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# Report and financial statements for the year ended 31 December 2019

**Multiple Sclerosis International Federation**

*(A company limited by guarantee)*

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**Company registration number:** 05088553

**Charity registration number:** 1105321

**Registered address:** Skyline House, 200 Union Street, London SE1 0LX

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## Introduction

During 2019, the MS International Federation and its members – the global MSIF Movement – have advanced many key objectives in our strategy ‘Together we’re Stronger than MS’. This report provides an overview of the exciting progress made by the Movement.

We have together improved scientific understanding of MS and accelerated new treatments, strengthened our global movement and the many collaborations within it, provided people affected by MS with much information they need to make confident and informed decisions, and advocated for positive changes in attitudes, policies and practices.

At the heart of our strategy is a unified vision. This vision guides not just the MSIF secretariat, but rather the entire MS Movement which works together to pursue its aims. Through this approach of collaboration and active engagement, we ensure that the expertise and resources of MSIF’s members are put to global use.

Our movement hosts many countries, many cultures and many different realities of what it means to live with MS. In this report, you will see the many diverse parts of the Movement that have contributed, as well as the many areas where we have an impact on the lives of people affected by MS around the world.

The needs of people affected by MS drive us on to pursue our aims with our ambitions urgent and high. We inspire, mobilize and bring the world together – because we know: international collaboration changes lives!

Mai Sharawy

Chair

# Who we are and what we do

## The Strategy for 2017-2021

‘**Together we’re stronger than MS**’ is the strategy for the whole global MSIF movement.

The focus of this strategy is to mobilise the entire MSIF movement; organisations, people affected by MS, volunteers and staff, to achieve our common mission: To bring the world together to improve the quality of life of everybody affected by MS and to end MS forever.

We are building a stronger, broader, global movement made up of effective MS organisations, engaged individuals and strategic international collaborations. Together we tackle challenges for people affected by MS in countries rich and poor.

## Our aims, objectives and activities

Our five aims show the impact we aim to achieve as a movement over the next 10 to 15 years. These aims are connected and support each other. In order to work towards these aims, we have identified a number of objectives and actions for the five-year strategic period. See more: [www.msif.org/about-ms/our-strategy/](http://www.msif.org/about-ms/our-strategy/). The table below outlines those we set out to achieve in 2019.

The long term Aims in the 2017-2021 Strategy	2019 objectives and actions towards these aims
Better scientific understanding leading to new ways to treat, prevent and stop MS.	<ul style="list-style-type: none"> <li>• Advance systems for enabling data sharing, focusing on Patient Reported Outcomes. In 2019 we will aim to widen this work through an important collaboration with a European organisation in the field of medical research and clinical application.</li> <li>• Continue to engage our member organisations in a second phase strategy for the Progressive MS Alliance.</li> <li>• Continue to fill strategic gaps in the MS research workforces throughout the world.</li> </ul>
Improved access to effective treatments and Health care.	<ul style="list-style-type: none"> <li>• Continue our focus on getting MS drugs on the World health Organisation’s Essential Medicines List and undertake research into special challenges and possible solutions in Latin America.</li> </ul>
Access to accurate and trustworthy information and resources to make informed decisions to live well with MS.	<ul style="list-style-type: none"> <li>• Repurpose and translate materials for adaption and use around the world by facilitating the international resource group, made of dedicated staff from the membership, to produce resources in relation to fatigue and probably one other subject.</li> <li>• Deepen networks of membership staff and volunteers in communications, care and services, building on first meetings during the 2018 World conference in Rome.</li> </ul>
Positive changes in policies and practices, attitudes and behaviours that are obstacles to living well with MS.	<ul style="list-style-type: none"> <li>• Develop advocacy tools for national, local and individual action, in particularly by coordinating World MS Day and continuing the work on an update of the Atlas of MS.</li> </ul>

<p>A stronger, broader MSIF movement made up of effective MS organisations, engaged individuals and strategic international collaborations</p>	<ul style="list-style-type: none"> <li>• Strengthen MS organisations in countries with challenging socio-economic conditions, with a continued focus the Arab region, Latin America and India.</li> <li>• Enhance the effectiveness of member organisations and MSIF, including through our International Networking meetings and a People with MS Forum in October 2019.</li> <li>• Ensure effective and inclusive international collaborations with a renewed structure and criteria for membership.</li> <li>• Strengthen communication and networking across the MSIF movement.</li> </ul>
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### Contribution of volunteers

One volunteer supports the MSIF Secretariat in the organisation of its biannual international networking meetings. In 2019 one volunteer worked on a report on HSCT (hematopoietic stem cell transplantation). Our trustees are unpaid volunteers. Around the world many other members of committees and working groups, including people affected by MS and health care professionals, also contribute to our common global work.

### How we measure and assess success

MSIF sets annual milestones and longer term objectives for each project and for the strategy and organisation as a whole, the latter is available to the public in MSIF's 2017-2021 Strategy on [www.msif.org/about-us/reports-and-resources](http://www.msif.org/about-us/reports-and-resources)

We regularly monitor and evaluate projects against these indicators in order to learn and improve our work, ensure accountability and good governance. Annual reports are prepared for major funders, with six-monthly updates provided to the board and all members through a Strategy Progress Report. Our annual trustee report and accounts are published on our website.

Methods we use to assess and measure success include:

- Surveys of our membership and/or the global MS community e.g. World MS Day evaluation survey, survey of our research grant recipients;
- Number of subscribers to our e-newsletters;
- Number of new MS organisations fulfilling MSIF membership criteria;
- Number of downloads of our information resources, advocacy publications and toolkits;
- Number of MS organisations and individuals taking part in our events e.g. World MS Day;
- Comparison of organisational self-assessments made during capacity building projects;
- Qualitative feedback gathered via focus group discussions and semi-structured interviews;
- Reports by external consultants on the results and effectiveness of MSIF's projects;
- Logs of any complaints received and our response to them;
- Evaluation forms from training, conference and meeting attendees.

Ultimately MSIF's purpose is to benefit people with and affected by MS around the world, both through our member organisations and network but also directly, especially where no such MS organisations exist. To help assess our success, our People with MS Advisory Committee provides advice to the board on any issues in relation to the needs of people with and affected by MS. A number of our project work groups, have members who have or are affected by MS, as does our Board of Trustees. We also consult with a wider network of people with and affected by MS.

In 2019 we developed a formal complaints policy and procedure, which is sign-posted on our website. The definition of a complaint we use is 'any expression of dissatisfaction, whether justified or not. About any aspect of

MSIF and its work with the global MSIF movement'. We received 10 complaints as posts on our Facebook channels and one complaint by telephone. Selections of feedback from evaluation forms etc. have been incorporated, into the trustee's report of progress against 2018 priorities.

## **Grant making policy**

### **Capacity building grants**

Capacity building grants aim to support emerging organisations, or representatives of those organisations, in countries with economic challenges and/or a less well-developed civil society sector and are awarded on the judgement of MSIF staff. These grants are either given to registered organisations, emerging MS support structures or to service providers/consultants. In exceptional cases grants are paid to intermediary non-governmental organisations or individuals to help them undertake capacity building work to help create a local MS support structure.

The grants are given for travel to MSIF or other meetings and training events or for time-limited project work, such as production of materials, training opportunities or awareness-raising or advocacy activities. They can include costs for staff or consultants.

Travel grants to MSIF meetings normally require that grantees pay part of the costs themselves or find match- funding.

Project or activity grants are awarded through a thorough and (where appropriate) competitive process, through public tendering and/or calls for applications.

Such criteria may involve both organisational and country factors, such as:

- Due diligence in relation to the organisations involved (including: audited accounts; official registration documents; satisfactory capacity and processes to implement the grant)
- Organisation type (patient-led/health professional-led)
- Organisations' responsiveness and readiness
- MS prevalence rate
- Accessibility to treatment by people with MS
- Travel risk
- World Bank country classifications (e.g. per capita income and poverty rates).

These grants are decided by a panel of staff members of the MSIF Secretariat and formalised in grant agreements. They are normally provided in instalments dependent on reporting on progress towards objectives and expenditure.

Some other grants, for example those relating to World MS Day, are used to support a wider range of organisations and members.

### **Research grants and awards**

Research grants aim to encourage or facilitate international collaboration in medical or socio economic research into MS and through this the search for understanding the cause, for better treatment and ultimately to end MS.

Grants may be provided to institutions, groups of researchers or individual researchers. The grants to individuals have a strong emphasis on researchers from emerging countries and also aim to reinforce research and clinical capacity in such countries, as well as the development of MS organisations.

Grants may be given in the form of:

- Fellowships or travel grants for researchers to spend time gaining experience in another country (McDonald Fellowship and Du Pré grant)
- Awards in recognition of life time achievements or outstanding research contributions (Charcot Award and Young Investigator Award)
- Ad-hoc contributions to certain international research collaborations

Calls for proposals are normally publicly distributed within the research community and publicised on MSIF's website and mostly judged on a competitive basis by panels of members from MSIF's International Medical and Scientific Board (IMSB).

