

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 2018



The MND of SA's long-serving patron, Aviva Pelham, singing star of the South African stage and operatic music scene and mentor of young talent, with MND patient John Vass from Kuils River at the Cape's International ALS/MND Global Awareness Day get-together in Bellville on 21 June (see story and more photographs inside).

MISSION STATEMENT of the MND 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 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

John Hall for producing the design and DTP (desk top publishing) work.
Optimal Print (Kensington) for the printing of our magazine

FROM THE OFFICE



NOTICE IS HEREBY GIVEN
OF THE
25th ANNUAL GENERAL MEETING
OF THE
MOTOR NEURONE DISEASE ASSOCIATION OF SA
TO BE HELD ON
WEDNESDAY 10 OCTOBER 2018 AT 11.00 am
GROUND FLOOR, WBHO HOUSE,
GLEN ROY ROAD,
PINELANDS

TO FACILITATE SEATING AND CATERING ARRANGEMENTS

PLEASE RSVP

By phoning the office on 021 531 6130

Or emailing on mndaofsa@global.co.za

BY LATEST MONDAY 1 OCTOBER 2018



Condolences to family and friends

Our sympathy goes to the families and friends of those who have passed on in the months since our last newsletter. We remember: Lambert 'Bertie' van Sittert (27/4), Keith Biljon (12/5), Dawood Botha (14/5), Ebrahim Abrahams (21/5), Nelson Machado (28/5), Ray Norman (4/6), Hanlie van Wyk (18/6), Abel Joseph (20/6), Pieter Wessels (22/6), Johannes Myburgh (5/7), Mattie Alexander (22/7), Adriaan Botes (30/7), André van der Westhuizen (10/8) and Marie Wing King (29/8). We'd also like to extend our sincere condolences to the families of the late Hubertus Peeperkorn and Frank Carney.

Equipment for sale

Suzanne Havemann, currently of Johannesburg but moving to Witbank before the end of the year, is offering an electric wheelchair (as new) for sale at R14 800.00.

Contact Suzanne on cell 078 803 0757 or email havemannsuzanne@gmail.com



Gauteng families and friends Walk the Talk for MND with MTN and 702

Johannesburg's Cielia Potgieter, whose sister has MND, braved the mid-winter morning chill with her family and friends on a sunny Highveld July weekend, to take part in the annual charity MTN Walk the Talk with 702. Their special mission was to raise awareness of MND by proudly donning the association's new T-shirts (and kindly making a donation by insisting on purchasing eight T-shirts and paying for the postage up from our Cape Town office).

Cielia said they thoroughly enjoyed the event and would probably have been joined by her sister, Marthie O'Callaghan, if she hadn't been watching her daughter playing in the finals (U16) of the SA Schools Netball tournament (see her website mnd-marthie.co.za)

For those considering following in Cielia's footsteps at next year's event, there are three routes. The late-morning 5km walk meanders through Emmarentia and Greenside. The mid-morning 8km route skirts the Parkview Golf Course. And the early-morning 15km challenge offers the experience of crossing the Emmarentia fly-over bridge, exploring Wits University campus, traversing the iconic Nelson Mandela bridge in Braamfontein, sightseeing in the historic Constitution Hill Precinct and then wending your way through Parktown and Westcliff to the finish at Marks Park Sports Club.



The Potgieter and Scheepers families in MNDALS T-shirts for the charity MTN Walk the Talk event: (back) Laura Scheepers, Cielia's husband Alf, daughter Kristi with Michiel and Marina Scheepers; (front) Cielia's oldest daughter Heili and Kayla Scheepers.

Out with the old, in with the new among Cape Town's city centre clinics

Some of our Cape Town patients and families will no doubt have heard of (and even visited) the District Six Community Day Centre in Cape Town's city centre, which opened its doors earlier in the year.

The brand new District Six CDC building is situated on the grounds of the old Peninsula Maternity Hospital in Caledon Street. It provides health care services to a population in and around Woodstock, Salt River, Vredehoek, Bo-Kaap, the City Bowl and central Cape Town (estimated at between 70 000 and 90 000), as well as those commuting into the CBD. The centre effectively takes over the services of two of the city's oldest primary health care facilities: the Woodstock Community Health Centre and Robbie Nurock Day Hospital in Buitenkant Street. Both have now closed their doors after offering medical services to predominantly low- and no-income patients for over a century. All patient medical records from the old facilities will have been transferred to the new District Six CDC.

