



MDFSA

NEWSLETTER

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The Muscular Dystrophy Foundation of South Africa is a non-profit organization that supports people affected with muscular dystrophy and neuro-muscular disorders and endeavours to improve the quality of life of its members.

THE ROLE OF THE MDF

We assist affected persons and their families by providing information, support, referrals to genetic counseling, health facilities and providing assistive devices such as motorized wheelchairs.

Creating public awareness is an important aspect of the Foundation's work. We also strive to keep our members updated via the MDF website and MDF magazine.

WHAT IS MUSCULAR DYSTROPHY?

The term muscular dystrophy (MD) describes a disorder that affects the muscles, resulting in progressive wasting and weakness of the muscle.

HOW YOU CAN HELP

Your support means hope if you

- ◇ become a member
- ◇ become a corporate member
- ◇ make a financial donation
- ◇ make a bequest
- ◇ volunteer your time at your local branch

and your help will enable us to provide continued support to our members

Message from the Chairman of The National Executive Committee



Up until now, the Foundation has focused on psycho-social support to help improve the quality of life of individuals with Muscular Dystrophy. We have raised public awareness, provided specialised disability equipment when funds allowed, maintained a registry of members diagnosed with the condition and more!

To stay relevant in today's rapidly changing world and aligned with international trends, the Executive Committee made the following strategic decisions: to expand our focus to include access to genetic testing and possible treatments, the establishment of support groups, and the building of international relationships and affiliations.

We are deeply grateful to our loyal donors, funders, and the individuals who, despite challenging financial times, continue to support us so generously. Your contributions have been instrumental in enabling us to provide services to our members and their families. With gratitude, we look forward to your continued support in the years ahead.

A special acknowledgment goes to our largest financial partner, Crossbow Marketing. Your partnership over the years has been invaluable, and we express our sincere thanks to the management and staff for their commitment and hard work in securing a steady income stream for the MDFSA.

I also wish to applaud our dedicated staff and management across all our offices for their dedication, commitment, and service to our remarkable members.

In closing, I extend my heartfelt appreciation to the EXCO for your support and for ensuring that we remain true to the mission of MDFSA. You are greatly valued, and I look forward to another year of working together to achieve our shared goals.

Erik Andersen



Get into the Green Scene for Muscular Dystrophy Awareness

The Muscular Dystrophy Foundation of South Africa (MDFSA) has proudly launched the "GET INTO THE GREEN SCENE" campaign every September since 2018, in honor of International Muscular Dystrophy Awareness Month. This initiative aims to raise awareness about muscular dystrophy among businesses and individuals, many of whom may be unaware of the disease and its significant impact on those affected and their families.

During our visits to various organizations and individuals, we educate them about muscular dystrophy, stressing that, unfortunately, there is currently no cure. These interactions often turn into valuable educational experiences, with participants showing genuine interest and asking thoughtful questions. It's incredibly rewarding to witness their engagement and the insights they gain.

To add a fun element to the campaign, we encourage participants to wear bright green accessories for a photo session, symbolizing their support for our cause. These photos are then

shared on MDFSA's social media platforms as well as those of the participating businesses and individuals. This joyful experience not only strengthens relationships but also amplifies awareness of muscular dystrophy.

Beyond raising awareness, the campaign serves as a platform to highlight MDFSA's mission and the various support services we offer, including social integration for affected individuals. Many businesses and participants not only join the campaign but also help spread the message by sharing photos and information about muscular dystrophy on their own social media channels. This collaboration is vital in educating the wider public about the challenges faced by those with muscular dystrophy.

In summary, the "GET INTO THE GREEN SCENE" campaign has evolved into a powerful tool for raising awareness, fostering community engagement, and building lasting relationships—all while spreading joy and support for an important cause.



Nobody fights alone!

Join the Muscle Riders Charity Cycle Team for the 947 Ride Joburg!

Are you passionate about cycling and looking for a way to make a difference? The Muscular Dystrophy Foundation of South Africa, Gauteng Branch, invites you to join the Muscle Riders Charity Cycle Team for the 947 Ride Joburg event! By riding with us, you'll be helping raise awareness and much-needed funds to support individuals living with muscular dystrophy.