Ad hoc grants may be made on the basis of established priorities in MSIF's strategy and decided by the CEO, seeking advice from the chair of the IMSB and/or its Executive Committee or other qualified researchers.

Criteria used to decide on grants may include:

- Scientific merit of the proposals
- Relevance to MSIF's strategic priorities
- Income category of the researcher's country ('emerging countries': with a low, lower middle or upper middle income as defined by the World Bank)
- Extent of international and collaborative involvement

Where grants are awarded for the duration of more than one year they are paid in instalments, subject to reporting on progress and expenditure.

# Governance for a global movement

## Governing document and Board of Trustees

Multiple Sclerosis International Federation is a charity established under a Memorandum and Articles of Association and incorporated as a company limited by guarantee and not having a share capital on 30 March 2004. The Federation was registered with the Charity Commission on 5 August 2004.

At an extraordinary Annual General Meeting of MSIF's Council on 11 April 2019 a special resolution was passed to allow for more than one member organisation per country and the Memorandum and Articles of Association were amended.

On 17 October 2019 at the Annual General Meeting of MSIF's Council a new Board slate was approved.

For the purpose of the Companies Act 2006, the Board of trustees is regarded as the Board of Directors of the company. The trustees of the company throughout the period are as follows:

Weyman Johnson (USA) **Chairman (retired October 2019)**

Mai Sharawy (Egypt) **Chair (appointed October 2019)**

Marie Vaillant (Canada) **Vice Chair**

Martin Stevens (UK) **Secretary**

Victoria Annis (UK) **Treasurer**

Maria-José Wuille-Bille (Argentina, retired October 2019)	Mario Battaglia (Italy)
Desmond Graham (Australia, appointed October 2019)	Alessandro Perfetti (Italy, appointed October 2019)
Matthew Miles (Australia, retired July 2020)	Wissam Al Haj (Lebanon, appointed October 2019)
Charles van der Straten Waillet (Belgium)	Marlies Jansen-Landheer (Netherlands, retired October 2019)
Dr Brenda Banwell (Canada, appointed October 2019)	Liesbeth kooij (Netherlands, appointed October 2019)
Daniel Larouche (Canada, retired October 2019)	Magdalena Fac-Skhirtladze (Poland, retired March 2020)
Pamela Valentine (Canada, appointed October 2019)	Pedro Carrascal (Spain)
Christian Bardenfleth (Denmark)	Xavier Montalban (Spain, retired October 2019)
Klaus Høm (Denmark)	Ana Torredemer (Spain)
Guillaume Courault (France)	Nick Moberly (UK, appointed October 2019)
Herbert Temmes (Germany, appointed October 2019)	Andrea Prato (Uruguay, appointed October 2019)
Reinhard Hohlfeld (Germany, retired October 2019)	Peter Galligan (USA)
Dimitra Kalogianni (Greece)	Kim Phillips (USA, appointed October 2019)
Anne Winslow (Ireland, retired October 2019)	Cynthia Zagieboylo (USA)
Viresh Oberoi (India)	

## **Methods for recruiting, appointing, training trustees**

The Council, MSIF's supreme governing body, elects a Nominating Committee. The Nominating Committee reviews skills required for the Board and invites MSIF member organisations and relevant others to nominate candidates. It reviews submissions, interviews candidates when necessary and meets to discuss and finalise a slate of candidates to fill all Board positions. The Committee distributes supporting papers to Council members and submits them with the slate for discussion and election. Under the Articles of Association, the members of the Board of Trustees are elected at the biennial Council Meeting. The Board shall consist of no less than three members. Guidance is in place for rotation of Board members.

New trustees receive written induction information upon appointment, attend an induction within the first six months of appointment.

## **Charity Code of Governance**

As a global organisation based in the United Kingdom, MSIF follows and benefits from the regulatory framework and standards in the highly developed Charity sector in the UK adding elements that reflect its international character.

The Board has adopted the key principles of the Charity Code of Governance, which is considered an important standard for governance in the UK charity sector.

There is a recommendation within the code for board size of between 5 – 12 trustees. In 2019 our board had 27 members. We have members and organisations we work with in more than 90 countries and continue to grow our reach, including in areas where support for people affected by with MS is patchy. It is our opinion, that having this larger board gives us greater diversity and is more representative of the communities and countries we operate in. Diversity and inclusion provide more breadth of opinion and experience in the discussions and decision making that take place across the organisation. The Board of trustees values people's differences and is fully committed to encouraging diversity. In this year we have recruited more people with MS and younger people as Trustees. Our aim was to strive to have at least 25% of seats on the board filled by people with MS by 2021. We have met this in 2019, with 8 out of the 27 trustees being persons with MS. It is important that their voices are heard in the Board, and we want to send a strong message to the outside world that all operations of the Federation support this.

We continue to monitor the effectiveness of our board through an annual evaluation of its own skills and performance and of individual trustees, and that of its committees internally and externally. In April 2019 our board worked with an external facilitator as part of this process.

## **Risks and risk-management**

The trustees have given consideration to the major risks to which the charity is exposed and satisfied themselves that systems or procedures are established in order to manage those risks.

Every six months the trustees review the major governing, operational and financial risks which the Federation faces and adjust mechanisms to lessen these risks when judged necessary and consider how to manage them when they might occur. The risk register gets updated accordingly.

Some of the risks are more temporary, other risks are more permanent and include the risk of individual health care companies' changes in strategy and reducing or stopping grants to MS patient organisations.

Equally the risk of sudden political instability or of security or disaster in a country where we operate, including the risk to staff is always present. Control procedure include following foreign office travel advice and use of insurance company security briefings, as well as adequate travel and event insurance.

Another permanent risk is that of adverse publicity, due to a failing for example in governance or fundraising practice, leading to reduced trust and confidence, for example amongst beneficiaries and funders.

The COVID-19 situation does create risks in various ways and the Trustees considered these within a revised risk register. They include a reduction in future income from our membership fees as members face lower income from the inability to hold in person fundraising events and our ability to deliver some of our collaborative overseas projects due to travel restrictions. In the first 6 months of the pandemic, some

conferences and meetings have been cancelled or moved online including the April and October 2020 Board meeting, however, this has not been detrimental to working towards our strategic goals.

## Management and structure

The structure of the organisation consists of a Council, made up of representatives from its member organisations, that elects the Board of Trustees. In 2019, the trustees held two meetings, the first in London in the United Kingdom; the second meeting held in Athens, Greece, facilitated by our Italian member, the Greek MS Society.

Trustees are responsible for the overall strategic direction of the charity while decisions on tactical means to achieve these objectives are taken by the Chief Executive in conjunction with staff and with input from people affected by MS, member organisations and other stakeholders throughout the world.

Additionally, operational working groups often made up from staff and or volunteers from Member Organisations, take on responsibilities for specific projects, either reporting to the CEO or directly to the board of trustees depending on the nature of each project.

## Pay and remuneration

Pay and remuneration levels of the CEO are set by the Chair of the Board of Trustees at the time of recruitment in consultation with other key board members, taking into account the skills set and experience required, the remuneration of CEOs of comparable organisations in the UK and abroad and what the charity can afford. Pay and remuneration levels of other key management personnel are set by the CEO according to the same principles.

Annual increases in pay and remuneration follow the same policies, including inflation and performance increments generally set at the same percentages, as for all staff. Ratio between highest and lowest paid staff in the organisation is a maximum of 4.

**Chief Executive** Peer Baneke

**Deputy CEO** Ceri Angood Napier (with Nick Rijke as Interim Deputy CEO during Ceri's absence for the first part of the year)

Bankers	Auditors	Solicitors
Coutts & Co. 440 Strand, London WC2R 0QS	Moore Kingston Smith, Devonshire House 60 Goswell Road London EC1M 7AD	Collyer-Bristow LLP, 4 Bedford Row, London WC1R 4DF
CCLA Investment Management Ltd, COIF Charity Funds, Senator House, 85 Queen Victoria Street London EC4V 4ET		

## Public benefit

The trustees confirm that they have complied with the duty in section 4 of the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit. In line with this we are committed to providing high quality information and services to the global MS community. As well as offering services and information for our network of MS organisations, the vast majority of our materials containing information for people with and affected by MS, clinicians, and advocates can be accessed by the public via our website [www.msif.org](http://www.msif.org).

In agreeing our activities for each year we have regard to the legal responsibilities outlined in the Charity Commission's general guidance on public benefit. The trustees always ensure that the programmes are in line with our charitable objects as set out in MSIF's governing document the Articles of Association.

The benefits of our activities for individuals are available worldwide and have most relevance in those areas where the incidence of MS is highest. They are not dependent on membership of MSIF or of one of the national MS organisations. They are directed in the main to people with MS, their caregivers, their families and others affected by it.

## Trustees report

The trustees present their report and financial statements for the period ended 31 December 2019. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) “Accounting and Reporting by Charities” issued 2015 in preparing the annual report and financial statements of the charity.

