Muscular Dystrophy
Support Centre
inspiring independence

IMPACT REPORT
2019-20

COMMUNITY FUND

Welcome

Welcome to our Impact Report for 2019-20.

The last year has been an unpredictable time as we found ourselves in the midst of a global COVID-19 pandemic just as we were beginning work on our ambitious five-year strategy. As always, our aim is to provide access to therapies and support for people living with MD in the Midlands and our staff and volunteers worked incredibly hard to ensure we did exactly that, whilst never losing sight of our plans to expand access to therapies throughout the Midlands.

In the first 3 quarters of the year, we continued to provide our core therapies physiotherapy and osteopathy as in-clinic services, as well as other therapies from our main Centre at Hereward College in Coventry, and at satellite locations in Birmingham and Droitwich, adding our Loughborough satellite in August 2019. Our service user numbers continued to grow with an additional 71 new service user referrals.

This year has seen the charity develop and evolve to meet unprecedented challenges and the needs which arose from these; many of our service users were advised to shield, and to support them we acted fast to implement an online service that included one-to-one sessions, group classes, drop-in sessions and pre-recorded resources. These new remote services opened up a new option for all service users to engage with their therapists from the comfort and safety of their homes, and to connect with peers during a time of isolation and uncertainty, they've been so well received that they're now a permanent part of the support we offer.

As soon as government guidelines allowed, we put in place a range of measures to ensure that we could practice safely in a Covid-secure environment and reopened our doors to those who were able to come in for face-to-face therapy. Initially we offered limited appointments and then increased availability as measures were relaxed nationally. **We have continued to support our service users as a crucial healthcare provider throughout this challenging time both in-person, and online.**

During the year we provided 2,553 therapy sessions, of which 1,524 were face-to-face contact hours delivered from August 2019 to March 2020 and 1,029 were online therapy sessions delivered from March to July 2020.

The pandemic unfortunately forced us to close our new Satellite Clinic in Loughborough, we are actively looking for a new site to ensure that this pause in local therapy for the East Midlands region is a short one. To help us grow our services, we recruited an Executive Director to lead our team and a Fundraising Assistant to help us in growing and diversifying our income.

As the sole provider of regular physiotherapy for people with MD in our region, it is essential that we continue to meet increasing demand as things begin to open back up and referrals increase as a result.

We are continuing with the plans to transform our service to be able to meet the needs of all people with MD across the Midlands who need it. We have been expanding our team and as well as looking to relaunch our East Midlands Satellite Clinic, we will be opening the first of several additional satellite clinics scheduled for the next five years, next Summer in the Black Country.

Through collaboration with the people who use our services, we want people with MD to be as involved as possible as we grow the charity ensuring our service continues to meet the needs of the community we serve. People with MD are represented at all levels of our organisation from the Board of Trustees to our Fundraising and Awareness Groups and also among our staff and volunteers.

The creation of more opportunities for people with MD to get involved in the governance of the organization and having a say in our decision-making is an important part of our five-year strategy and we have plans to launch a service user led Steering Group and Project Board next year that will form a crucial part of this work.

Of course, as we grow our services, we will need to increase and diversify our income. We continue to be indebted to our tireless supporters who go above and beyond to raise funds for us in their local communities, running events and a huge range of other activities to help keep funds coming in. Our regular donors continue to help by providing vital cash donations, and we are also grateful to a number of charitable trusts and foundations for their generous contributions. And as ever, we are endlessly grateful to our many volunteers who selflessly provide skills, time and support and to our team members, who work tirelessly to help people with MD.

On behalf of the Board of Trustees, thank you to everyone who has contributed to the very real difference Muscular Dystrophy Support Centre makes to the lives of the people with muscular dystrophy and their families. Our work is only possible thanks to you.

Ruth Hereford
Chair of Trustees

Who we are

About us

Muscular Dystrophy Support Centre was set up by and is led by people with muscular dystrophy (MD) and their families. Our Board of Trustees has seven members, all of whom either have MD themselves or have a family member with muscular dystrophy. We have been providing therapies since January 2013.