District Six CDC operates from Mondays to Fridays between 7.30am to 4pm and people are encouraged to make an appointment if wanting to be attended by a clinician. Tel 021 833 5400.

[Information courtesy of www.iol.co.za/capeargus]



MNDA members mark International ALS/MND Global Awareness Day on 21 June 2018

Cape Town

An unexpected treat awaited our Cape Peninsula and Boland MND patients and their families and carers attending the ALS/MND Global Awareness Day gathering at the Bellville NG Church Hall on Global Awareness Day: an inspiring operatic performance by Cape Town Opera tenor Khanya Sakube, organised by MNDA patron Aviva Pelham, one of SA's best-loved singers and stage performers.

The church hall is the venue for regular support group meetings run by Cape-based MNDA advisors Joey Bayley, Tracey Cuff and Desirée Diedricks. But on this special day the usual proceedings were given a festive lift, spear-headed by indefatigable MNDA vice-chairperson Sheila Kendal Slabber. Accompanying the usual tea, coffee, juice and biscuits were bottles of bubbly and an array of sweet and savoury snacks. These included two home-baked cakes courtesy of Joey (renowned for her chocolate confection complete with icing in signature MNDA blue) and advisor Peggy Saxon (a gourmet cook who whipped up a delicious lemon sponge for the occasion).

The big surprise came after an informative talk and demonstration on breathing aids by Cecile van Gent from Sleepnet medical equipment company. Khanya, in formal black suit and red tie, supported by JBL backing tracks and with no microphone required, proceeded to fill the hall with his rich, powerful renditions of three pieces: 'Dein is mein ganzes Herz', an aria by Franz Lehár from the 1929 operetta The Land of Smiles; David Foster's 'The Prayer', a duet made famous by world-renowned Italian tenor Andrea Bocelli and Canadian songstress Céline Dion, and for which he was accompanied by Aviva; and finally, 'Nessun Dorma' from Puccini's opera Turandot, popularised by acclaimed Italian tenor Luciano Pavarotti at the 1990 FIFA World Cup.

When introducing Khanya, Aviva spoke about how each person's need to find meaning and inspiration in their individual journeys in life could be met by things of beauty such as nature, art, theatre and, most of all, music. Actively involved herself in educating and mentoring young musical talent, she described music as an international communicator, crossing all boundaries of age, colour, religion, culture and gender. She also pointed out how music, despite resonating deeply and differently for each individual or group, had the capacity always to uplift and heal.

As an illustration of hope, the gathering moved outside and, undeterred by the beginnings of a drizzle (welcomed by all true Kapenaars in the drought-stricken Cape), together released bunches of cheerfully bright blue and white balloons into the windy, wintry sky amidst much laughter and camera calls.

Speaking to the MNDA over a cup of tea after his performance, Khanya admitted to being deeply moved by the courage of all in his audience (some listeners would have picked up a moment towards the end of 'Nessun Dorma' when emotion briefly got the better of him). He described it as an honour and privilege to sing for everyone present. Our heartfelt thanks to him and Aviva for a very special experience.



A wintry sky was brightened by the release of bunches of blue and white balloons during the Cape's ALS/MND Global Awareness Day at Bellville's NG Church Hall.



Front row seats at a 'pop-up' performance by CTO's Khanya Sakube in a duet with MNDA patron Aviva Pelham.

FROM THE OFFICE



Sleepnet's Brenda Allen, Cecile van Gent and Robyn Holtzhausen joined the Cape's Global Awareness Day activities.



The MND/ALS Cape 'team' preparing for Global Awareness Day: Tracey Cuff, Sheila Kendal Slabber, Joey Bayley, Wendy Toerien and Peggy Saxon.



Anthony Graham, Eddie van Schalkwyk and Wilna du Bois marked Global Awareness Day in Cape Town.



Sean van Eeden, John Vass, Chris Nilsen and Anthony Graham helped MND/ALS vice-chair Sheila Kendal Slabber (kneeling) and patron Aviva Pelham (behind) release Global Awareness Day balloons.

Gauteng

MND patient in Gauteng Göran Söderholm and wife Karen, members of the support group run by one of our Gauteng advisors Victoria Goodstein, organised a memorable evening of good food, fine wine, inspirational words and live music at the nostalgic The Landmark Cocktail Bar and adjoining Italian eatery Café del Sol Botanico in the Bryanston Shopping Centre to mark International ALS/MND Global Awareness Day.

