

Annual Report 2018

Muscular Dystrophy Foundation of South Africa



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# 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.

# 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 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.

# National Chairman’s MessageImage may contain: 1 person, smiling

It is with a deep sense of pride that I submit to you the Annual Report for the year 2017/2018 financial year.

MDF is a non-profit organisation (NPO) founded in 1974 and with a proud history of offering services to children, adults and families across South Africa. In providing these services, MDF aims to support people affected by Muscular Dystrophy and Neuromuscular disorders. The end goal is to improve the quality of life of its members and advocate for the protection of people with disabilities and enabling them to grow in safe and nurturing environments. We have been through some very hard times, particularly in the finance area, and we have had to make many difficult decisions, all in the interests of our very special members. However, despite the challenges, this Foundation has a proud history of 44 years. . It is a remarkable achievement given the political and socio-economic changes experienced in our country throughout the years.

On behalf of the Foundation I wish to thank those organisations, businesses and individuals who have assisted us to bring our much-needed services to our members and their families. I offer my gratitude to:

* LOTTO;
* FC Robb Charitable Trust;
* Titanus Slew Rings;
* Healthman; and
* Our long-time partner – Crossbow Marketing.

To our dedicated staff members, I thank you most sincerely for your contribution to the success of the Foundation and the well-being of our very special members. We wish all the branches the best in their continued work to ensure that disabled people benefit from the rights that our Constitution promises them.

Good and strong governance is the heart of every well-functioning NPO. In this regard I am grateful to my fellow EXCO members who selflessly offer their professional knowledge towards the betterment of the lives of people affected by muscular dystrophy. I look forward to another year working together to achieve our common goal.

**Maatjan Ferreira**

# General Manager’s Report

I am delighted to present the Annual Report for the Muscular Dystrophy Foundation of South Africa for the period September 2017 to August 2018.

## Governance

National Executive Committee

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

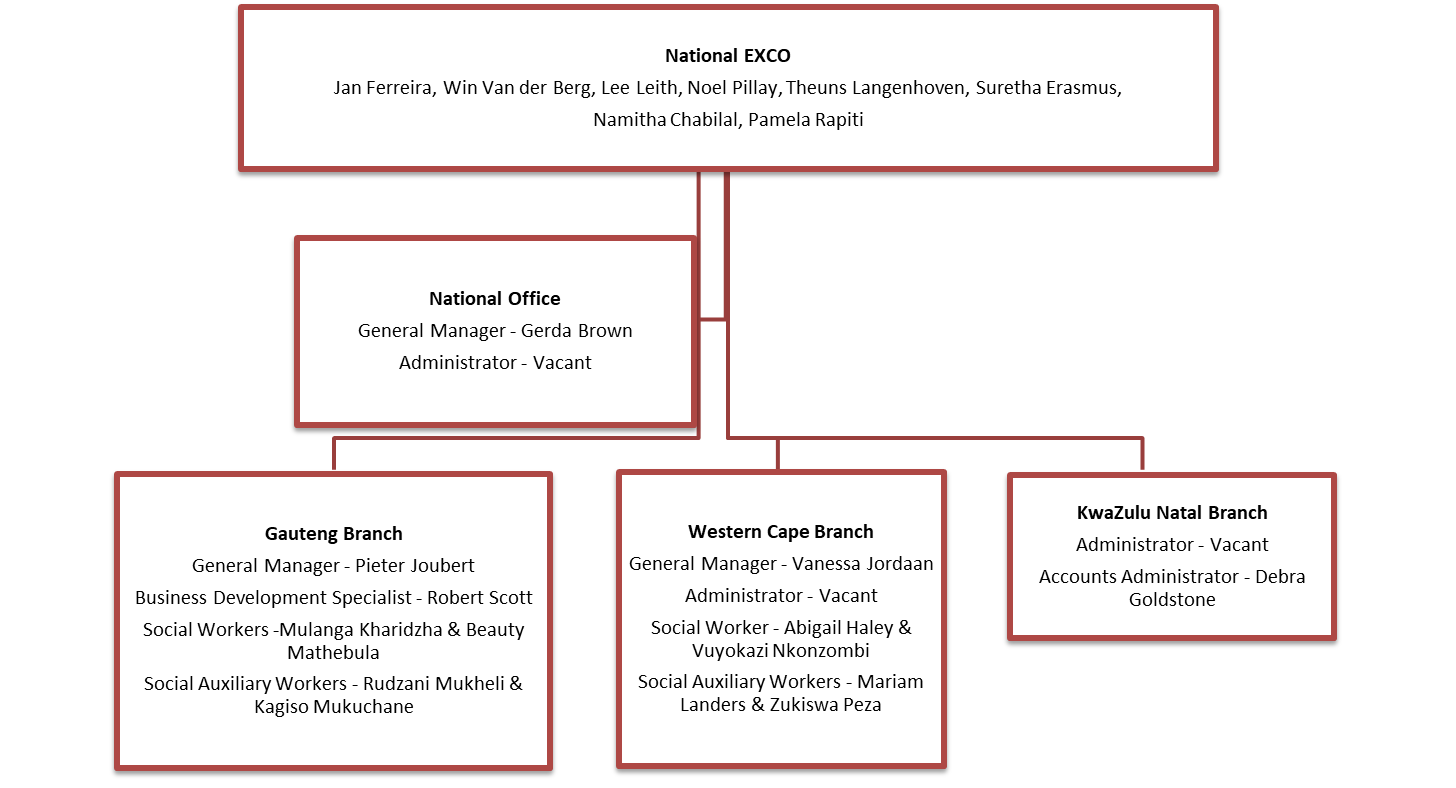
* Gauteng: Theuns Langenhoven, Jan Ferreira (Chairperson) and Suretha Erasmus.
* Western Cape: Win van der Berg (Vice chairperson), Lee Leith (Secretary), Gilda van der Merwe.
* KwaZulu Natal: Pamela Rapiti, Namitha Chabalal and Noel Pillay (Treasurer).