Operating from our Centre in Coventry, and with primary satellite clinics in Birmingham and Loughborough (to be launched in 2019), we support people primarily by providing specialist physiotherapy on a long-term basis. We are the only organisation in the Midlands region to do so, and one of only two in the UK. The majority of our referrals currently come from GPs and specialist Consultants in hospitals across the Midlands.

Need

Muscular dystrophy is a life-long, progressive condition that affects around 70,000 people nationwide. There are more than 60 different sub-types of muscular dystrophy and related neuromuscular conditions which cause the muscles to weaken over time and waste away. Their severity and how they affect the individual varies from person to person. Some conditions begin in childhood and are ultimately life-limiting while others are diagnosed in adulthood.

As the person's muscle strength deteriorates, life can become extremely challenging, especially as most people lack access to regular physiotherapy that is central to preservation of strength and effective management of the condition.

Regular physiotherapy can help improve muscle usage, reduce pain and slow down muscle deterioration, enabling people to better manage their condition and retain greater functionality and independence. Around 11,000 people with muscular dystrophy live in the Midlands.

But current provision of appropriate therapy is very poor, and falls behind other long term conditions. For example, there are 100,000 people in the UK with another degenerative condition - Multiple Sclerosis - and over 50 therapy centers to serve their needs. For the 70,000 people with MD however, there are just 2 therapy centres. This leaves over 8,000 adults in the Midlands alone unable to access the therapy they need.

Our aim as an organisation is to transform access to therapy for everyone with MD in the Midlands region **who needs it.**

Our approach

Our goal is “inspiring independence”. There is currently no cure for MD, but evidence from our work shows that regular physical therapies can help reduce pain and slow down muscle deterioration, enabling people to take control of their condition and retain greater functionality and independence. Key to our approach is its long-term nature – we never discharge service users once registered.

We are:

Committed – We don’t discharge service users once registered so they can rely on us to help them manage their condition long-term and access our therapies/support as needed. Some service users attend therapy fortnightly or monthly, others less frequently.

Specialised – As MD conditions are rare, many GPs and community physiotherapists have had little exposure to it. This matters because with muscular dystrophy, the muscles do not rebuild or respond in the way they would with other patients. Our staff are specialist neurological physios with concentrated experience of working with muscular dystrophy. Treatment from our physios includes hands-on muscle manipulation, work on the core, and use of assisted exercise equipment as well as exercises to carry out at home.

Preventative – When someone begins to lose muscle function in one area, they may compensate by over-using another muscle which can start a downward spiral. Regular therapy helps identify these progressions quickly, focusing on efficient muscle use and retaining the best possible overall condition. With early intervention, many people see an improvement in their muscle function after a few months’ therapy. The subsequent decline typical of muscular dystrophy can be slowed down or lessened accordingly.

Multi-disciplinary – Every newly referred person has a detailed assessment with a physiotherapist at their first appointment. Then, depending on their needs and wishes, they may use any of our services: physio, osteopathy, hydrotherapy, complementary therapies, or online services including group classes, drop-in sessions, pre-recorded resources and one-to-one sessions.

Our progress this year

We received 71 new referrals, this is slightly less than the previous year but a decrease is to be expected given the impact of the pandemic.

During the year, the number of registered service users grew to 375. We provided 2,552 hours of therapy, an increase of 24% on the previous year. As we were initially forced to reduce the number of available appointments, our waiting list grew to around 12 months.

Prior to lockdown, at our satellite clinic in Birmingham (held at Acorns Children's Hospice in Selly Oak), we were providing over 13 hours of therapy per month in Birmingham, and we plan to increase this as soon as we are able to reopen. This clinic was the blueprint for our Satellite Clinic model, which we plan to expand throughout the Midlands over the next 4 years.

We have continued to recruit and develop therapists over the past year. We now have 5 neurological specialist physios, 3 osteopaths and 1 complementary therapist in our therapy team. We have also recruited a new Executive Director and plan to recruit other team members to support the administration and development of the Charity.

