



Annual Report

Apr 2023- Mar 2024

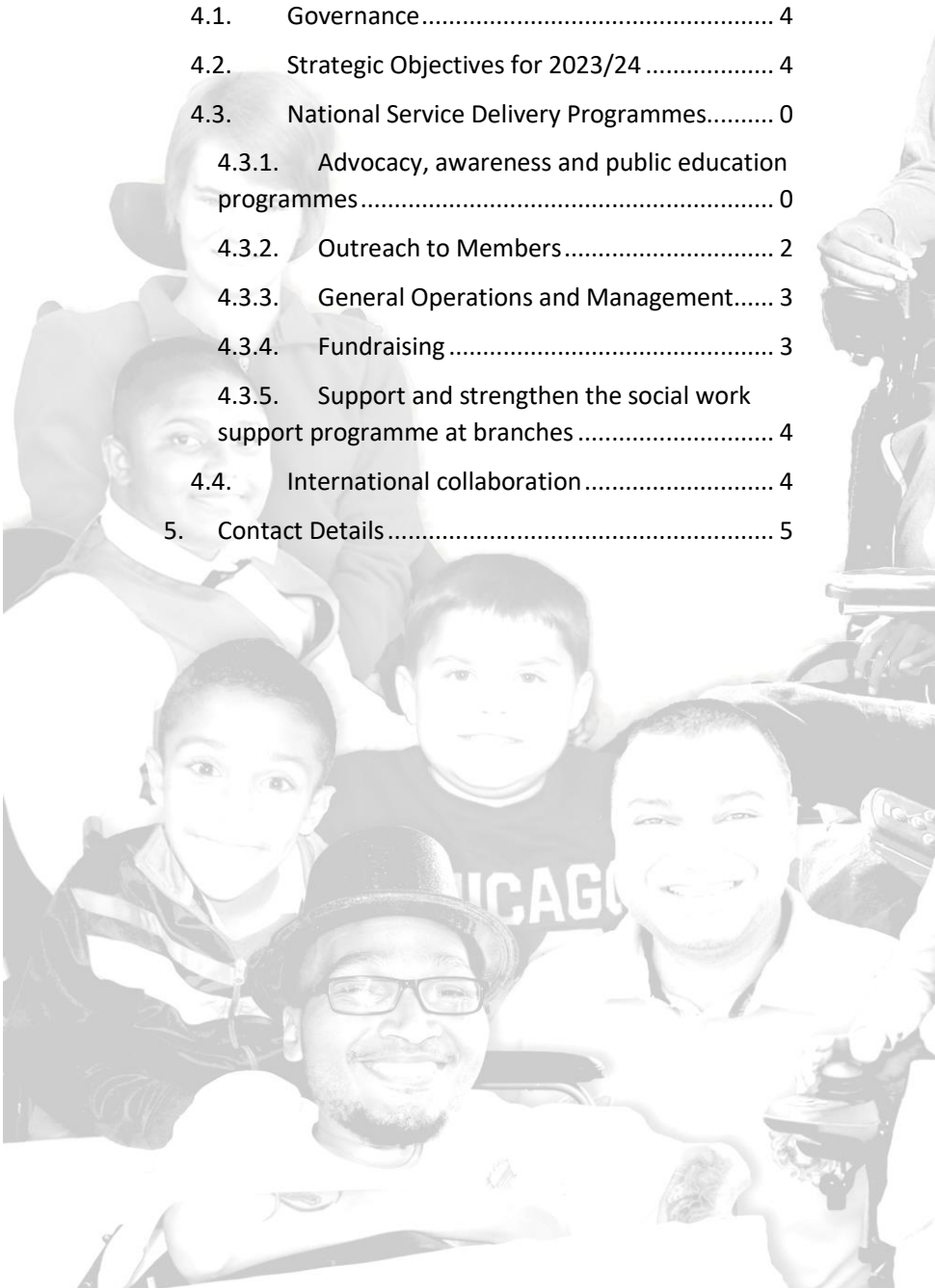
Muscular Dystrophy Foundation
of South Africa – National
Office

Annual Report 2023/4

Muscular Dystrophy Foundation of South Africa – National Office

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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.

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. National Chairman's Message

It is an honour, as Chairperson of the National Executive Committee of the Muscular Dystrophy Foundation of South Africa, to present our Annual Report. This report highlights the accomplishments made between April 2023 and March 2024.