The event included top-notch Italian fare from Café del Sol Botanico, highly rated by *Eat Out and Dining Out* critics; inspiring words from physiotherapist Sue Fuller-Good recounting her 2017 two-week mountain bike ride with her international 'Women on a Mission' teammates on a first-time bike crossing of Ethiopia's desert-like Danakil Depression; and a musical performance by SA acoustic-digital band Shyen. A big thank you to Sue and the musical duo of Simone (a friend of the Söderholms) and her partner in music, Owl, who offered their services free of charge, as well as to our own Victoria, who emceed proceedings with great aplomb!



Members of the Gauteng MND/ALS support group Göran Söderholm and wife Karen, the dynamic duo behind the memorable 2018 Global Awareness Day event at The Landmark/Café del Sol Botanico in Bryanston.

FROM THE OFFICE

A wonderful response from Gautengers in the Söderholms' wide circle, support and contact group ensured a fully booked event, with part of the proceeds from ticket sales swelling the coffers of the MNDA. We thank sponsors of items offered up for an always-entertaining auction: Bang & Olufsen for an exclusive wine cooler and Pandora for a beautiful bracelet. Active bidding raised an additional sum donated to the association. A special thank you to Donna Kroutz from The Landmark and Café del Sol Botanico for going beyond the call of duty to help with sponsorship of water and some of the drinks for the evening.

To top it all came a most generous additional individual donation from one of the guests who chose to remain anonymous, the embodiment of the mantra of the internationally marked ALS/MND Global Awareness Day: 'People who care make a world of difference'.

Last but not least we thank Göran and Karen for initiating such a special event, bringing together those living with the disease to celebrate life, experience times of fun and, for a while, be lifted above ongoing every-day challenges. 'Mid-June is a solstice [the southern hemisphere's winter solstice which marks the day with the shortest period of sunlight and longest night of the year] – a turning point – and each year the ALS/MND community expresses hope that this day will be another turning point in the search for the cause, treatment and a cure.'

KwaZulu-Natal

The MNDA's energetic KZN advisor Kasturi Pillay was the mover and shaker behind some very festive awareness- and fundraising events to mark International ALS/MND Global Awareness Day in Durban this year.

Thursday 21 June was spent at the Pick 'n Pay Centre and Sunday 24 June at the bright and light The Pavilion Shopping Centre, both in Malvern, where Kasturi and helpers, including Jenny McCallum (who lost husband Stuart to MND in 2015), manned a table in white and blue regalia with the MNDA's banner prominently displayed. Jenny baked up a storm, providing large round cakes and cupcakes beautifully decorated with blue and white icing to sell to passersby feeling peckish and who stopped to find out more about MND, the association and its services and make a small donation. Cupcakes were also sponsored by World Cargo Logistics.

Further funds were raised from the sale of sturdy blue MND/ALS Global Awareness Day branded shopping bags, specially made and generously donated by RML Productions in Durban. These will continue to carry the message of Global Awareness Day and MND out there long after the day itself. Kasturi has extra stocks for anyone interested in purchasing and can be contacted via the MNDA head office on Tel 021 531 6130 or mndaofsa@global.co.za.



Members and supporters of the MNDA in KwaZulu-Natal Jerry Mandhiri, Marion Davies and Jenny McCallum, who embody the Global Awareness Day mantra 'people who care make a world of difference', at Pick 'n Pay Malvern.



Above: Our KZN advisor Kasturi Pillay with members of her MND patient support group and families and helpers at The Pavilion Shopping Centre MND awareness and fundraiser.

Eastwood Primary School staff support Global Awareness Day

Staff of Pietermaritzburg's Eastwood Primary School used International Global Awareness Day on 21 June to remember the late husband of one of their own.

Carolyn Brophy, who lost husband Gaston to MND in April, asked her colleagues to wear the MNDA's signature blue to work on Global Awareness Thursday and make a R50 donation towards the association which was able to support the family during Gaston's illness. The kind complement of teachers rose to the occasion with aplomb and next thing our account was boosted with a very generous deposit.

We thank Carolyn and all the teachers (including son Sherwin) for their kindheartedness (some gave more than R50) and sense of spirit (there was attire in all shades of blue). We all know how tough things are out there economically and yet people still find something to give.



Blue balloons brighten a chalkboard at Eastwood Primary in Pietermaritzburg on Global Awareness Day when staff (including Carolyn Brophy, front second from left) wore blue and collected a sum for donating to the MNDA.