85% of available therapy hours were filled compared to 86% the previous year so there has been very little change to date despite the impact of the pandemic. Our administration team works hard to refill cancelled sessions as they are in such high demand, but some last-minute cancellations, especially due to illness, are to be expected.

As a charity we began measuring outcomes at set intervals in physiotherapy for each service user (participation is voluntary). The aim is to compile data which will help inform interested parties of the trajectory of the condition of individuals receiving physiotherapy over time. As part of our 5 year strategy (Transforming Access to Therapies) we will be looking at how we use these and other new outcome measures to provide an evidence base for our care model and to enhance the services that we provide.

Due to the impact of Covid-19 including government lockdown restrictions and social distancing measures, we have been unable to hold our usual annual Open Day, but we hope to host an event as soon as we are able - this will likely be an online event. We plan to take our annual service user survey online at the same time.

Feedback

I am absolutely thrilled with the online physio sessions run by specialist physios. It is an amazing service on hand during the unprecedented COVID pandemic. Many of us would have missed our time attending the clinic in Coventry but hey presto, with modern technology and the dedication of the superb specialist physio team, the service has continued and has been truly inspirational. It has been of great benefit not only to myself, but I am sure other patients have gained so much to stay in touch and to meet as a group meaning we do not feel isolated. The sessions have helped with my overall well-being; I look forward to the hour every week (I now take part in three sessions) that has been arranged by the dedicated team. The expertise relayed by the team has kept us on track with exercises to keep our muscles going. Thank you one and all.

Jayne, service user

Everybody that I've met through the centre now feel like my part of my extended family and the online support has been extremely beneficial if not vital especially during lockdown and due to my own personal situation.

Emily, service user

Before coming to the MD Support Centre, the limited help I received with my condition was always reactive – following a fall or some other kind of injury. What's so good about the MD Support Centre is that their support's proactive. I feel like I don't have to worry now, because I know I have the ongoing support and regular therapy from the centre and their therapists as well as my peers who I can talk to in their online social group.

Ian, service user

Sharing our skills

We recently created a series of four videos demonstrating different approaches to treating people with muscular dystrophy based on our experience. The videos are accompanied by a 50-page practice guide which details our approach to assessment, treatment and review. We plan to share this material with interested health and care professionals and to monitor uptake of the new materials among professionals in the field, this includes collecting feedback on their use and possible development in future. With the profound impact of COVID-19 on health and care professionals this year, we have not yet progressed the sharing and monitoring aspect of the project but we look forward to disseminating the material in the near future.

Our partnerships

We work in partnership with **Hereward College**, a college for young people with complex disabilities and learning challenges. Hereward is our landlord, from whom we have rented our Centre space since our inception in 2012, and we share their physiotherapy suite. The two physio teams share best practice, knowledge and skills, and we are forever grateful to everyone at Hereward College for this partnership.

Acorns Children's Hospice is the partner organisation for our Birmingham satellite clinic.

We continue to work to build relationships with local **Clinical Commissioning Groups** (CCGs) to grow NHS contributions to our income.

We regularly signpost service users to **Muscular Dystrophy UK**'s advocacy service for support with areas such as benefit entitlements and care packages. They signpost to us for physiotherapy on their website. We would normally attend their national conference and play an active role in their East and West Midlands Muscle Groups but COVID-19 has significantly restricted these events and groups in this year. We continue to hold a range of MDUK's printed materials in our main Centre location for our service users, including MDUK's Alert Cards.