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
Chairperson: Executive Committee

4. General Manager's Report

I am delighted to present the Annual Report for the Muscular Dystrophy Foundation of South Africa for the period April 2023 to March 2024.

4.1. Governance

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

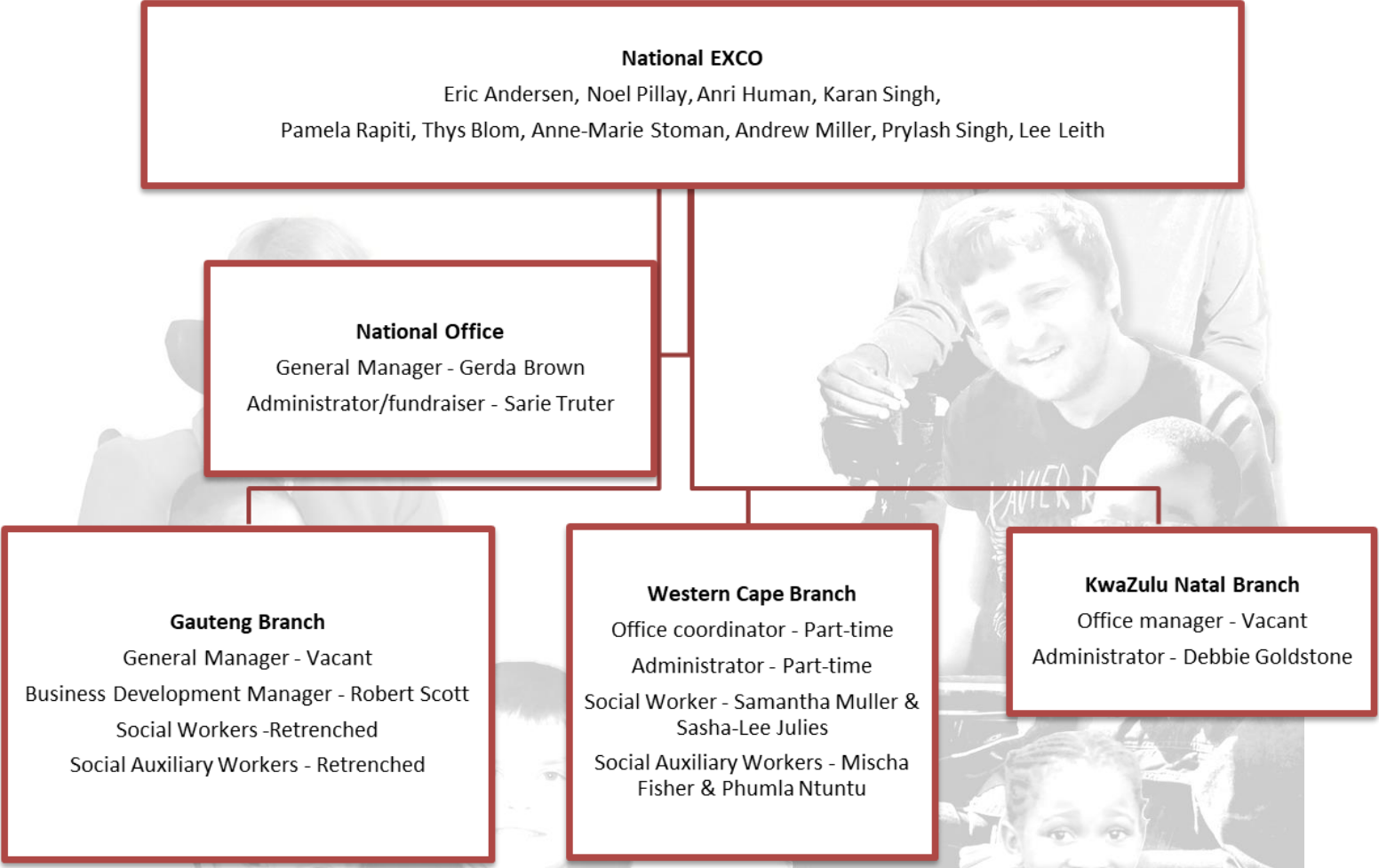
- Gauteng: Andrew Miller (Treasurer), Karan Singh and Anri Human (Secretary).
- Western Cape: Lee Leith Anne-Marie Stoman and Thys Blom.
- KwaZulu Natal: Erik Andersen (Chairperson), Pamela Rapiti, Noel Pillay (Vice chairperson) and Prylash Singh.

