ANNUAL REPORT 2025/26

MUSCULAR DYSTROPHY FOUNDATION OF SOUTH AFRICA

NATIONAL OFFICE

1. Mission Statement

The mission of the Foundation shall be to support people affected by Muscular Dystrophy and Neuromuscular disorders and endeavor to improve the quality of life of its members with evidence-based research.

2. About Us

The Muscular Dystrophy Foundation of South Africa (MDFSA) is a registered non-profit organisation – Reg. No. 004-152 NPO – consisting of a national office and three branches which operate in the nine provinces of South Africa.

The Organisation was founded in 1974 by Mr. and Mrs. Newton Walker of Potchefstroom who, at the time, had a son affected with Duchenne Muscular Dystrophy. The Foundation was established with the aim of reaching out to other parents and families in a similar situation and to support research into this disease with the ultimate goal of finding a cure. The Foundation has been actively involved in carrying out this aim for the past 40 years.

The Foundation's role within social integration, support services, Muscular Dystrophy awareness programmes and Muscular Dystrophy diagnostic research support is to:

- Enable people to participate in identifying Muscular Dystrophy needs and to respond appropriately.
- Develop equal caring and coping services for people affected by Muscular Dystrophy.
- Support affected people with specialised assistive equipment.
- Create public awareness on Muscular Dystrophy issues and disability.
- Strive for the recognition and protection of the rights of people affected by Muscular Dystrophy as a disability.
- Support and promote diagnostic research into the causes and treatment of Muscular Dystrophy.
- Generate funds to support and sustain our work.
- Collaborate and communicate on a national, provincial, international, governmental and non-governmental basis on policy matters relating to all aspects of muscular dystrophy.
- Assist individuals to form self help and support groups.

3. Chairperson's Message

Good morning, members, colleagues, partners and friends of MDFSA.

It is my pleasure to welcome you to our Annual General Meeting and to reflect briefly on the year that has passed and, more importantly, on the future direction of the Muscular Dystrophy Foundation of South Africa.

The past year has been a period of both opportunity and challenge. As a Board, our focus has been on ensuring that MDFSA remains relevant, sustainable and responsive to the changing needs of people living with muscular dystrophy.

Strategic direction and sustainability

One of our key priorities has been to strengthen the organisation for the future. We recognise that the environment in which non-profit organisations operate has changed significantly, and MDFSA must continue to adapt.

The development of a new organisational model is an important part of this process. Our aim is to ensure that MDFSA has a structure that is sustainable, clearly focused on its core objectives, and able to deliver services effectively at a national level.

Financial sustainability remains one of our greatest strategic challenges. The difficult economic environment has placed pressure on traditional sources of funding, while competition for donor and corporate support has increased.

We therefore need to broaden our funding base, develop stronger partnerships and explore new approaches to fundraising. Sustainability will require not only additional funding, but careful stewardship of the resources entrusted to us.

Our strategic priorities

Looking ahead, we remain committed to our core priorities:

- improving access to information, support and appropriate services;
- strengthening diagnosis and access to genetic testing;
- supporting research and participation in international research initiatives;
- increasing awareness and understanding of muscular dystrophy;
- strengthening our partnerships locally and internationally; and
- ensuring good governance, accountability and long-term sustainability.

Our participation in international networks and research initiatives is particularly important. Muscular dystrophy does not stop at national borders, and we must remain connected to global developments in diagnosis, treatment, research and standards of care.

Looking ahead

There are significant challenges ahead, but there are also opportunities.

Our responsibility as the Board is to provide strategic leadership, ensure good governance and protect the long-term interests of MDFSA and the community we serve.

I believe that MDFSA has a strong foundation, built over many years through the commitment of our members, staff, volunteers, donors and partners. Our challenge now is to build on that foundation and ensure that MDFSA remains a strong and sustainable organisation for future generations.

I would like to thank everyone who has contributed to MDFSA during the past year. Your commitment makes it possible for us to continue our work and to ensure that people affected by muscular dystrophy are not forgotten.

As we look to the future, our direction is clear: to remain sustainable, relevant, accountable and focused on the needs of our community.

And, as always: Never give up Hope!

Thank you.

Erik Andersen
Chairperson: Executive Committee

4. Director's Report

I am delighted to present the Annual Report for the Muscular Dystrophy Foundation of South Africa for the period April 2025 to March 2026.

4.1. Governance

The Muscular Dystrophy Foundation's National Executive Committee was comprised of eight executive members representing each Branch in the following portfolios:

- Gauteng: Izelle Smuts (Treasurer), Karan Singh (Treasurer) and Anri Human (Secretary).
- Western Cape: Win van der Berg, Lauren Schultz, Gilda van der Berg and Riande van den Berg.
- KwaZulu Natal: Erik Andersen (Chairperson), Pamela Rapiti, Noel Pillay (Vice chairperson) and Prylash Singh.