This year, we're excited to have the generous backing of our amazing sponsors—**Wheelchairs on the Run**, **Cool Tech**, and **Moo Moo Steakhouses**—whose donations have greatly contributed to the success of the team. Their logos will be proudly displayed on the Muscle Riders' jerseys as a symbol of their commitment to this important cause.

Whether you're a seasoned cyclist or just starting out, this is

your chance to ride for a purpose. By joining the Muscle Riders, you'll not only enjoy an exhilarating race, but also play a vital role in supporting our mission to enhance the lives of those affected by muscular dystrophy.

To join the Muscle Riders team, please contact **Mr. Robert Scott** via email at mdfgauteng@mdsa.org.za or call **011 472 9824**. Let's ride together for hope, strength, and support!



MDFSA Gauteng Branch & Groot FM Team Up to Support Young Member!

The Muscular Dystrophy Foundation of South Africa, Gauteng Branch, is proud to partner with Groot FM to make a difference in the life of a young member affected by Duchenne Muscular Dystrophy.

Together, we were able to provide him with the much-needed disability equipment that will greatly improve his quality of life!

This collaboration highlights the power of community and the importance of working together to support those affected by Muscular Dystrophy. We extend our heartfelt thanks to Groot FM for their dedication and generosity in making this possible.

Thank You for Your Support on Casual Day 2024!

The Muscular Dystrophy Foundation of South Africa, Gauteng Branch, would like to extend our heartfelt gratitude to all our supporters who helped make Casual Day 2024 a success! Your enthusiasm and dedication in selling stickers for this important cause have truly made a difference.

Thanks to your efforts, we raised crucial funds that will go a

long way in supporting the essential services we provide to our members living with muscular dystrophy. These services, including much-needed care, support, and advocacy, are made possible through your continued commitment to our mission.





Celebrating 50 Years of Hope: MDFSA's Golden Anniversary

On 21 September, the Muscular Dystrophy Foundation South Africa (MDFSA) proudly celebrated its 50-year anniversary with a memorable breakfast event in the scenic surroundings of Muldersdrift. This milestone marked five decades of dedicated service to individuals and families affected by muscular dystrophy, as well as the Foundation's ongoing efforts to advance research and raise awareness across South Africa.

A Legacy of Compassion and Advocacy

Since its founding in 1974, MDFSA has provided vital support to those living with muscular dystrophy, a group of genetic disorders characterized by progressive muscle weakening. Over the past 50 years, the Foundation has grown into a symbol of hope, offering services such as counseling, information, and support groups, while advocating for those affected by the condition.

A Morning of Reflection and Gratitude

The anniversary brunch brought together long-standing supporters, donors, community members, and special guests to honor the Foundation's remarkable journey. The program featured personal testimonies from individuals whose lives have been touched by MDFSA's work.

Attendees also paid tribute to the Founders, volunteers,

and partners who have played an instrumental role in the Foundation's growth over the past five decades. The atmosphere was one of gratitude, reflection, and a shared commitment to continuing the Foundation's mission.

Looking to the Future

While the event celebrated MDFSA's legacy, it also emphasized the importance of looking ahead. The brunch served as a powerful reminder of the challenges that still lie ahead for individuals with muscular dystrophy and the need for ongoing support and advocacy.

As MDFSA enters its next chapter, the commitment to providing essential services remains as strong as ever. The Foundation continues to inspire hope and positive change for those affected by muscular dystrophy, ensuring that the next 50 years will be just as impactful as the last.

The brunch in Muldersdrift was a fitting celebration of a legacy of hope, strength, and progress—marking the start of a new era for the Muscular Dystrophy Foundation South Africa.





Is South Africa Turning Its Back on Muscular Dystrophy Patients?

Across the world, September is Muscular Dystrophy awareness month. But in South Africa, a huge amount of effort is still required from the country to even acknowledge the struggles faced by families grappling with this devastating muscle wasting condition...

Muscular Dystrophy (MD) is an umbrella term that describes a range of NeuroMuscular Disorders (NMD) that result in progressive muscle wasting. Many forms of MD can prove to be fatal, and even when the condition is not life-threatening it has a devastating impact on patients and their families.

But as severe as MD conditions are, South Africa's troubling reality is most MD patients face enormous struggles simply to access the healthcare that is – in theory at least – guaranteed to them by the country's constitution.