### MSIF’s progress against 2019 priorities

In MSIF’s Report and Financial statements for the year ending 2018 we set out objectives and actions to contribute to the aims outlined in our 2017-2021 Strategy. Here we restate those objectives and report on the progress we have made in the year towards them, the difference we have made and what we have learnt.

**To contribute to our aim of: Better scientific understanding leading to new ways to treat, prevent and stop MS.**

#### **We set objectives for 2019 to:**

- Advance systems for enabling data sharing, in particular focusing on Patient Reported Outcomes. In 2019 we will aim to widen this work through an important collaboration with a European organisation in the field of medical research and clinical application
- Continue to engage our member organisations in a second phase strategy for the Progressive MS Alliance.
- Continue to fill strategic gaps in the MS research workforces throughout the world.

### Data sharing

We have set up a collaboration with the European Charcot Foundation on international Patient Reported Outcomes (PROMS), with the Italian MS Society (AISM) as lead agency and involvement from staff from the US, UK, Australia and Germany, as well as a representative of our sister organisation, The European MS Platform (EMSP). Outcomes of clinical trials and data collected in registries often focus on outcome measures reported by healthcare professionals. This initiative explores which outcomes reported by patients are the most meaningful, effective and useful for people with MS, researchers, clinicians and regulatory bodies. The mission of the project is to ensure that relevant PROs will be taken up by clinical practice and regulatory/HTA agencies – which we hope will contribute to research on more treatments that make a real difference in the quality of life of people with MS. During 2019 we established the structure of the initiative, with an Executive Committee that includes researchers, leadership from the Italian, **US**, And Canadian MS Societies and The Charcot Foundation and MSIF. A scientific steering committee has also been established, with its first meeting in November<sup>1</sup>.

### Progressive MS Alliance

We have continued to play an active role in the governance and work-teams (scientific, fundraising and communications) of the International Progressive MS Alliance, our collaboration with many of our member organisations to progress the search for understanding and treatment of progressive MS. During 2019 the Brazilian MS Society (Associação Brasileira de Esclerose Múltipla, ABEM), joined the Alliance. With many of our member organisations we contributed to the development of a new strategy for a second phase of the work of the Alliance<sup>2</sup> and as part of that invited researchers to come forward with more proposals for research projects which would be funded by the Alliance<sup>3</sup>.

At the end of 2019, 18 MSIF members had participated in pooling funds for the Alliance.

<sup>1</sup> For details see: <https://www.msif.org/news/2019/11/22/patient-reported-outcomes-initiative-for-ms-reaches-another-key-milestone/>

<sup>2</sup> For details see: <https://www.msif.org/news/2019/07/22/first-ms-organisation-in-latin-america-joins-the-progressive-ms-alliance/>

<sup>3</sup> <https://www.msif.org/news/2019/12/16/challenges-in-progressive-ms-awards-taking-risks-to-reap-rewards/>

## Fill strategic gaps in the pipeline of the MS Research workforce

During the whole or part of 2019 11 of MSIF's research-grant awardees were working on their research assignments. We awarded 2 new McDonald Fellowships and 5 Du Pré Grants. These grants enable promising young researchers from countries with low, lower middle or upper middle income (as defined by the World Bank) to undertake short working visits or extensive research programmes at global research centres of excellence. This helps to enhance the skills of researchers and clinicians from such countries and promotes more globally representative research collaborations.

Several of our research grants were supported by the Foundation for Support of MS Research (ARSEP, France) and the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS).<sup>4</sup>

**To contribute to our aim of: Improved access to effective treatments and healthcare.**

**We set objectives for 2019 to:**

- Continue our focus on getting MS drugs on the World Health Organisation's Essential Medicines List and undertake research into special challenges and possible solutions in Latin America.

In 2018 we submitted a proposal to the World Health Organisation (WHO) to put three disease modifying treatments (DMTs) onto the its 'Essential Medicines' (EML) list. The 'theory of change' underpinning this choice is that if we succeed in this, MS organisations around the world can use the listing as a strong argument in their advocacy to persuade national governments to ensure at least some of those drugs are available and reimbursed in their country. In July 2019 the WHO informed us that they would not include the proposed three drugs into the EML and requested a revised proposal.

In July we brought together our International Working Group on Access, reinforced with several international experts to develop our further strategy, including a reflection on the process of the EML. The barriers to accessing healthcare are many and complex. They vary from country to country, but also between demographics within countries.

The working group included participants from all world regions as well as virtual online presence of people affected by MS from Indonesia, Latvia, Morocco, Sri Lanka, the United States, Uruguay and Zambia. The meeting was an important step in advancing the global MS access agenda.

Topics discussed at the meeting<sup>5</sup> included:

- The development of pragmatic diagnostic and treatment guidelines for MS in low-resource settings
- Training and models of healthcare provision for MS healthcare professionals in low-resource settings
- The availability and affordability of safe and effective MS treatments

We undertook a scoping exercise in relation to the regulatory systems for drugs in Latin American countries. One of the main conclusions from the exercise is a lack of transparency about how various drugs are being approved and a lack of good pharmacovigilance systems. Both are of particular importance in relation to the production of biosimilar DMTs.

**To contribute to our aim of: A stronger, broader MSIF movement made up of effective MS organisations, engaged individuals and strategic international collaborations**

**We set objectives for 2019 to:**

- Strengthen MS organisations in countries with challenging socio-economic conditions, with a continued focus the Arab region, Latin America and India.
- Enhance the effectiveness of member organisations and MSIF, including through our International Networking meetings and a People with MS Forum in October 2019.
- Ensure effective and inclusive international collaborations with a renewed structure and criteria for membership.

<sup>4</sup> For details see: <https://www.msif.org/news/2019/11/18/2019-mcdonald-fellowship-and-du-pre-grant-recipients-announced/>

<sup>5</sup> See: <https://www.msif.org/news/2019/10/22/the-next-steps-for-improving-access-to-treatments-around-the-world/>

- Strengthen communication and networking across the MSIF movement.

## **Strengthen MS organisations in countries with challenging socio-economic conditions**

### **Arab region**

In Morocco the three MS organisations with which MSIF is working, continued to advocate for a reduction in import taxes on MS treatments. During 2019 the organisations had a variety of contacts with the authorities in the country. Local consultants are supporting the organisations to carry out their advocacy work.

Organisational changes in the Arfa MS Society in Saudi Arabia led to us pause our work in the country, In the interim, we facilitated a visit to the MS Society of Canada for the President of Arfa where she learnt more about the services they provide. We also supported representatives to attend the MSIF global networking meetings in Athens in October where they benefitted from various workshops and contacts with other organisations

There was a small MSIF skill sharing Regional Workshop for MS organisations in MSIF's network at the time of the MENACTRIMS congress which took place in in December in Dubai.

### **India**

We supported the MS Society of India (MSSI) advocacy work group (made up of representatives from each of the MSSI's Chapters) in their country-wide advocacy project linked to the implementation of the Rights of Persons with Disability Act 2016. The focus is primarily to make changes to the disability assessment guidelines so they better reflect both the visible and invisible symptoms and disabilities of people living with MS. In parallel, the Chapters are supporting people with MS at state level to access disability certificates which, in turn, enable them to access disability entitlements. The Chapters are sharing their successes and learnings with each other in this area.

In September, our advocacy consultant in India facilitated a workshop in Bangalore where MSSI's advocacy work group members had the opportunity to receive further advocacy and communications training and worked together to develop some of the tools to use in the project.

### **Latin America**

After two years of running the Latin America Programme, a mid-point region-wide survey was carried out in the first quarter of 2019. This gave us greater insight into the key challenges people with MS face as well as a deeper understanding of the current role of MS organisations, and their training needs. Advocacy, awareness-raising campaigns and diversification of funds emerged as the top three organisational needs.

Resulting from this, the 'Time Bank' and 'Seed Grants' were developed. The Time Bank provides one-to-one bespoke support in the form of regular calls with the Regional Capacity Building Manager. During these calls, tools are shared, information provided, and support given to develop strategies and work plans for specific areas the organisations are working on.

The Seed Grants look to support organisations to develop, strengthen, co-fund or continue national projects related to advocacy, fundraising or both.

Several webinars have been delivered. One was aimed at introducing the Time Bank. Another focused on "Corporate Fundraising".

An online bulletin is regularly circulated to the region containing key information, news and dates relevant to the organisations' national and regional work, including relevant aspects of MSIF's global work.

The MS Latin-American Network (LATEM), supported by MSIF has grown to include 17 countries in the region. MSIF supported the MS organisations in building the agenda for the 5th Regional Meeting of Latin American MS Organisations, held in Colombia in November, which focused on access to treatments<sup>6</sup>.

<sup>6</sup> <https://www.msif.org/news/2020/02/06/stronger-together-ms-organisations-from-latin-america-reunite/>

## **Enhance the effectiveness of member organisations and MSIF**

After several rounds of discussions and consultations in 2017 and 2018, the membership structure of MSIF was changed to allow more than one organisation per country to become members of the federation. The extraordinary Annual General Meeting of MSIF's Council met on 11 April 2019 and amended the Memorandum and Articles of Association to give effect to this change.