4.2. Strategic Objectives for 2023/24

Strategic Planning was conducted on 12 March 2022. The strategic objectives for the year were as follows:

- **Strategic objective 1:** To create advocacy, awareness and public education programs regarding muscular dystrophy.
- **Strategic objective 2:** Outreach to members.
- **Strategic objective 3:** Govern and manage the organisational structure of MDSA.
- **Strategic objective 4:** Fundraising.
- **Strategic objective 5:** Support and strengthen the social work support programme at branches.





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graph TD; EXCO["National EXCO  
Eric Andersen, Noel Pillay, Anri Human, Karan Singh,  
Pamela Rapiti, Thys Blom, Anne-Marie Stoman, Andrew Miller, Prylash Singh, Lee Leith"]; OFFICE["National Office  
General Manager - Gerda Brown  
Administrator/fundraiser - Sarie Truter"]; GAUTENG["Gauteng Branch  
General Manager - Vacant  
Business Development Manager - Robert Scott  
Social Workers - Retrenched  
Social Auxiliary Workers - Retrenched"]; WESTERN["Western Cape Branch  
Office coordinator - Part-time  
Administrator - Part-time  
Social Worker - Samantha Muller & Sasha-Lee Julies  
Social Auxiliary Workers - Mischa Fisher & Phumla Ntuntu"]; KWAZULU["KwaZulu Natal Branch  
Office manager - Vacant  
Administrator - Debbie Goldstone"]; EXCO --- OFFICE; EXCO --- GAUTENG; EXCO --- WESTERN; EXCO --- KWAZULU;
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National EXCO

Eric Andersen, Noel Pillay, Anri Human, Karan Singh,
Pamela Rapiti, Thys Blom, Anne-Marie Stoman, Andrew Miller, Prylash Singh, Lee Leith

National Office

General Manager - Gerda Brown
Administrator/fundraiser - Sarie Truter

Gauteng Branch

General Manager - Vacant
Business Development Manager - Robert Scott
Social Workers - Retrenched
Social Auxiliary Workers - Retrenched

Western Cape Branch

Office coordinator - Part-time
Administrator - Part-time
Social Worker - Samantha Muller & Sasha-Lee Julies
Social Auxiliary Workers - Mischa Fisher & Phumla Ntuntu

KwaZulu Natal Branch

Office manager - Vacant
Administrator - Debbie Goldstone

4.3.National Service Delivery Programmes

4.3.1. Advocacy, awareness and public education programmes

One of the most important roles of the National Office is informing and educating people about the work of the Foundation, Muscular Dystrophy and disability in general. In this reporting period MDFSA remained committed to sharing the message about Muscular Dystrophy to our communities.

Radio

In this reporting period the general manager of the National Offices was interviewed on Radio sonder Grense and Radio Islam to create public awareness about Muscular Dystrophy, Spinal Muscular Atrophy and the services that MDFSA offers.

Online media

Social media has become the pillar of online awareness programmes. In this reporting period the Foundation posted 207 updates on the MDFSA Facebook page. Our following grew from 2130 to 2401 followers.

The Foundation is also the proud owners of a YouTube channel where we post interesting interviews with experts in the field of muscular dystrophy, as well as life stories told by some of our members. In this reporting period 30 videos were posted. The channel currently has 105 subscribers.

Furthermore, our website is updated regularly to keep it interesting and current. Please view our website at www.mdsa.org.za.

Please also visit our newly launched Blog at <https://mdfblog.org.za/> for interesting information about Muscular Dystrophy. Thank you to Erik Andersen for developing the landing page. It is much appreciated.

MDFSA Mascot

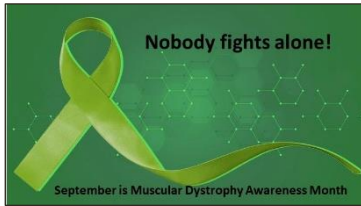
Vega School agreed to assist the Foundation with the animation of Abiri's story. The clips can be viewed on our Facebook page and YouTube channel.

The Foundation wishes to express our heartfelt gratitude for the outstanding video clips, addressing muscular dystrophy, that these students created. Their hard work, creativity, and dedication are truly commendable. The animation not only showcases their exceptional skills but also plays a significant role in raising awareness about this important health condition.