4.2. Strategic Objectives for 2025/26

Strategic Planning was conducted on 19 January 2026. The strategic objectives for the year were as follows:

- Strategic objective 1: To educate, protect, support, and improve the well-being of all affected persons.
- Strategic objective 2: To promote and support all aspects of research into the cause, nature, treatment, and cure of the condition
- Strategic objective 3: To raise public awareness about the condition, its impact, and the need for action.
- Strategic objective 4: To keep a record of affected persons to help identify new cases early and ensure quick and effective treatment.
- Strategic objective 5: To ensure that MDFSA operates efficiently, transparently, and in alignment with its strategic goals by maintaining sound administration and governance while effectively managing daily operations.
- Strategic objective 6: To collect, raise funds, receive donations, any cash or asset of whatsoever nature as may be employed towards the furtherance of MDFSA's objectives.

4.3. National Service Delivery Programmes

Strategic objective 1: To educate, protect, support, and improve the well-being of all affected persons.

Although assisting members with assistive devices falls outside the core scope of the National Office, MDFSA successfully secured funding from an international donor to provide much-needed support. Seventeen (17) members were assisted with a variety of disability equipment, improving their quality of life through enhanced mobility, independence and overall well-being.

MDFSA continued to establish and maintain online support groups, providing members with opportunities to connect, share experiences and access peer support. Discussions were monitored and moderated to promote a safe, inclusive and supportive environment. These groups strengthened

members' sense of community, reduced isolation and increased access to information, resources and peer support.

Informative manuals on Becker Muscular Dystrophy (BMD) and Myotonic Muscular Dystrophy (MMD) were developed for affected individuals, families and healthcare providers. The manuals contribute to increased awareness and understanding of these conditions and provide practical information to support affected individuals and their families.

Three (3) informative and engaging MDFSA newsletters were developed and distributed to members, friends of the Foundation, donors, medical professionals and other relevant organisations. The newsletters provided an important platform for sharing information on muscular dystrophy, MDFSA activities, research developments, services and opportunities for support and participation.

Twenty-two (22) members were genetically tested during the reporting period, providing individuals with an opportunity to confirm their clinical diagnosis. Genetic confirmation can contribute to improved access to appropriate care, treatment options, clinical trials, research opportunities and support services.

MDFSA also provided an accessible WhatsApp platform through which individuals affected by muscular dystrophy could submit MD-related questions and receive expert responses from healthcare professionals and specialists. This initiative improved access to accurate and reliable information, empowered individuals to better understand their condition and strengthened the connection between members and professional support services.

A series entitled "Unstoppable You", consisting of fifteen (15) episodes, was produced for the MDFSA YouTube channel. The series provides cost-effective tips and practical strategies to assist individuals with muscular dystrophy in managing daily activities that may be challenging due to muscle weakness. The episodes focus on easily accessible tools, adaptations and practical solutions that can promote greater independence.

Strategic objective 2: To promote and support all aspects of research into the cause, nature, treatment, and cure of the condition

The National Office continued to populate the Treat-NMD Global Registries Platform with information relating to members affected by spinal muscular atrophy (SMA), limb-girdle muscular dystrophy (LGMD) and Duchenne muscular dystrophy (DMD). These registries support research, facilitate improved understanding of the conditions and assist in creating opportunities for affected individuals to participate in international research initiatives. At the end of the reporting period, 39 individuals with SMA, 42 individuals with LGMD and 46 individuals with DMD were registered. This ongoing contribution helps improve the representation of South African patients in global research initiatives.

MDFSA continued its collaboration with the University of Nevada on genetic research into Facioscapulohumeral Muscular Dystrophy (FSHD) and to facilitate the participation of MDFSA members in research studies. The collaboration contributes to a greater understanding of the genetic mechanisms associated with FSHD and may contribute to future advances in diagnosis and treatment. The study also provides an opportunity for participants to have their clinical diagnosis genetically confirmed. During the reporting period, Twenty five (25) members participated in the study.

Strategic objective 3: To raise public awareness about the condition, its impact, and the need for action.

Public awareness activities continued through a range of communication and media platforms, including radio interviews, public service announcements (PSAs), newspaper and magazine articles, websites, social media and the distribution of educational brochures and pamphlets. These activities aimed to increase public understanding of muscular dystrophy, its impact on individuals and families, and the need for greater support and inclusion.

Social media remained a cornerstone of MDFSA's public awareness and communication strategy. During the reporting period, the MDFSA Facebook page published 216 updates, with its following increasing from 2,507 to 2,624 followers. The MDFSA YouTube channel published 21 posts/videos and had 179 followers, while 41 posts were published on the MDFSA Blog. These platforms enabled the Foundation to reach a broader audience with educational information, awareness messages, member stories and organisational activities.

MDFSA continued to recognise relevant Muscular Dystrophy Awareness Days and Months through targeted awareness activities. Video clips highlighting the characteristics of different types of muscular dystrophy were shared on Facebook and YouTube. These initiatives aimed to increase the visibility of muscular dystrophy, promote greater understanding of the different conditions and highlight both the challenges and achievements of people living with MD.