## **Ensure effective and inclusive international collaborations**

A major part of the strategy, this objective cuts across every aim, objective and action taken in 2019 and requires constant attention. In every area of our work we have established a number of working groups, committees and champions drawn from across the MS organisations ensuring our collaborative projects are truly international.

## **Strengthen communication and networking across the MSIF movement**

In 2019 we held two International Networking Meetings. The first was small and held in London in the United Kingdom.

The second was large, some 90 people from 34 countries, which included the People with MS Forum. It is the opportunity for people affected by MS to make their voices heard at the heart of the MSIF movement. This year, the Forum focused on well-being and quality of life with MS. We had an interactive session on the Interactive Progressive MS Alliance's global research strategy for enhancing well-being for people affected by progressive MS.<sup>7</sup>

Other topics covered during these meetings included:

- Relations with the healthcare industry.
- Reviewing the movement's strategy.
- Exploring how large the movement's ambition in the area of access to treatment and capacity building should be.

In between these two in-person meetings we made extensive use of online and digital communications, collaboration tools to facilitate communication and collaborative working between different functional groups within our member organisations.

**To contribute to our aim of:** Access to accurate and trustworthy information and resources to make informed decisions to live well with MS.

### **We set objectives for 2019 to:**

- Repurpose and translate materials for adaption and use around the world by facilitating the international resource group, made of dedicated staff from the membership, to produce resources in relation to fatigue and probably one other subject.
- Deepen networks of membership staff and volunteers in communications, care and services, building on first meetings during the 2018 World conference in Rome.

## **Repurpose and translate materials for adaption and use around the world**

The International Resource Group, which was formed in 2017 has continued to adapt and repurpose materials for national use around the world. One of those was about low self-esteem and MS and

<sup>7</sup> <https://www.msif.org/news/2019/10/24/the-global-msif-movement-gathers-in-athens/>

mental health, based on an earlier animation produced by the UK MS Society<sup>8</sup>. In this way the use of the best national materials in the global MS movement is extended for the benefit of many more MS organisations and through them many more people affected by MS around the world. This animation was translated by MSIF and a range of member organisations in Arabic, Bengali, Dutch, French, Hebrew, Hindi, Indonesian, Polish, Portuguese, Punjabi, Russian, Spanish, Telegu, and Urdu.

We continued to provide other high-quality information to the global MS community. We have worked with MS Research Australia to produce research content for the MSIF website and the research newsletter.

Our e-newsletters are produced as a resource for member organisations to reuse in their own country, to reach their own audiences as well as for our subscribers.

Both our e-newsletters, MS Connections and MS Research News, are available in English, Spanish and Arabic, as are the majority of resources on our website.

Our social media pages are an important way to share our content and engage with our audiences, beyond our newsletters.

### **Build networks of membership staff and volunteers in communications, care and services.**

During the course of 2019 it was decided that rather than spread our limited resources too widely, we will focus our resources on facilitating networking of the International Resource Group and, for now, not to pursue further networking in care and services. Fatigue was identified as the next resource to be created reflecting the best materials existing in the global movement.

**To contribute to our aim of: Positive changes in policies and practices, attitudes and behaviours that are obstacles to living well with MS**

**We set objectives for 2019 to:**

- Develop advocacy tools for national, local and individual action

### **Develop advocacy tools for national, local and individual action**

The advocacy tools we developed and or worked on in 2019 related to World MS Day and the next Atlas of MS.

### **World MS Day**

For World MS Day 2019, the MS movement came together to focus on the invisible side of MS. Through the #MyInvisibleMS tools and resources, 214 organisations across the world shone a spotlight on the invisible impact of MS on quality of life.

Around 900 activities took place online and offline, across 107 countries. A wide range of activities took place, from invisible symptom simulations and art exhibitions, to lighting up landmarks and advocacy events with government officials.

MS Australia produced an excellent animation for World MS Day. We have encouraged MS organisations throughout the world to translate it for their audiences. Member organisations have subtitled it 14 languages. Esclerosis Múltiple España a fully adapted version by recording a Spanish voiceover which was shared with MS organisations in Latin America. The staff member leading on this from MS Australia has supported communications staff in other MS organisations to help them translate and add subtitles to the animation. This is an exciting example of the movement's staff and volunteers around the world collaborating, supporting each other and sharing tools and expertise.

### **Atlas of MS**

Much work was done in 2019 for the production of the 3rd edition of the Atlas of MS, which is to be published in two instalments in 2020 and 2021. We have been able to do extra work due to the National

<sup>8</sup> <https://www.msif.org/news/2019/12/20/low-self-esteem-and-ms-challenging-the-invisible/>

MS Society (US) providing support in kind through McKing Consultancy. This gives us high quality, independent support and analysis, focusing on the epidemiology aspect, and enabling us to raise quality of analysis overall.

We piloted the epidemiology (numbers of people with MS and similar data) and clinical management (access to diagnosis, treatment and healthcare professionals) modules in the third quarter of 2019 and launched these modules to our country coordinators in the last quarter of 2019. We have recruited over 124 countries to take part so far. Data from these modules are expected in the first half of 2020, which will subsequently require validation, quality control, and analysis. Some results from Phase 1 will be published at the ECTRIMS/ACTRIMS World Congress in 2020.

Phase 2 - the survey direct to people affected by MS – will be launched in late 2020 for publication in 2021. This is the first time that a direct survey to people affected by MS has been part of the Atlas process. We hope to get many data, particularly in relation to access to treatment in different parts of the world.

### **Financial oversight of the strategy**

During 2019, our Finance Committee met in person once and three times by digi-meet. In the final meeting 3 year preliminary figures were presented up to 2022 alongside a fundraising plan and the 2020 budget was approved.

### **Performance of material fundraising against fundraising objectives**

The targets for voluntary income at the start of 2019 were to raise £630,000 from pharmaceutical companies, £188,402 from the Vanneau Trust and £1,049,500 from other sources (individuals, companies, member organisations, foundation and trusts, Kiss Goodbye to MS and other digital sources), altogether a total of £1,867,902.

We raised £555,330 from pharmaceutical companies, £188,400 from the Vanneau Trust, and £1,067,948 from other sources (individuals, companies, member organisations, foundations and trusts, Kiss Goodbye to MS and other digital sources), altogether a total of £1,811,678. In total we raised £56,224 less than the objectives set out in the budget, with some targets being adjusted to account for restricted funds brought forward from 2018.

### **Impact of fundraising expenditure on current and future income**

The total cost of direct fundraising activities for 2019 was £104,908 approximately £43,592 less than budgeted. This was due to less fundraising activity being possible in the Middle East, due to changing legislation in the region and reduced capacity for local MS organisations to engage with our fundraising programme. Approximately two-thirds of these costs (£70,000) was for income generated in 2019 and approximately one third (£35,000) was an investment in future income, in particular an investment in the Kiss Goodbye to MS fundraising programme, the Cykelnerven cycling fundraising programme and the new May 50K fundraising programme.

### **Investment performance against objectives set**

The priorities for MSIF fundraising in 2019 were:

- Increase current income levels
- Grow newer income streams (for individual donations via Kiss Goodbye To MS, Cykelnerven, DIY fundraising, May 50K and for the Middle East)

We aimed to increase 2018 income levels from existing channels in 2019, in particular income from the health care industry. In practice, this stayed similar to 2018 income. We did not receive the income from the Middle East we hoped for.

Even so, our income has increased by £313,425 from 2018 to 2019. In-kind donations of £121,481 (£106,481 from the National MS Society (USA) for the Atlas of MS and £15,000 legal fees for conveyancing for a renewed lease on our office) account for part of this increase. Other increases included those related to membership donations for the Progressive MS Alliance (£111,900), Vanneau Trust (£39,900) and individual donors (£38,707). The latter reflect the investment in growing individual donations.

## **Managing external relationships**

MSIF maintained and developed existing relationships with donors and sponsors, including companies within the healthcare industry, individuals and foundations.

## **Protecting vulnerable people**

MSIF employs two fundraising staff and, through its community fundraising and digital fundraising platforms (such as Against MS, and Kiss Goodbye to MS) it encourages members of the public to fundraise from their networks and through third party events. In 2019 there were three areas of MSIF's fundraising which have the potential to impact vulnerable people; MSIF's fundraising platforms, participation in third party events and web donations.

As we didn't conduct any email fundraising in 2019, making donations through the web was entirely voluntary and donors must have a credit card or PayPal account to complete a transaction. Both of these require a bank account, which have safeguarding practices of their own.