'It really is time to significantly raise national awareness of what MD patients go through, and the way their constitutional rights are being denied,' says Gerda Brown, General Manager of the Muscular Dystrophy Foundation of SA (MDFSA) National Office. 'Our mainstream press never cover the subject, and it's very difficult to understand why this is. It's almost as if we're saying that people with certain types of illnesses just don't matter in this country.'

If South Africa's constitution is to mean anything at all, the country's media have a responsibility to highlight the plight of individuals who are being denied their constitutional rights. To date, however, there is almost no

awareness in the public domain of the three major challenges the country needs to urgently address.

The first is simply paying enough attention to screening for the condition at an early age. In South Africa, very few hospitals in the public or private sector screen for NMD at all. Which means that a lot of people who have MD conditions, and could take crucial preventative interventions early on in life, are denied the opportunity to do so.

'The knock-on effects of are unnecessary physical trauma and enormous financial cost – for the patients, and for the health system itself,' says Brown. 'Patients face increasing physical challenges in terms of muscle loss, breathing and mobility as they age, and as the consequences become more severe the cost to the national health system rises as it is forced to address their symptoms. Regular screening at an early age could dramatically reduce the costs for all.'

Another related challenge is the pressure placed on MD patients and families to cover the day-to-day costs of living with a debilitating muscle wasting condition. In theory, MD is covered on the South African Prescribed Minimum Benefits (PMB) list, which means that public hospitals and private medical aids are legally obliged to pay for care and treatment. In reality, however, the South African PMB list is so poorly articulated that funders have historically found many reasons to reject claims for key services such as physiotherapy, mobility aids, hospital stays, and much more, forcing patients to

somehow raise huge amounts of money simply to stay alive.

‘The PMB list is supposed to be revised every two years,’ explains Brown, ‘but this simply isn’t happening. The negative impact of this lack of clarity has a huge negative impact on MD patients, and yet no progress ever seems to be made.’

In 2024, being diagnosed with MD is not an entirely hopeless scenario, as it often was in the 20th century. New generation genetic treatments are fast emerging internationally for certain MD conditions which slow the rate of muscle wasting and, in some instances, even allow patients to gain a certain level of strength. Unfortunately, however, the majority of these treatments are vastly expensive, with many priced in the millions of Rands. As a result, only the luckiest of South African private medical aid MD patients have managed to secure

treatment, with public health patients left entirely out in the cold. The country does have a Rare Disease Access Initiative in place, made up of multiple stakeholders, which is supposed to be developing a crucial policy approach which will define how it intends to meet the cost of genetic treatments, but thus far it has not progressed beyond discussions around the complexity of the issue.

‘It’s incredibly ironic and more than a little bit unfair, that people who have already experienced the worst luck that life has to offer now have to hope to be amongst the luckiest patients in the country simply to secure the healthcare that is guaranteed to them in our constitution,’ concludes Brown. ‘The tragedy of the situation is compounded by the fact that there is so little awareness in South Africa that this is even an issue at all. Hopefully this awareness month the media and the public will finally sit up and take notice!’



Raising awareness at Vista Nova High School

On Thursday, 1 August 2024, our MDF team conducted an awareness session with the educators at Vista Nova High School in Pinelands. This session was particularly important as several learners at the school are affected by Muscular Dystrophy. The educators found the session valuable, actively engaging and asking essential questions to better understand and support their learners with MD. The MDF team also proposed ongoing support groups at the school to empower these learners and ensure they receive the necessary assistance.



Norval Foundation Outing

On Wednesday, 7 August 2024, our children's support group had a wonderful and engaging day at the Norval Foundation in Tokai. The group was introduced to contemporary art and various forms of artistic expression. With Cape Town recently experiencing severe storms, it was a delight for the children to enjoy the beautiful weather while exploring the entire exhibit. They immersed themselves in different art mediums, including

sculptures, paintings, and drawings. The guides provided insightful perspectives on how to view art through new lenses, which inspired the children to create their own unique works. It was heartwarming to see the joy on their faces as they curated their own mini exhibit. We extend our sincere gratitude to the Norval Foundation for hosting us. The children had such a fantastic time that they are already eager to return for another exciting



What do you see?

Poem by Sasha-Lee Julies

My body is a temple
 Yet my body needs to be assembled
 A rippled effect of hope
 Met by doctors examining me with a scope

The trick is too always try
 To live in the moment and not deny
 That since birth we are fighters
 Our condition will not to define us

HOPE