September is Muscular Dystrophy Awareness Month, an important period for raising awareness and mobilising support for individuals and families affected by muscular dystrophy. MDFSA once again implemented its annual "Get into the Green Scene" campaign, with green being the recognised colour associated with muscular dystrophy awareness. The campaign remains MDFSA's signature social media initiative during Awareness Month. Supporters were encouraged to post photographs of themselves "going green", use the universal hand gesture for hope and change their Facebook and WhatsApp profile photographs to the official MDFSA logo.
A total of 21 corporates, and 28 individuals participated, making the campaign a resounding success.

Radio Sonder Grense supported the "Get into the Green Scene" campaign through the broadcasting of public service announcements, helping to extend the campaign's reach and increase public awareness. Gerda Brown and Marinus Mans were also interviewed on Radio Sonder Grense to highlight International Muscular Dystrophy Month and to raise awareness of the challenges experienced by people living with muscular dystrophy.

Strategic objective 4: To keep a record of affected persons to help identify new cases early and ensure quick and effective treatment.

MDFSA continued to maintain an accurate, up-to-date and well-organised internal database of members. Member information was regularly updated, new members were added, and records were verified and reviewed to improve the quality and reliability of the information held. The database supports effective communication with members, assists with tracking service delivery and enables MDFSA to generate information and reports that help identify trends, gaps and areas for improvement in services to affected individuals and families.

Our sincere gratitude is extended to Erik Andersen for his development of, and ongoing commitment to, the improvement and maintenance of the MDFSA database.

A special thank you is also extended to Mr Laurence Milner from CEEI for hosting the MDFSA database free of charge. This generous contribution represents an important saving to the organisation and supports the Foundation's ability to maintain an effective and accessible member information system.

Strategic objective 5: To ensure that MDFSA operates efficiently, transparently, and in alignment with its strategic goals by maintaining sound administration and governance while effectively managing daily operations.

During the reporting period, MDFSA continued to strengthen its administrative, financial and governance systems to promote efficient, transparent and accountable operations. Daily administrative and financial activities were managed, with bi-monthly financial and progress reports prepared and tabled at Executive and Branch Committee meetings. An annual Strategic Plan was developed and implemented to establish organisational priorities, while monthly Strategic Planning meetings provided an ongoing mechanism to monitor progress and ensure that activities remained aligned with MDFSA's vision and mission.

The annual budget was prepared and implemented in accordance with the organisation's strategic objectives, supporting responsible financial planning, resource allocation and financial oversight. Minutes of Strategic Planning meetings, together with financial and progress reports, were maintained as evidence of ongoing monitoring, accountability and governance.

MDFSA also prepared and submitted its narrative report to the Department of Social Development, supporting the organisation's continued compliance with NPO reporting and governance requirements.

A task team was established to develop the organisational model that MDFSA will follow going forward. The development of this model is intended to streamline operations, clarify roles and responsibilities, strengthen coordination between the National Office and Branches, and enhance service delivery. The model will contribute to a more efficient, responsive and well-managed MDFSA that is better positioned to meet the needs of individuals and families affected by muscular dystrophy.

Strategic objective 6: To collect, raise funds, receive donations, any cash or asset of whatsoever nature as may be employed towards the furtherance of MDFSA's objectives.

Crossbow Marketing Consultants (PTY) LTD has remained MDFSA's most significant funding partner since 1988. The Foundation expresses its sincere appreciation for their longstanding commitment and continued financial support, which remains an important contribution to MDFSA's sustainability and ability to provide services to the muscular dystrophy community.

During the reporting period, MDFSA continued to facilitate and coordinate fundraising initiatives aimed at generating income to support essential programmes and services. Fundraising activities

included the “Stop the Bleed” fundraising initiative, held in May 2025, as well as efforts to engage donors and identify additional funding opportunities.

A communal fundraising initiative was also organised to bring together the four MDFSA offices. The initiative aimed to raise funds, increase public awareness of muscular dystrophy and strengthen collaboration and collective support across the Foundation.

Fundraising remained challenging within the broader economic environment. Rising living costs, financial pressures on households and businesses, reduced disposable income and increased competition among non-profit organisations for limited donor and corporate funding affected MDFSA’s fundraising efforts. These challenges highlight the importance of diversifying income streams, strengthening donor and corporate relationships and developing sustainable fundraising initiatives to support the Foundation’s programmes and services.

MDFSA remains committed to exploring new fundraising opportunities, strengthening existing partnerships and developing innovative fundraising approaches to ensure the sustainability of the organisation and the continued delivery of essential services to persons affected by muscular dystrophy.

4.4. International Collaboration

Recognising that the needs of members extend beyond direct psycho-social support, MDFSA continued to focus on providing access to current and reliable information on research, diagnosis, treatment and developments in the field of muscular dystrophy. Many members identified access to the latest information and opportunities to participate in international initiatives as an important need.

To strengthen access to international expertise, information and collaborative opportunities, MDFSA maintained and established affiliations with the following international organisations:

- Muscular Dystrophy Foundation, Mauritius
- World Duchenne Organisation
- World FSHD Alliance
- LGMD Awareness Foundation
- TREAT-NMD

These international relationships provide MDFSA with opportunities to share information, access international developments in research and care, participate in global awareness initiatives and strengthen the Foundation’s ability to connect South African individuals and families affected by muscular dystrophy with relevant international resources and opportunities.

Gerda Brown
Director