MSIF's digital fundraising platforms and marketing of the third-party events both used social media, but both involve personal communication with MSIF. Through the donor support programme, we interact directly with the individuals creating pages or signing up for events and staff are instructed to speak to the Director of Fundraising & Engagement if they have any concerns about an individual. We communicate with Facebook donors and audiences through the Facebook platform, both as a group to encourage fundraising and individually after they have donated. Facebook's own safeguarding policies therefore apply. MSIF has a refunding policy and in 2019 we refunded three donations through our owned fundraising platforms. We are aware of two donors who contacted us about Facebook refunds, but these are all managed by Facebook directly, so we cannot confirm if these were completed or if there were any other claims of which we are not aware.

It is unlikely to be known when a donation is received that it is from a vulnerable person. However, MSIF is committed to protecting vulnerable people and if we are alerted to donation from a vulnerable person, or if a staff member has concerns, the Acceptance and refusal of donations policy (section 4.4) details the process that MSIF will adopt.

## **Regulations, standards and schemes**

MSIF is subject to the UK Charity Commission and the Fundraising Regulator, plus the Information Commissioner's Office. MSIF has also published its Supporter promise on its website, which outlines the key principles by which we operate. We have a Data protection policy and a Data security policy. All of the policies relating to public fundraising are available on the MSIF website.

## **Complaints**

In 2019 MSIF received no complaints about its fundraising.

## **Financial review**

Income overall was £177,705 less than budgeted, excluding the donations in kind received. A substantial part of this was due to receipts from the healthcare industry staying at approximately the same level as in 2018 - £74,670 less than anticipated. The other substantial difference was that we achieved £79,418 less income from foundations than anticipated.

Expenditure was £131,445 lower than budgeted. Key areas where expenditure was lower than anticipated were conferences (around £50,000), Travel (around £27,000), premises and maintenance (around £24,000) and salaries (around £30,000).

As at 31 December 2019 we have unspent restricted funds of £109,130 and unrestricted funds of £916,178 and a designated fund of £20,000 towards a potential office move at the end of our current lease in 2024.

The reserves policy aims to reduce the unrestricted reserves over time to represent half a year of core running costs (staff and overheads).

### Looking ahead, 2020 priorities

Long term Aims in the 2017-2021 Strategy	2020 objectives and actions towards these aims
Better scientific understanding leading to new ways to treat, prevent and stop MS.	<ul style="list-style-type: none"> <li>• Advance systems for enabling data sharing, in particular focusing on Patient Reported Outcomes. In 2020 we continue PROMS, our collaboration with the European Charcot Foundation, with the Italian MS Society as our lead agency.</li> <li>• Continue to engage member organisations in and facilitate global communications about the Progressive MS Alliance.</li> <li>• Fill gaps in the MS research workforces throughout the world.</li> </ul>
Improved access to effective treatments and health care.	<ul style="list-style-type: none"> <li>• Explore the ambitions for our work in this area, develop our strategy and implement parts of this.</li> <li>• Use the Atlas to collect some global data relating to access to treatment.</li> </ul>
Access to accurate and trustworthy information and resources to make informed decisions to live well with MS.	<ul style="list-style-type: none"> <li>• Repurpose and translate one or two materials for adaptation and use around the world.</li> <li>• Maintain networks of membership staff and volunteers in communications.</li> </ul>
Positive changes in policies and practices, attitudes and behaviours that are obstacles to living well with MS	<ul style="list-style-type: none"> <li>• Develop advocacy tools for national, local and individual action, in particularly by coordinating World MS Day and continuing the work on an update of the Atlas of MS.</li> </ul>
A stronger, broader MSIF movement made up of effective MS organisations, engaged individuals and strategic international collaborations	<ul style="list-style-type: none"> <li>• Strengthen MS organisations in countries with challenging socio-economic conditions, with a continued focus on the Arab region, Latin America and India.</li> <li>• Enhance the effectiveness of members and MSIF, including through our International Networking meetings.</li> <li>• Implement the 'more than one member per country' policy.</li> </ul>

In 2020 we will hold two board and global networking meetings. We will report progress against the above objectives and actions in the 2020 Report and Annual Accounts.

### Audit information

So far as each of the directors at the time the trustees' report is approved is aware:

- a) there is no relevant information of which the auditors are unaware; and
- b) they have taken all relevant steps they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

### Auditors

The auditors, Moore Kingston Smith LLP, are deemed to be reappointed under section 487(2) of the Companies Act 2006.

### Note of appreciation

We would like to offer our thanks for the generosity and support received from the people affected by MS, national MS society staff and volunteers, scientists and other professionals, together with our corporate and individual donors and sponsors who enable us to continue our activities.

## Statement of trustees' responsibilities

The trustees (who are also directors of the Multiple Sclerosis International Federation for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires trustees to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of the financial statements may differ from legislation in other jurisdictions. In preparing this report the Trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

On behalf of Trustees



Victoria Annis, Treasurer

Date: 22 October 2020

# Independent auditor's report to the members of Multiple Sclerosis International Federation

## Opinion

We have audited the financial statements of Multiple Sclerosis International Federation ('the company') for the year ended 31 December 2019 which comprise the Statement of Financial Activities, the Summary Income and Expenditure Account, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 'The Financial Reporting Standard Applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2019 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

## Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs(UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

## Other information

The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

## **Opinions on other matters prescribed by the Companies Act 2006**

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' annual report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- trustees' annual report have been prepared in accordance with applicable legal requirements.

## **Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit. or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption in preparing the Trustees' Annual Report and from preparing a Strategic Report.

## **Responsibilities of trustees**

As explained more fully in the trustees' responsibilities statement set out on page 11, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

## **Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (UK) we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purposes of expressing an opinion on the effectiveness of the charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

### **Use of our report**

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to any party other than the charitable company and charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

*Moore Kingston Smith LLP*

Date: 27 October 2020

Luke Holt (Senior Statutory Auditor)  
for and on behalf of Moore Kingston Smith LLP, Statutory Auditor

Devonshire House  
60 Goswell Road  
London  
EC1M 7AD

# Statement of Financial Activities for the year ended 31 December 2019

	Note	Unrestricted Funds £	Restricted Funds £	2019 Total Funds £	2018 Total Funds £
<b>Income and Expenditure</b>					
<b>Income from:</b>					
Donations	2	87,705	1,381,720	1,469,425	1,161,310
<b><i>Income from charitable activities</i></b>					
Membership dues		327,989	-	327,989	321,778
<b>Investment Income</b>					
Bank Interest		4,149	-	4,149	3,053
<b>Other</b>					
Meeting Income		10,115	-	10,115	12,112
<b>Total income</b>		<b>429,958</b>	<b>1,381,720</b>	<b>1,811,678</b>	<b>1,498,253</b>
<b>Expenditure on:</b>					
Raising funds		67,326	68,124	135,450	167,109
<b><i>Charitable activities</i></b>					
Stopping MS		20,000	628,450	648,450	515,091
Improving access to treatment		158,842	23,605	182,447	157,296
Supporting informed decision making		119,572	85,748	205,320	197,072
Changing policies and practices		86,376	262,562	348,938	233,708
Stronger, broader MSIF movement		215,874	287,819	503,693	549,948
<b>Total expenditure</b>	<b>3 &amp; 4</b>	<b>667,990</b>	<b>1,356,308</b>	<b>2,024,298</b>	<b>1,820,224</b>
<b>Net income/(expenditure)</b>		<b>(238,032)</b>	<b>25,412</b>	<b>(212,620)</b>	<b>(321,971)</b>
<b>Net movement in funds</b>		<b>(238,032)</b>	<b>25,412</b>	<b>(212,620)</b>	<b>(321,971)</b>
<b><i>Reconciliation of funds:</i></b>					
<b>Total funds brought forward</b>		<b>1,174,210</b>	<b>83,718</b>	<b>1,257,928</b>	<b>1,579,899</b>
<b>Total funds carried forward at 31 December 2019</b>	<b>10</b>	<b>936,178</b>	<b>109,130</b>	<b>1,045,308</b>	<b>1,257,928</b>

All gains and losses arising in the period have been included in the Statement of Financial Activities and relate to continuing operation.

The accompanying notes on pages 27 to 45 are an integral part of these financial statements.

## Balance Sheet as at 31 December 2019

	Note	2019 £	2018 £
<b>Fixed Assets:</b>			
<b>Tangible Assets</b>			
Equipment	6	<u>3,329</u>	<u>7,038</u>
		<b>3,329</b>	<b>7,038</b>
<b>Current Assets:</b>			
Debtors & prepaid expenses	7	323,939	260,934
Cash at bank & in hand	8	<u>1,077,259</u>	<u>1,200,884</u>
		<b>1,401,198</b>	<b>1,461,818</b>
<b>Creditors: Amounts falling due within one year</b>	9	<u>(359,219)</u>	<u>(210,928)</u>
<b>Net current assets</b>		<b>1,041,979</b>	<b>1,250,890</b>
<b>Total Net Assets</b>	10	<u><u>1,045,308</u></u>	<u><u>1,257,928</u></u>
<b>The funds of the charity:</b>			
Unrestricted funds		916,178	1,094,210
Designated fund	11	20,000	80,000
Restricted funds	12	<u>109,130</u>	<u>83,718</u>
		<b><u>1,045,308</u></b>	<b><u>1,257,928</u></b>

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

The accompanying Notes on pages 27 to 45 are an integral part of these financial statements.