Strategic Objectives for 2017/18

Strategic Planning was conducted on 24 February 2018. The strategic objectives for the last two years have been identified:

* Strategic Objective 1: To facilitate and coordinate 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.

Organisational Structure



The National Office was in the fortunate position to appoint a volunteer with funding received from LOTTO. A big, heartfelt thank you to Sarie Truter for making herself available to assist with the administrative duties of the office.

## National Service Delivery Programmes

Advocacy, awareness and public education programmes

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

* **Celebration of Muscular Dystrophy Month and World Duchenne Day**

The month of September is Muscular Dystrophy Awareness Month with special emphasis on Duchenne Muscular Dystrophy Day on 7 September. This month is a special opportunity to educate the public about muscular dystrophy and issues within the muscular dystrophy community. During September a press release was published in local newspapers and on Facebook to educate communities about muscular dystrophy.

Gauteng and Cape branches also participated in the celebration for World Duchenne Day by releasing red balloons on 7 September 2017.

* **Radio**

On 25 April 2018 Gerda Brown was interviewed by Voice of the Cape to create awareness for muscular dystrophy and on 18 September 2018 by Rise FM.

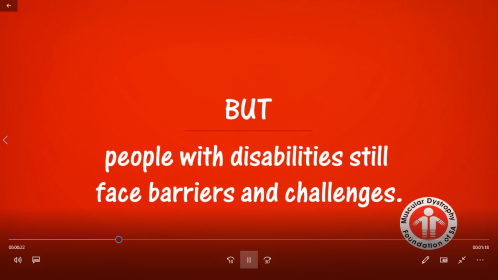
* **Television**

eTV graciously aired our advert 43 times in different time slots during September 2017 to coincide with Muscular Dystrophy Awareness Month. We would like to express our appreciation to eTV for always being willing to partner with us in raising awareness.

On 28 September 2017, Gerda Brown and Bernadette Francois were also interviewed by Ronald Abvajee from 'Shape Your Life' on African News Network 7 to raise awareness about muscular dystrophy and the role of the Foundation.