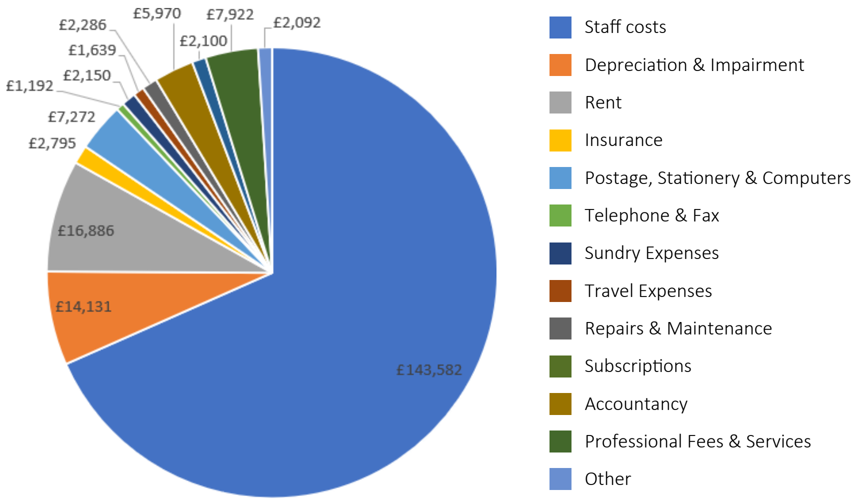
We remain in regular contact with other relevant parties such as the **NeuroMuscular Centre**, the only other therapy centre like ours in the UK. We are continuing talks with Coventry University to explore future physiotherapy research partnerships. We utilise MDUK information and research findings in our fundraising literature wherever appropriate.

Financial update

Expenditure

We increased our expenditure in 2019/20 to £209,997 - up from £180,325 the previous year.

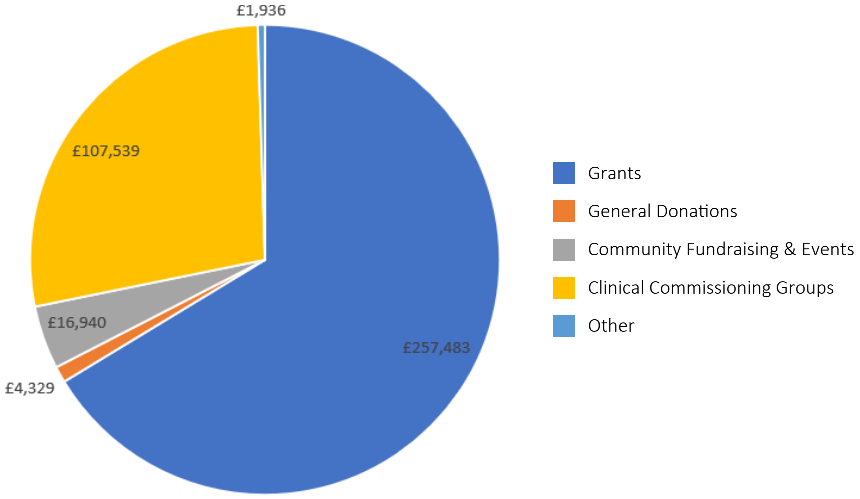
What is the breakdown of our expenditure?



Income

We had a strong year for income growth in 2019/20. Total income was £398,840 up from £237,065 the previous year.

What is the breakdown of our income?



Fundraising efficiency: For every £1 we invested in fundraising, we generated £8.70.

Our plans for the future

Increasing demand for our service remains a challenge for the Charity. We are committed to meeting the needs of people with muscular dystrophy and are seeing a steady increase in referrals month by month. This, along with reduced face-to-face capacity for part of the year due to COVID-19, has increased pressure on our service and driven up our waiting list. There are no other providers of our service in the Midlands region and it is incumbent upon us to have a strategy in place for our long-term sustainability and growth.

The rapid growth of our therapy services in order to meet the needs of people with muscular dystrophy is something the whole team is immensely proud of, but it has also created challenges to which the Charity must respond. To date, the Charity has been run with significant involvement of volunteers, most notably being managed on a day-to-day basis by the Chair of Trustees, Ruth Hereford. The organisation has now reached a point where its size and complexity necessitate a professional team, we have recruited a number of key roles in this regard and the completion of this process is a priority over the coming period. This work will ensure the organisation remains sustainable in the long-term.

In May 2020 we started work on our five-year capacity-building project (delayed by the Covid-19 pandemic) ‘Transforming Access to Therapies’. This project is being supported by a grant from the National Lottery Community Fund.

The aim of this project is to help our charity grow sustainably in order that we can provide therapies for people across the Midlands who are in need. This will improve the ability of people with muscular dystrophy to live well with their condition by growing our capacity, scope, reach, and relevance to younger people with MD.