Public awareness



The Foundation celebrated International Muscular Dystrophy Awareness Month during September by running the “Get into the Green Scene” campaign for the sixth consecutive year. This campaign is our signature social media event to recognize Muscular Dystrophy Awareness Month. The campaign is designed to stand out on social media by combining the campaign’s official colour (green) with an eye-catching image.



The MDFSA staff, 37 corporates and 35 individuals participated in the campaign by posting their “green” photos on the MDFSA Facebook page. We had a very successful campaign with many new faces participating.

Celebrating awareness days/months

Raising awareness is very important to the Foundation. Our role is inter alia to dispel the lack of knowledge, mythologies and stigma around disability and muscular dystrophy. This is achieved by allowing our affected members to share their journeys on specific awareness days.

In this reporting period the following awareness days were marked by interviewing selected members about living with muscular dystrophy:

- Spinal Muscular Atrophy Awareness Day
- World Duchenne Day
- Limb Girdle Awareness Day
- Rare Diseases Day
- Myasthenia Gravis Month
- World FSHD Day
- International Fredrich’s Ataxia Day
- Becker Awareness Week

The recordings of the interviews are available on the MDF Facebook page and YouTube channel.

A special thank you to Marinus Mans for conducting the interviews with such compassion and letting our members feel at ease to share their stories.

Webinars

A very insightful FSHD webinar was hosted on 23 June 2023 by Dr. Mark Tarnopolsky who is a Professor in the Department of Pediatrics and the Division Head of Neuromuscular and Neurometabolic Disorders. Dr Tarnopolsky presented on FSHD, nutrition and exercise. The recording of the presentation is available on the MDF YouTube channel and Facebook page.

Speaking engagements

The general manager and treasurer addressed 61 geneticists about muscular dystrophy and access to new genetic treatment options.

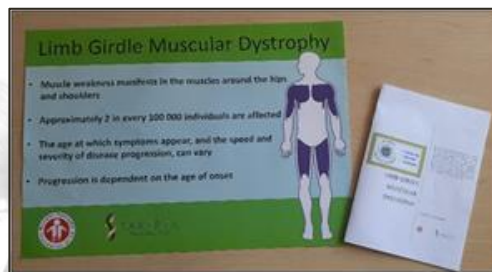
The general manager was also invited as the guest speaker at Sarepta Pharmaceuticals to mark Rare Disease Day.

Awareness material

Like many rare diseases, there are many misconceptions about Muscular Dystrophy. Most people are not familiar with MD until a family member or friend gets diagnosed with it.

To create awareness at clinics and hospitals, and to empower newly diagnosed individuals, posters and information manuals were developed for Limb Girdle Muscular Dystrophy (LGMD) and Facioscapulohumeral Dystrophy (FSHD).

We want to express our sincere gratitude to Sarepta for their generous funding to develop the mentioned awareness materials. Their support has been instrumental in allowing us to create impactful and informative resources that are essential in educating the public about this condition.



4.3.2. Outreach to Members

The Foundation's role within social integration and support services is mainly to provide support to members affected by Muscular Dystrophy and their families. Support is largely provided by means of psycho-social support, provision of assistive devices and dissemination of information.

MDF Newsletter

In the ever-evolving landscape of information dissemination, the Foundation embraced and transformed the traditional magazine into a more interactive and accessible format—a quarterly newsletter in PDF format, as well as a blog.

The first issue of the Newsletter was circulated in June 2024.

Access to treatment

MDFSA supports the notion that members should join a registry if one is available for their condition. Registries are databases that contain information about individuals affected by a particular condition. With permission, researchers and companies can view this information and recruit eligible patients for trials. The information registries contain can also help clinicians to understand more about the condition and develop care standards.

The Foundation is currently affiliated with TREAT-NMD for the LGMD and SMA datasets. Curators have been appointed on fixed term contracts to add members to the Global Registry Portal.

The Foundation is currently also offering assistance with genetic testing for three types of muscular dystrophy. It is of great importance that members confirm their diagnoses genetically to enable them to access treatment when it becomes available.

- Spinal Muscular Atrophy: To date, a total of 33 members' information has been captured on the LGMD register of Treat-NMD and 5 members have been assisted with free genetic testing.
- Limb Girdle Muscular Dystrophy: To date, a total of 49 members' information has been captured on the LGMD register of Treat-NMD and 24 members have been assisted with free genetic testing. This project will continue until the end of 2024.
- Facioscapulohumeral dystrophy: 49 Members has been assisted with free genetic testing since the inception of this project. The Foundation is currently in the process of negotiating access to the FSHD registry with TREAT-NMD.