* **Written media**

Awareness adverts were published in ThisAbility Newspaper.

* **Public awareness**

Idea Saints designed an awareness video on disability and challenges in community participation. We would like to thank Idea Saints for doing the video pro bono for the Foundation. The video can be viewed on the MDF YouTube channel and on the MDF Facebook page.

* **Internet**

Social media has become the pillar of online awareness programmes. In this reporting period the Foundation posted 165 updates and the following grew from 827 to 993 followers. This represents a significant increase in the number of people the Foundation interacts and engages with.

We also want to express a heartfelt thank you to KM Hosting for updating the Foundation’s website pro bono.

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.

* **Support services**

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 different branches.

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.

The focus of the sessions is to:

* Provide supervisory support with regards to individual cases, and group work.
* Development of new resources.
* Quality assurance of social work programme.
* **MDF Magazine**

The Foundation distributes a magazine to our members, medical professionals, as well as national and inter-national NGOs three times per year. The aim of the magazine is to keep members informed of all activities and research, nationally and internationally.



Over the past few years technology has however changed dramatically and has become vital in today’s world. In order to keep in line with worldwide trends, we transformed our paper magazine into an e-magazine that is emailed to our members and also shared on our Facebook page.

Thank you to everyone that contributed all the insightful articles to our Magazine, as well as the companies that placed advertisements.

* **Coordination of the online adult support group**

An online adult support group was established during October 2017. This is a private social group for people who share the bond of Muscular Dystrophy. There are currently 35 members.

General Operations and Management

* **Management of member database**

Unfortunately we have to report that our member database crashed during December 2017. Since then we have been operating an Excel-based database. We are however in the fortunate position that a Cape Town based company; Find the Gap, offered to design a new database for us pro bono.

* **Certification of World Duchenne Care Centre**

Red Cross Children’s Hospital applied for certification as a Duchenne Care Centre with Parent Project Muscular Dystrophy, USA. It is envisaged that certification would pave the way for clinical trials in South Africa. In conjunction with Parent Project, MDF conducted a site visit to confirm the services provided by the hospital. The Certification Team was of the opinion that exceptional services are provided to boys diagnosed with Duchenne and recommended certification. On 27 October 2017, Parent Project Muscular Dystrophy awarded the Red Cross Children’s Hospital’s neuromuscular service certification as a Global Duchenne Care Centre. This certification is the first of its kind outside the borders of the United States and confirms that Duchenne-specific patient care and management is provided to affected boys at this centre in agreement with international standards.

* **In-service training**

A business or organisation should never stagnate and therefore nor should the development of staff, who are the key asset in driving a business forward. Regular staff training is essential in helping this ongoing skill development.

Employees were subjected to an in-service training programme, via Skype, during this reporting period. The focus of the programme was to increase knowledge about the different types of muscular dystrophy.

Governance and administration

* **SARS**

The Foundation met with representatives of SARS during November 2017 to discuss our tax liability with regards to the income received from the Crossbow campaign. A final decision is still pending from SARS legal division.

* **Grants to branches**

It is with sadness that we have to report that the grants to branches had to be terminated at the beginning of this financial year.

Fundraising

* **LOTTO funding**

A total amount of R343 400.00 has been allocated to the Foundation, inclusive of the National Office and KZN branch. The bulk of the funding was earmarked for wheelchairs (R250 000.00) but allowance was also made for some operational expenses.

Our appreciation is extended to LOTTO for the funding.

* **FC Robb Charitable Trust**

We give thanks to the Trust for their continued support and for financing the development of a children’s storybook about muscular dystrophy; and an information leaflet to parents.

* **Casual Day**

The Foundation has been made a national beneficiary of Casual Day. This will result in the Foundation receiving a share of “non NGO” contributions to the campaign (in addition of the R4.00 from sticker sales). This could be an enormous opportunity for fundraising.

* **Crossbow Fundraising Campaign**

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

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

* **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.

# 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 Town Branch**

3 Wiener Street, Goodwood

Tel 021 592-7306

**Gerda Brown**

**General Manager: National Office**