The accounts were approved by the Board and authorised for issue on 22 October 2020 and signed on its behalf by:



.....  
**Victoria Annis**  
Treasurer

## Cash Flow Statement for the year ended 31 December 2019

	2019 £	2018 £
<b>Cash generated from / (used in) operating activities</b>		
Net cash (used in)/provided by operating activities	<u>(127,774)</u>	<u>(538,161)</u>
<b>Cash flows from investing activities</b>		
Dividends, interest and rents from investments	4,149	3,053
Purchase of property, plant and equipment	<u>-</u>	<u>(9,988)</u>
<b>Net cash provided by/(used in) investing activities</b>	<u>4,149</u>	<u>(6,935)</u>
<b><i>Change in cash and cash equivalents in the reporting period</i></b>	<u>(123,625)</u>	<u>(545,096)</u>
Cash and cash equivalents at the beginning of the reporting period	1,200,884	1,745,980
<b>Cash and cash equivalents at the end of the reporting period</b>	<u><u>1,077,259</u></u>	<u><u>1,200,884</u></u>

### Reconciliation of net income/(expenditure) to net cash flow from operating activities

	2019 £	2018 £
<b>Net income/(expenditure) for the reporting period (as per the statement of financial activities)</b>	(212,620)	(321,971)
<b>Adjustments for:</b>		
Depreciation charges	3,709	3,709
Dividends, interest and rents from investments	(4,149)	(3,053)
(Increase)/decrease in debtors	(63,005)	(33,730)
Increase/(decrease) in creditors	<u>148,291</u>	<u>(183,116)</u>
<b>Net cash provided by/(used in) operating activities</b>	<u>(127,774)</u>	<u>(538,161)</u>

## Prior Year Statement of Financial Activities

		Unrestricted Funds £	Restricted Funds £	2018 Total Funds £
<b>Income and Expenditure</b>				
<b>Income from:</b>				
Donations	2	75,973	1,085,337	1,161,310
<b><i>Income from charitable activities</i></b>				
Membership dues		321,778	-	321,778
<b>Investment Income</b>				
Bank Interest		3,053	-	3,053
<b>Other</b>				
Meeting Income		12,112	-	12,112
<b>Total income</b>		<b>412,916</b>	<b>1,085,337</b>	<b>1,498,253</b>
<b>Expenditure on:</b>				
<b><i>Raising funds</i></b>				
Raising funds		136,324	30,785	167,109
<b><i>Charitable activities</i></b>				
Stopping MS		56,533	458,558	515,091
Improving access to treatment		55,114	102,182	157,296
Supporting informed decision making		16,347	180,725	197,072
Changing policies and practices Stronger, broader MSIF movement		34,389	199,319	233,708
		256,762	293,186	549,948
<b>Total expenditure</b>	<b>3 &amp; 4</b>	<b>555,469</b>	<b>1,264,755</b>	<b>1,820,224</b>
<b>Net income/(expenditure)</b>		<b>(142,553)</b>	<b>(179,418)</b>	<b>-321,971</b>
<b>Net movement in funds</b>		<b>(142,553)</b>	<b>(179,418)</b>	<b>-321,971</b>
<b><i>Reconciliation of funds:</i></b>				
<b>Total funds brought forward</b>		<b>1,316,763</b>	<b>263,136</b>	<b>1,579,899</b>
<b>Total funds carried forward at 31 December 2018</b>	<b>10</b>	<b>1,174,210</b>	<b>83,718</b>	<b>1,257,928</b>

# Notes to the financial statements

## 1. Accounting policies

### Basis of preparation

The financial statements have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), published on 16 July 2014. The Charitable Company is a public benefit entity for the purposes of FRS 102 and therefore the charity also prepared its financial statements in accordance with the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (The FRS 102 Charities SORP including update Bulletin 2), the Companies Act 2006 and the Charities Act 2011.

### Currency

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest pound.

### Going concern

The financial statements have been prepared on a going concern basis.

Having carried out a detailed review of the Charity's resources and the current economic challenges, particularly in relation to the impact of COVID19, facing both the Charity and its members the Trustees are satisfied that the Charity has sufficient cash flows to meet its liabilities as they fall due for at least one year from the date of approval of the financial statements.

### Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less.

### Critical accounting estimates and judgements

In the application of the Charity's accounting policies, the board is required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

The estimates and assumptions which have a significant risk of causing a material adjustment to the carrying amount of assets and liabilities are outlined below.

### Useful economic lives

The annual depreciation charge for property, plant and equipment is sensitive to changes in the estimated useful economic lives and residual values of the assets. The useful economic lives and residual values are re-assessed annually. They are amended when necessary to reflect current estimates, based on technological advancement, future investments, economic utilisation and the physical condition of the assets. See note 6 for the carrying amount of the property, plant and equipment. The useful economic lives is currently three years and depreciation is provided on fixed assets in excess of £1,000.

## **Incoming resources**

Income is recognised in the accounting period to which it relates. Membership dues, legacies and meeting income are accounted for when entitled, can be reasonably measured and the receipt is probable. Donated services are valued at the advised commercial rate.

## **Resources expended**

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Wherever possible costs are directly attributed to these headings. The costs of generating funds are those costs of seeking potential funders and applying for funding. Support costs are those costs incurred in support of the charitable objectives. Governance costs are those incurred in connection with administration of the charity and compliance with constitutional and statutory requirements.

## **Grant making policy**

Grants are awarded by the Board to both individual and institutional recipients on the basis of their work. See Trustees' Report for detailed information.

## **Fund accounting**

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors. The aim and use of each restricted fund is set out on the following pages.

## **Foreign currency**

Transactions in foreign currency during the year are converted at the rate ruling at the date of transaction and any exchange differences arising are taken to the Statement of Financial Activities.

## 2 Donations

	Unrestricted Funds £	Restricted Funds £	Total 2019 £	Total 2018 £
BiogenIdec	-	56,250	56,250	37,410
Celgene	-	56,413	56,413	51,609
Donation in kind	-	15,000	15,000	-
Genzyme	-	160,194	160,194	167,612
Med Day	-	15,000	15,000	-
Merck Serono	-	167,473	167,473	152,607
MS Organisations - ECTRIMS	-	63,995	63,995	64,000
MS Organisations - MENACTRIMS	-	-	-	21,501
MS Societies	-	364,687	364,687	256,622
MS Society donation in kind	-	106,481	106,481	-
Hertie ^	-	32,045	32,045	-
Novartis	-	60,000	60,000	42,040
Roche	-	40,000	40,000	115,000
Vanneau Trust	-	188,400	188,400	148,500
Wolfensohn Family Foundation*	-	7,537	7,537	7,166
Other	87,705	48,245	135,950	97,243
	<b>87,705</b>	<b>1,381,720</b>	<b>1,469,425</b>	<b>1,161,310</b>

Personal donations from Trustees during the period amounted to £3,862

\* Income received from CAF

^ Income received from the German MS Society

### Prior Year Donations

	Unrestricted Funds £	Restricted Funds £	Total 2018 £	Total 2017 £
BiogenIdec	-	37,410	37,410	115,000
Celgene	-	51,609	51,609	7,406
Genzyme	-	167,612	167,612	165,742
Med Day	-	-	-	50,000
Merck Serono	-	152,607	152,607	125,000
Mr. Kamran Amour				
Dawoodzadeh and Family	-	-	-	37,781
MS Organisations - ECTRIMS	-	64,000	64,000	63,993
MS Organisations - MENACTRIMS	-	21,501	21,501	15,726
MS Societies	-	256,622	256,622	529,774
Novartis	-	42,040	42,040	-
Roche	-	115,000	115,000	130,000
Teva	-	-	-	110,000
Vanneau Trust	-	148,500	148,500	160,000
Wolfensohn Family Foundation*		7,166	7,166	7,406
Other	75,973	21,270	97,243	51,873
	<b>75,973</b>	<b>1,085,337</b>	<b>1,161,310</b>	<b>1,569,701</b>

Personal donations from Trustees during the period amounted to £1,914

\* Income received from CAF

### 3 Expenditure

	Direct Activities £	Grant Funding £	Support Costs £	Total 2019 £
<b>Raising funds</b>				
Raising funds	104,908	-	30,542	135,450
<b>Charitable activities</b>				
Stopping MS	30,711	419,220	198,519	648,450
Improving access to treatment	85,732	-	96,715	182,447
Supporting informed decision making	52,618	-	152,702	205,320
Changing policies and practices	155,957	9,730	183,251	348,938
Constantly improving the MSIF movement	61,993	85,375	356,325	503,693
	<b>491,919</b>	<b>514,325</b>	<b>1,018,054</b>	<b>2,024,298</b>

Grants payable comprises:

	Grants to Institutions £	Grants to Individuals £	Total £
Stopping MS	416,207	3,013	419,220
Changing policies and practices	5,062	4,668	9,730
Constantly improving the MSIF movement	14,706	70,669	85,375
	<b>435,975</b>	<b>78,350</b>	<b>514,325</b>

Grants payable to institutions comprises:

	Grants £
Progressive MS Alliance - National MS Society, USA	260,210
Karolinska Institute Stockholm, Sweden	32,000
National Institute of Neuroscience Tokyo, Japan	32,000
University of California San Francisco, USA	32,000
University of Basel, Switzerland	32,000
MS Society, India	9,062
Bruno Brochet Centre Hospitalier Universitaire, France	6,000
Children's Hospital Philadelphia, USA	6,000
UMass Memorial Medical Center Worcester, USA	6,000
University Hospitals Birmingham, UK	5,000
University of California San Francisco, USA	4,997
ALEM, Columbia	4,530
ASOGEM, Guatemala	2,000
MS Society, Greece	1,000
Polskie Towarzystwo Stwardnienia Rozsianego, Poland	900
MS Society, Uruguay	900
MS Society, Portugal	600
ALSEP, Lebanon	600
AMMASEP, HANASEP, NORD.MA.SEP (Medact), Morocco	163
Al Razi, Morocco	13
<b>Total</b>	<b>435,975</b>

### 3 Expenditure continued

Grants payable outstanding comprises:

	<b>Grants £</b>
Progressive MS Alliance - National MS Society, USA	44,004
University of Basel, Switzerland	32,000
University of California San Francisco, USA	32,000
National Institute of Neuroscience Tokyo, Japan	32,000
Bruno Brochet Centre Hospitalier Universitaire, France	6,000
Children's Hospital Philadelphia, USA	6,000
UMass Memorial Medical Center Worcester, USA	6,000
University Hospitals Birmingham, UK	5,000
University of California San Francisco, USA	4,997
MS Society, India	4,000
ASOGEM, Guatemala	2,000
ALEM, Columbia	1,500
	<u><u>175,501</u></u>

#### Prior Year Expenditure

	<b>Direct Activities £</b>	<b>Grant Funding £</b>	<b>Support Costs £</b>	<b>Total 2018 £</b>
<b><i>Raising funds</i></b>				
Raising funds	139,745	-	27,364	167,109
<b><i>Charitable activities</i></b>				
Stopping MS	26,057	306,621	182,413	515,091
Improving access to treatment	56,977	-	100,319	157,296
Supporting informed decision making	47,218	13,042	136,812	197,072
Changing policies and practices	35,881	33,661	164,166	233,708
Stronger, broader MSIF movement	132,909	116,059	300,980	549,948
	<u><u>438,787</u></u>	<u><u>469,383</u></u>	<u><u>912,054</u></u>	<u><u>1,820,224</u></u>

	<b>Grants to Institutions £</b>	<b>Grants to Individuals £</b>	<b>Total 2018 £</b>
Grants payable comprises:			
Stopping MS	305,121	1,500	306,621
Supporting informed decision making	7,542	5,500	13,042
Changing policies and practices	30,798	2,863	33,661
Stronger, broader MSIF movement	77,845	38,214	116,059
	<u><u>421,306</u></u>	<u><u>48,077</u></u>	<u><u>469,383</u></u>

## Prior year expenditure continued

Grants payable to institutions comprises:

	<b>Grants</b>
	<b>£</b>
Progressive MS Alliance - National MS Society, USA	146,884
Associazione Italiana Sclerosi Multipla, Italy	39,628
Biogen - return of unspent restricted funds	32,700
Karolinska Institute Stockholm, Sweden	32,000
National Institute of Neuroscience Tokyo, Japan	32,000
University of Valencia, Spain	32,000
University of Melbourne, Australia	32,000
University of British Columbia, Canada	12,000
Genzyme - return of unspent restricted funds	9,491
MS Society, India	6,481
APEMED, Paraguay	8,293
University of Alberta, Canada	6,000
Bruno Brochet Centre Hospitalier Universitaire, France	6,000
Harvard Medical School, USA	5,800
AMMASEP, Morocco	5,000
AMMASEP, HANASEP, NORD.MA.SEP (Medact), Morocco	4,440
Saed MS Society, Saudi Arabia	1,514
ALSEP, Lebanon	1,500
Polskie Towarzystwo Stwardnienia Rozsianego, Poland	1,270
MS Society, New Zealand	1,000
Asociación de Lucha contra la Esclerosis Múltiple, Argentina	1,000
Ligue National Belge de la Sclerose en Plaques, Belgium	1,000
Sazgar MS Society, Iraq	891
Al Hayat MS Society Iraq	775
Unie Roska česká MS společnost, Czech Republic	620
Al Razi MS Society, Morocco	582
Stichting MS Research, The Netherlands	437
	<b>421,306</b>

Grants payable outstanding comprises:

	<b>Grants</b>
	<b>£</b>
University of Valencia, Spain	32,000
University of Melbourne, Australia	32,000
National Institute of Neuroscience Tokyo, Japan	32,000
Progressive MS Alliance - National MS Society, USA	9,165
University of Alberta, Canada	6,000
University of British Columbia, Canada	6,000
Bruno Brochet Centre Hospitalier Universitaire, France	6,000
Harvard Medical School, USA	5,800
AMMASEP, HANASEP, NORD.MA.SEP (Medact), Morocco	2,200
	<b>131,165</b>

#### 4 Breakdown of expenditure

	Raising Funds	Stopping MS	Improving access to treatment	Supporting informed decision making	Changing policies & practices	Constantly improving the MSIF movement	Total 2019
	£	£	£	£	£	£	£
<b>Direct Activities</b>							
Conferences & Meetings	4,883	12,049	6,014	661	3,148	21,700	48,455
Travel & Accommodation	9,230	13,855	11,645	3,605	5,407	15,176	58,918
Professional Fees	89,256	3,425	68,073	43,271	147,220	25,117	376,362
Printing & Publications	1,539	1,382	-	5,081	182	-	8,184
Grants (note 3)	-	419,220	-	-	9,730	85,375	514,325
<b>Sub Total</b>	<b>104,908</b>	<b>449,931</b>	<b>85,732</b>	<b>52,618</b>	<b>165,687</b>	<b>147,368</b>	<b>1,006,244</b>
<b>Support Costs</b>							
Staff Costs (note 5)	25,094	163,112	79,463	125,469	150,564	292,767	836,469
Governance Costs	734	4,767	2,323	3,667	4,402	8,557	24,450
Education & Training	161	1,047	511	806	967	1,881	5,373
Rent, Rates & Insurance	3,177	20,649	10,059	15,882	19,058	37,063	105,888
Premises Maintenance	406	2,637	1,286	2,029	2,435	4,736	13,529
IT Support & Maintenance	694	4,514	2,199	3,471	4,166	8,101	23,145
Office Expenses	83	535	261	410	496	961	2,746
Financial Expenses	82	535	261	411	495	961	2,745
Depreciation (note 6)	111	723	352	557	668	1,298	3,709
<b>Sub Total</b>	<b>30,542</b>	<b>198,519</b>	<b>96,715</b>	<b>152,702</b>	<b>183,251</b>	<b>356,325</b>	<b>1,018,054</b>
<b>Total Expenditure</b>	<b>135,450</b>	<b>648,450</b>	<b>182,447</b>	<b>205,320</b>	<b>348,938</b>	<b>503,693</b>	<b>2,024,298</b>

Auditors' Fees during the period amounted to £5,150 + VAT. Auditors' Other Services during the period amounted to Nil. (2018 - Auditors' Fees £4,840 + VAT. Auditors' Other Services - Nil)

Support costs including governance costs are apportioned on the basis of staff time

The above expenditure includes unrestricted expenditure of £665,973 (2018: £555,469) and restricted expenditure of £1,356,248 (2018: £1,264,755)

#### 4 Prior year breakdown of expenditure

	Raising Funds	Stopping MS	Improving access to treatment	Supporting informed decision making	Changing policies & practices	Constantly improving the MSIF movement	Total 2018
	£	£	£	£	£	£	£
<b>Direct Activities</b>							
Conferences & Meetings	1,051	11,093	789	2,380	692	68,405	84,410
Travel & Accommodation	11,768	13,297	9,789	3,859	1,436	21,337	61,486
Professional Fees	125,347	1,667	46,399	39,566	33,541	43,126	289,646
Printing & Publications	1,579	-	-	1,413	212	41	3,245
Grants (note 3)	-	306,621	-	13,042	33,661	116,059	469,383
<b>Sub Total</b>	<b>139,745</b>	<b>332,678</b>	<b>56,977</b>	<b>60,260</b>	<b>69,542</b>	<b>248,968</b>	<b>908,170</b>
<b>Support Costs</b>							
Staff Costs (note 5)	23,106	154,038	84,720	115,529	138,630	254,160	770,183
Governance Costs	467	3,114	1,713	2,337	2,804	5,140	15,575
Education & Training	90	599	328	450	538	987	2,992
Rent, Rates & Insurance	2,505	16,704	9,184	12,529	15,031	27,555	83,508
Premises Maintenance	416	2,761	1,517	2,072	2,489	4,561	13,816
IT Support & Maintenance	554	3,691	2,030	2,769	3,321	6,091	18,456
Office Expenses	89	591	323	442	531	976	2,952
Financial Expenses	26	173	95	129	154	286	863
Depreciation (note 6)	111	742	409	555	668	1,224	3,709
<b>Sub Total</b>	<b>27,364</b>	<b>182,413</b>	<b>100,319</b>	<b>136,812</b>	<b>164,166</b>	<b>300,980</b>	<b>912,054</b>
<b>Total Expenditure</b>	<b>167,109</b>	<b>515,091</b>	<b>157,296</b>	<b>197,072</b>	<b>233,708</b>	<b>549,948</b>	<b>1,820,224</b>

Auditors' Fees during the period amounted to £4,840 + VAT. Auditors' Other Services during the period amounted to Nil. (2017 - Auditors' Fees £4,840 + VAT. Auditors' Other Services - Nil)

Support costs including governance costs are apportioned on the basis of staff time

The above expenditure includes unrestricted expenditure of £555,469 (2017: £218,510) and restricted expenditure of £1,264,755 (2017: £1,494,494)

Activity headings have changed in line with our new strategy.