By 2025, we will be providing over 1,100 people with regular therapy as well as providing numerous new volunteering and peer support opportunities for people in the muscular dystrophy community. This is a complete step change in enabling people to access therapies that improve their lives and help them retain their independence.

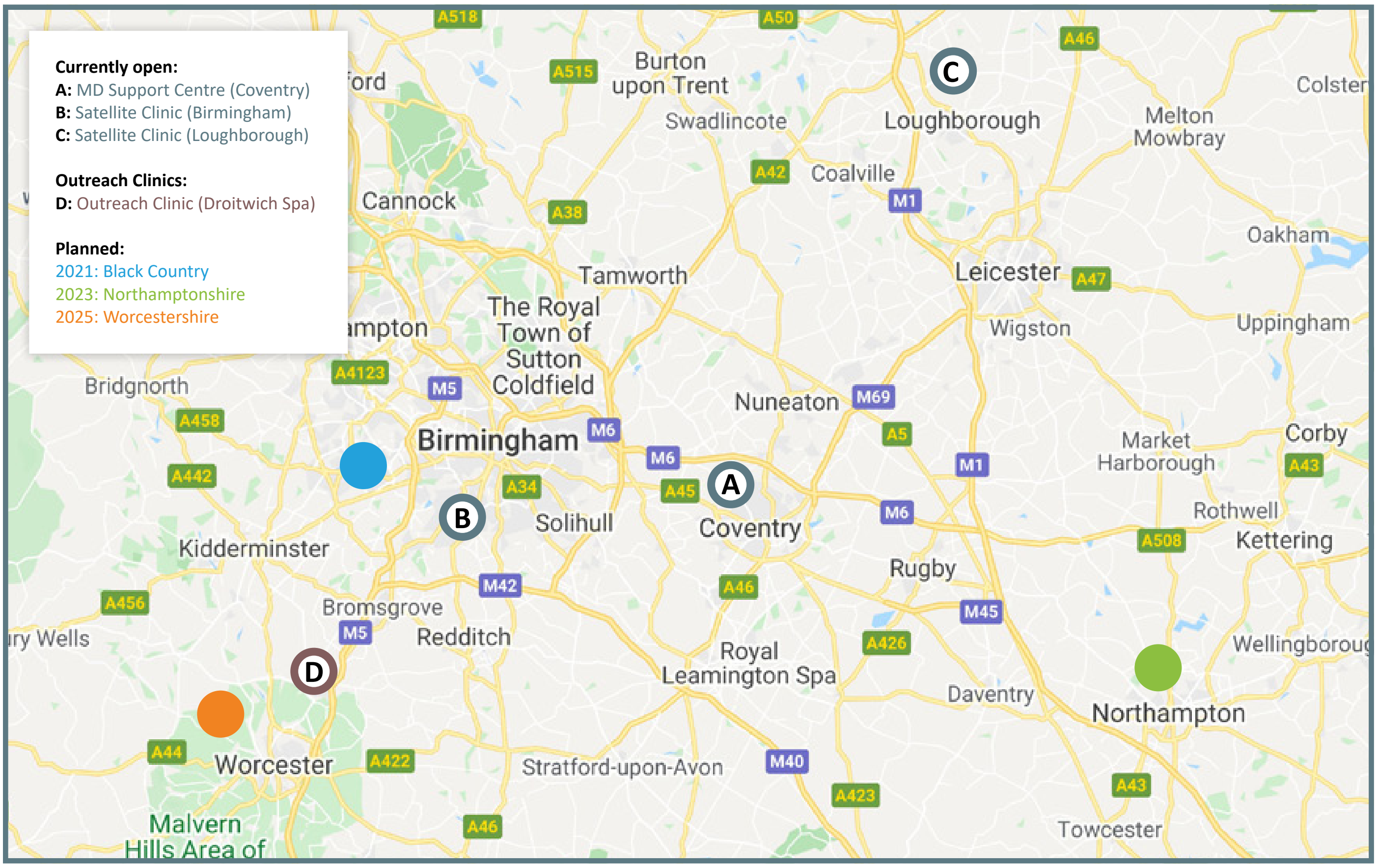
This will include three new satellite clinics with partner organisations in the Black Country, Northamptonshire and Worcestershire.