RESEARCH

Joost van der Westhuizen MND care and research clinic opens at Chris Hani Baragwanath

The new Joost van der Westhuizen Centre for Neurodegeneration, based at Chris Hani Baragwanath Academic Hospital in Soweto, Gauteng, held an official opening ceremony in July for its new Motor Neurone Disease Clinic, to which one of our Gauteng patient advisors, Edith Potgieter, was invited.

Edith regularly attends treatment sessions held for motor neurone disease (MND) patients at Chris Hani Baragwanath which will now be part of the new centre's services. Besides providing improved, focussed care for MND patients, the centre will drive research across the group of neurodegenerative diseases of which MND, also globally known as amyotrophic lateral sclerosis (ALS), is one.

Among those present at the clinic's opening was Dr Andre Mochan, head of neurology at Johannesburg's Netcare Rehabilitation Hospital and associate professor in the neurosciences department of the medical faculty at the University of the Witwatersrand, which uses Chris Hani Baragwanath as one of its teaching hospitals. Prof Mochan has been integrally involved in getting the facility up and running, supported by sponsorship from Aspen Pharmacare.

The clinic was officially opened by Gauteng Provincial MED for Health, Dr Gwen Ramokgopa, who unveiled a plaque bearing the name of rugby legend Joost van der Westhuizen. Diagnosed with MND in 2011, Joost used his international fame to actively raise awareness of MND and the search for a cure during his brave battle against the disease, before passing away in February 2017.

Right: MNDA advisor Edith Potgieter with Mrs Jesu Ranchod (and her son). Mrs Ranchod, whose late husband Dale had MND and was a clinic patient and MNDA member, has been lobbying provincial government to support MND awareness projects.



Aspen Pharmacare senior executive Stavros Nicolaou, Gauteng Health MED Dr Gwen Ramokgopa, MNDA advisor Edith Potgieter and Gauteng Sport & Recreation MED Faith Mazibuko at the opening of the new MND clinic.



Neurologist Prof Andre Mochan of Wits Medical School with MNDA advisor in Gauteng, Edith Potgieter.



DONATIONS

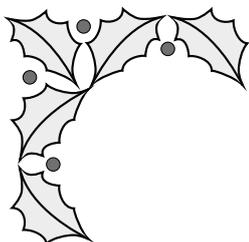
We have been the recipient of extraordinary generosity over the past few months and would like to express our gratitude. The late Harold Ewart Ranford bequeathed a substantial sum that came to the MNDA under the auspices of Peter Jerome, in memory of a long-time friend and late MND sufferer Mrs Anderson. Thank you to Matthew de Wet for his sizable annual contribution, and to generous regular donors David Cuthbert and Les Wiseman. A big thank you to AL Botma, and also to Ticktin Timbers. Special thanks to Vince and Ange Boule for an incredibly generous additional contribution above and beyond their support of the 21 June International ALS/MND Global Awareness Day fundraiser in Gauteng (see more elsewhere in this newsletter). Also thanks to ProMedCare.

Our equipment stock received a boost from several quarters recently. We thank Gary and Nelsa Canning in KZN for their donation of several aids for patients. In July, visiting assistant professor of social work at the University of Wisconsin-Milwaukee, the irrepressible Melinda S Kavanaugh, whom the MNDA has been assisting in an ongoing US/SA research project on the needs of young caregivers in families living with MND, lugged a collection of devices (such as eye trackers) with her on a lecture trip to Wits and Stellenbosch universities. These were donated by her regional chapter of the US MNDA. We thank donor and courier for going the extra mile!

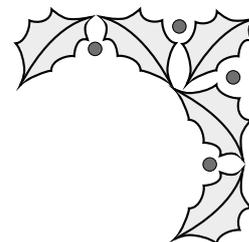
We are most grateful to local families of late MND patients – the Govenders and the Flemings/Van der Westhuizen of KZN – for gifting a BiPap plus suction machine and a Tobii eye gazer respectively to the MNDA. These expensive pieces of equipment are already benefitting other patients, a living legacy of their departed loved ones.

Coming to the end of another year, the MNDA wishes to thank some special people who donate their time and expertise: Peter Rosmarin who checks our books; David Cudlipp of Friedberg Miller Gruft who does the audit; John and Chris Hall for newsletter layout and design; and Andy Olivier of Optimal Print for the printing.

On that uplifting note, from all of us at the MNDA of SA:



*Wishes for a blessed time over Christmas
to all who celebrate this joyous season,
and to all,
peace in the year ahead*



**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

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