help me.

#Musings 1: When someone lifts up my leg to help me, without my request, when I’m climbing stairs slowly, that disables me. To friends and family watching me walk/reverse in tight spaces, especially on entering a car, please remember: a pro diver diving off the high board, or a pole vaulter (or a sloth) assesses body, distance, speed, angle, wind, mental state etc and marshal their resources to achieve the best [result]. Like them, at that moment I am in a quiet dialogue with my body parts, muscles, joints and neurones to convince them to work with me. It’s a slow process but necessary for me to test my remaining abilities and what my limitations are.

‘Talking to me or trying to do it for me or being excessively agitated about my progress and unnecessarily anxious, throws me off my game, interferes with my concentration, frustrates me and causes me to lose trust in myself. And having to pacify others attempting to help and to explain it to them exhausts me further, as to speak is almost impossible when I’m navigating unfamiliar and treacherous terrain. Everything in my body tenses up in those situations, especially in unfamiliar, uncharted areas. Keep in mind always that I definitely don’t want to fall a gazillion times more than you don’t want me to fall! Also, I NEED to surmount these challenges myself... until I can’t anymore.

‘Every fall, big or small, affects me profoundly and dealing with the aftermath takes my attention and energy away from my planned activities. I fell twice relatively recently with bloody results... falls, however careful I may be, are just inevitable.

‘Sudden surprises or changes can throw me off my game; literally, sometimes. When load shedding kicked in suddenly one night and I was reaching for something, briefly not anchored to my rollator, the high-pitched sound emitted with the change in energy [source]... caused me to jerk my neck and head backwards and I fell [backwards] against my clothes drying rack, thankfully with drying clothes still hanging which softened my landing [as it broke beneath my weight after more than 24 years of service]’. I sourced a better, more user-friendly one that doesn’t take up much space. [But the hunt for the right one] took much time and energy which diverted my focus from other activities... the business of living with this disease is exhausting, physically and mentally. And the need to focus on every movement every day with so much attention to detail always is draining. But my life is a cause for celebration.

Musings 4: When I’m falling, I’ve noticed there is a moment of potential imbalance, normally felt in my neck, just before I lose balance completely. It’s a particular sensation and I’m catching myself nowadays before I overbalance, due to strength from my regular Pilates classes, focusing on it and learning from bitter experience. Also, there’s a slight tension in my thigh muscles that also presages some falls, and if I engage those muscles quickly, then I can stave off these falls.’ [More in the December 2023 *Thumbs Up*].

Stellenbosch student needs help with study on challenges faced by MND carers

Stellenbosch University student Bailey Allan, attached to the Department of Psychology, is conducting a study for her master's thesis on the challenges and coping strategies among informal caregivers of people living with MND/ALS. Although this is independent of the Motor Neurone Disease Association of SA, we'd like to encourage our patients and their families to contact Ms Bailey as soon as possible – her protocol expiry date is June 2024. Under supervision of SU's Prof Ashraf Kagee, she has fulfilled all the necessary requirements for ethical research procedures and participation will involve just a 45- to 90-minute interview. Her study outcomes promise to be of benefit to our member patients and their families. Please see below for details:



Stellenbosch
University

CARING FOR PEOPLE LIVING WITH MOTOR NEURON DISEASE: A QUALITATIVE STUDY OF CHALLENGES AND COPING AMONG INFORMAL CAREGIVERS

YOU ARE ELIGIBLE TO PARTICIPATE IN THE STUDY IF YOU ARE:


- 18 years or older
- provide some measure of care to a family member or friend living with Motor Neuron Disease
- live in South Africa
- comfortable understanding and responding in English


If you participate in this study, you will complete one interview about your experiences with caring.

YOU ARE INVITED TO PARTICIPATE IN A RESEARCH STUDY

You can contact the researcher below for more information.

 Bailey Allan

 061 046 3368

 22982477@sun.ac.za

This study is being conducted under the support of the Department of Psychology at Stellenbosch University.

RESEARCH

MNDA chairman, neurologist Prof Franco Henning, to Alliance meeting in Basel

MNDA chairman Professor Franco Henning, associate professor in the Division of Neurology, Faculty of Medicine and Health Sciences at Stellenbosch University, travels to Basel, Switzerland in early December, to attend the annual meeting of the International Alliance of ALS/MND Associations.

The MNDA of SA has been a full, paid-up member of the UK-based Alliance since both organisations were formed some 30 years ago. The Alliance provides a forum for support and exchange of information among member MND bodies across the world. Although the Alliance does not support any member association financially, it does provide assistance in the form of a travel grant to its annual Meeting, a gathering of medical professionals involved in research and treatment of patients worldwide.

Prof Henning, a researcher with a special interest in MND/ALS who also consults at Stellenbosch University's teaching hospital Tygerberg, has attended (and presented papers) at previous meetings, travelling variously to Perth, Australia; Dublin, Republic of Ireland; Sydney, Australia; Brussels, Belgium, and Birmingham, England.

The annual Meeting is followed by a symposium for allied health professionals. MNDA vice-chair Sheila Slabber received a travel grant in 2017 for the gathering in Boston, USA.

Reminder for those interested in keeping up with latest MND/ALS research

Check out the website <https://www.rarediseasesnetwork.org> for the latest in research on MND/ALS, still officially categorised as a 'rare disease'.

Among the South African academics to have featured on the international Rare Diseases Clinical Research Network is associate professor in neurology at the University of Cape Town and consultant neurologist at Groote Schuur Hospital, Prof Jeanine Heckmann. Prof Heckmann has been interviewed in one of the network's series of podcasts:

the CReATe Author Series on www.rarediseasesnetwork.org/cms/create/CReATe-Podcasts. Look out for Episode 4 (hopefully still available), in which she discusses a 2022 paper on the genetics of ALS in Africans, and keep an eye on the site for new research developments.

The CReATe programme is an ongoing, internationally collaborative research project to develop biomarkers and therapies for MND/ALS. The MNDA's patient advisors are assisting Prof Heckmann in signing up willing patients to participate in the programme, thereby helping to find a future where MND/ALS is a treatable, or even curable, disease.

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

Banking details:

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