At the heart of this growth strategy is the requirement to be led by people with MD. We are very grateful for our active community of service users and their families and will be creating a number of new opportunities to get involved in the charity's development via satellite clinic steering groups, a project board, and additional Fundraising & Awareness Groups.

We are very grateful to the National Lottery Community Fund for supporting this project. Their grant of almost £300,000 over five years will cover around a third of the total cost. As a charity we will need to raise the remaining two thirds of the income.

In order to ensure we grow sustainably, we will diversify income streams and improve the Charity's communications and marketing, securing our ability to serve people with muscular dystrophy for the long-term.

Our locations plan



Meet the team in 2019-20

Ulrike Uta	Co-Lead Physiotherapist
Lynn Ward	Co-Lead Physiotherapist
Chandni Patel	Physiotherapist
Kelly Wooldridge	Physiotherapist
Kate Andrejevas	Physiotherapist
Taher Dhuliawala	Physiotherapist
France Quirin	Co-Lead Osteopath
Jane Field	Co-Lead Osteopath
Liz McGirl	Osteopath
Alison Sheff	Complementary Therapist
Sarah Ann Moore	Executive Director
Natasha Sweet	Philanthropy Manager
Nina Hanks	Fundraising Assistant
Cristian Mezei	Website Volunteer
Corrina Jacob	Reception and Administrative Coordinator
Louise Meadows	Reception and Administrative Assistant
Debbie Meadows	Reception and Administrative Volunteer
Vicki McGeown	Reception and Administrative Assistant
Bryan Gould	Engagement Officer
Anna Walker	Project Manager
Terry McDonagh	Administrative Volunteer
Linda Hill	Volunteer Safeguarding and Clinical Team Support

Our Trustees

Thank you...

We continue to value the incredible generosity of all the individuals, community groups, companies, charitable trusts and foundations that support the Muscular Dystrophy Support Centre. Although it's not possible to thank every single person or organisation who has supported us here, we'd like to give special thanks to:

Albert Hunt Trust
Armson Electrical
The Armson Family
Austin Edward Charity Trust
Aylesford Family Charitable Trust
Baron Davenport's Charity
Martin Batchelor
Bewley Charitable Trust
Sam Binnian
Birmingham District Nursing Charitable Trust
Bodenham Arboretum
Chris and Carol Clarke
Andy Collins
Anthony Corbett
Douglas Heath Eves Charitable Trust
Dumbreck Charity
Edward and Dorothy Cadbury Trust
Edward Cadbury Charitable Trust
Edward Gostling Foundation
Eric W Vincent Trust Fund
Eveson Charitable Trust
February Foundation
G J W Turner Trust
Garfield Weston Foundation
General Charity, Coventry
Geoff Hill Charitable Trust
Elizabeth Goodman
Gordon Trust
Grace Trust
Sheila Hawkins
Hearth Foundation
Heart of England Community Foundation
JC Seccombe Trust
The James Tudor Foundation
The John Avins Trust
Sir Jules Thorn Charitable Trust
Leamington Spa Community Fund
The Leathersellers' Company Charitable Fund
Leicestershire & Rutland Community Foundation
Little Sisters of the Poor
MK Rose Charitable Trust
Debbie Meadows
Louise Meadows
Michael Guest Charitable Foundation
Jennie Newman
The National Lottery Community Fund
Elizabeth Norman
Provincial Grand Lodge of Warwickshire
Rotary Club of Meriden
Rugby Group Benevolent Fund
David and Lesley Salt
Souter Charitable Trust
Stratford Town Trust
The Thompson Family
Tudor Lodge of Rifle Volunteers
W P H Charitable Trust
Annette Walklet
Warwickshire Mark Benevolent Fund
Judy Wellby
William Dudley Trust
Woodroffe Benton Foundation

...and all those who wish to support anonymously

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The Muscular Dystrophy Support Centre is a working name of NMC Midlands,
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