Our gratitude is extended to Dr Peter Jones from the University of Nevada, Sarepta and Newcastle University for making these projects possible.

Support groups

In conjunction with our members, support groups are available for FSHD, LGMD, DMD, Congenital MD and SMA. The efforts of Mina Du Plessis, Janeen Barber and Christel Rohrs, for coordinating these groups, are applauded.

MDFSA ambassadors

Our ambassadors invited five members to a pamper day which included a make-over and photoshoot. The Foundation wants to extend their gratitude to Liam and Ruan for hosting this fun day in celebration of our very special members.

4.3.3. General Operations and Management

Policy development

The nature of our organisation demands that certain systems and policies and procedures are in place. The policies relating to Finance, Corporate Image, Disciplinary Code and the management of volunteers were reviewed.

Internal database (Odi)

A tracking tool is now available in the database. This tool will provide a report of all contacts with affected members per month and would eventually provide a snapshot of all contacts per member for a year.

Our gratitude is extended to Erik for the development of the tool.

There's currently 1283 affected members registered on Odi.

4.3.4. Fundraising

Crossbow Fundraising Campaign

Crossbow Marketing Consultants (PTY) LTD remains our greatest funder. Since 1988 Crossbow has been assisting us to raise funds by designing, manufacturing, marketing and selling various products for and on behalf of MDFSA.

We wish to thank Crossbow for their unwavering support. The income generated by them allows us to work towards the goals of our organisation and we truly see this partnership as essential to our survival and longevity.

Grants & donations

We appreciate and give thanks to the individuals and companies for their kind donations. Support of the Muscular Dystrophy Foundation makes it possible to provide a service and support structure to families affected by this crippling and often fatal disease.

In particular, we wish to single out FC Robb Charitable Trust, Sarepta and Separations for their kind grants/donations.

MDFSA merchandise

The national office has a range of merchandise for sale as a fundraising campaign. Please contact Sarie Truter to order.



MDFSA High Tea

MDFSA hosted their first High Tea during July 2023.

We wish to express our appreciation to our two Ambassadors for their time and hard work to make the fundraiser so successful.

Champions 4 Charity

Shout out to Antoinette Rudolph for dedicating her boxing match to MDFSA to raise awareness about muscular dystrophy. Both Antoinette's sons have a muscle disease where the oldest had to have a heart transplant and the youngest's body is badly ridden by the disease.

4.3.5. Support and strengthen the social work support programme at branches

Psycho-social support services and the provision of assistive devices to affected members are provided by the three branch offices. Detailed information regarding the social work programme is available in the annual reports of the branches.

However, in terms of the Social Service Professions Act (110 of 1978, as amended) all social service professionals are required to work under the supervision of a senior social worker. Due to financial challenges and the subsequent absence of supervisory posts on branch level, it is the role of the National Office to oversee the social work programme and provide guidance to the social service professionals based at the Cape branch.

4.4. International collaboration

MDFSA realised that not all our members require psycho-social intervention and emotional support. Many of our members decline any form of support services.

These members express that access to the latest information with regards to research and treatment as their paramount need.

Very little information is available in South Africa and therefore working relationships were established with international organisations which specialize in specific types of muscular dystrophy. MDFSA is now affiliated with the World Duchenne Organisation, World FSHD Alliance, LGMD Awareness Foundation and TREAT-NMD.

The Foundation attended the World Action Duchenne Conference, World FSHD Summit, as well as the FSHD Annual World Leadership Summit in this reporting period.

The Foundation is affiliated to the following international Muscular Dystrophy organisations:

- World FSHD Alliance - The World FSHD Summit was attended on 26 & 27 June 2021.
- Action Duchenne
- Limb girdle muscular dystrophy Awareness Foundation
- Treat NMD

5. Contact Details

National Office

12 Botes Street, Florida Park
Tel 011 472-9703

Gauteng Branch

12 Botes Street, Florida Park
Tel 011 472-9824

KZN Branch

Office 7, 24 Somtseu Road, Durban
Tel 031 332-0211

Cape Branch

3 Wiener Street, Goodwood
Tel 021 592-7306



Gerda Brown
General Manager: National Office