## 5 Staff Costs

	2019	2018
	£	£
Salaries	710,988	654,158
Social Security	75,535	55,617
Pensions and Other Costs	49,946	60,408
	<u>836,469</u>	<u>770,183</u>

The average number of employees during the year was 17. The average number of part time employees was 5, with their full time equivalent being 4. (2018 The average number of employees during the year was 15. The average number of part time employees was 3, with their full time equivalent being 2).

One employee received total taxable emoluments of between £90,000 and £99,999 during the year (2018 one £90,000 - £99,999) and defined contributions of £5,616 to a pension scheme (2018 £5,616). One other employee received total taxable emoluments between £60,000-£60,999 (2018 one £60,000-£60,999) and defined contributions of £3,729 to a pension scheme. (2018 - one £3,614).

A defined contribution pension scheme is provided. The costs for the period were £36,954, of which £54 was outstanding at the balance sheet date. (2018 The costs for the period were £32,470, of which £459 was outstanding at the balance sheet date).

### Key Management Personnel

Key management personnel include the Trustees and senior management. The total employee benefits, including pension costs and employer's national insurance, of the charity's key management personnel were £222,250 (2018: £214,796).

No Trustee received any remuneration from the charity in the period. During the period nine Trustees received travel expenses totalling £23,861 from the charity (2018 - six trustees received £11,343).

## 6 Fixed Assets

	Equipment
	£
<b>Cost</b> brought forward at 1 January 2019	37,662
Additions	-
Disposals	(2,040)
Cost/depreciation carried forward at 31 December 2019	<u>35,622</u>
<b>Depreciation</b> brought forward at 1 January 2019	30,624
Depreciation for the year	3,709
Disposals	(2,040)
Cost/depreciation carried forward at 31 December 2019	<u>32,293</u>
<b>Net Book Value at 31 December 2019</b>	<u>3,329</u>
Net Book Value at 31 December 2018	<u>7,038</u>

## 7 Debtors and Prepaid Expenses

	2019	2018
	£	£
Other Debtors	274,344	217,766
Prepayments	35,940	35,224
VAT Reclaimable	13,655	7,944
	<u>323,939</u>	<u>260,934</u>

## 8 Cash at bank and in hand

	2019 £	2018 £
Bank Accounts	1,077,133	1,200,717
Cash	126	167
	<u>1,077,259</u>	<u>1,200,884</u>

## 9 Creditors: Amounts falling due within one year

	2019 £	2018 £
Deferred income	100,000	70,848
Other creditors	51,880	
Accruals	207,339	140,080
	<u>359,219</u>	<u>210,928</u>

Please refer to note 3 to see which grants are included in the Accruals and Other Creditors balances.

## 10 Analysis of Net Assets between Funds

	Unrestricted £	Restricted £	Total £
Fixed Assets	3,329	-	3,329
Current Assets	1,292,068	109,130	1,401,198
Current Liabilities	(359,219)	-	(359,219)
	<u>936,178</u>	<u>109,130</u>	<u>1,045,308</u>

### Prior Year Analysis of Net Assets between Funds

	Unrestricted £	Restricted £	Total 2018 £
Fixed Assets	7,038	-	7,038
Current Assets	1,378,100	83,718	1,461,818
Current Liabilities	(210,928)	-	(210,928)
	<u>1,174,210</u>	<u>83,718</u>	<u>1,257,928</u>

## 11 Designated fund movement

	Balance 01.01.19 £	Resources Incoming £	Resources Outgoing £	Transfers £	Balance 31.12.19 £
Unrestricted	1,094,210	429,958	(667,990)	60,000	916,178
<b>Designated fund:</b>					
Provision for potential office move	80,000	-	-	(60,000)	20,000
	<u>1,174,210</u>	<u>429,958</u>	<u>(667,990)</u>	<u>-</u>	<u>936,178</u>

Expenditure is anticipated in 2024 when our current lease expires

### Prior Year Designated fund movement

	Balance 01.01.18 £	Resources Incoming £	Resources Outgoing £	Transfers £	Balance 31.12.18 £
Unrestricted	1,236,763	412,916	(555,469)	-	1,094,210
<b>Designated fund:</b>					
Provision for potential office move	80,000	-	-	-	80,000
	<u>1,316,763</u>	<u>412,916</u>	<u>(555,469)</u>	<u>0</u>	<u>1,174,210</u>

## 12 Outline summary of restricted fund movements

	<b>Balance 01.01.19</b>	<b>Resources Incoming</b>	<b>Resources Outgoing</b>	<b>Balance 31.12.19</b>
	£	£	£	£
Research fellowships & grants	28,779	187,893	192,995	23,677
Strategy & research coordination	27,980	75,871	91,849	12,002
Progressive MS	-	295,515	295,476	39
Data sharing	-	31,800	27,468	4,332
Increasing resources	-	21,300	20,662	638
Improving access to treatment	-	23,605	23,605	-
Resource development	14,697	19,307	34,004	-
Digital communications	-	19,307	19,307	-
Skills networks	6,262	7,168	13,430	-
MSIF Communications	-	19,007	19,007	-
World MS Day	-	72,582	68,082	4,500
Atlas	-	222,435	186,493	35,942
Awards	-	7,687	7,687	-
Advocacy	-	300	300	-
Global capacity building	-	56,665	56,665	-
Regional Programmes - Arab Region	-	95,803	87,803	8,000
Regional Programmes - Asia	6,000	42,016	48,016	-
Regional Programmes - Latin America	-	104,322	84,322	20,000
Skills networking	-	11,013	11,013	-
Kiss Goodbye to MS	-	68,124	68,124	-
	<b>83,718</b>	<b>1,381,720</b>	<b>1,356,308</b>	<b>109,130</b>

## Prior Year Outline summary of restricted fund movements

	<b>Balance 01.01.18</b>	<b>Resources Incoming</b>	<b>Resources Outgoing</b>	<b>Balance 31.12.18</b>
	£	£	£	£
Research fellowships & grants	37,148	182,407	190,776	28,779
Strategy & research coordination	-	107,147	79,167	27,980
Progressive MS	-	178,615	178,615	-
Data sharing	-	5,000	5,000	-
Increasing resources	-	5,000	5,000	-
Improving access to treatment	6,369	95,813	102,182	-
Resource development	31,984	47,974	65,261	14,697
Digital communications	9,846	47,974	57,820	-
Skills networks	13,159	18,660	25,557	6,262
MSIF Communications	10,097	21,990	32,087	-
World MS Day	29,903	88,722	118,625	-
Atlas	19,069	20,654	39,723	-
Awards	-	7,166	7,166	-
Advocacy	33,805	-	33,805	-
Global capacity building	11,797	50,306	62,103	-
Regional Programmes - Arab Region	26,511	101,501	128,012	-
Regional Programmes - Asia	-	25,000	19,000	6,000
Regional Programmes - Latin America	33,448	50,623	84,071	-
Kiss Goodbye to MS	-	30,785	30,785	-
	<b>263,136</b>	<b>1,085,337</b>	<b>1,264,755</b>	<b>83,718</b>

The purposes of the restricted funds are as follows:

### **Stopping MS**

**Research Fellowships & Grants:** McDonald Fellowships are awarded to young researchers from emerging countries for research in MS. The two-year award includes a grant to cover travel and living costs, and an additional contribution of £2,000 per year to the host laboratory. The total award is a maximum of £30,000 per annum with up to three fellowships per year.

Du Pre Grants enable young researchers to undertake short visits to MS research centres of excellence. Each grant is £1,000 - £6,000 to cover travel costs or as a top-up to an existing grant. MSIF makes up to 5 grants per year. The Charcot Award is awarded for a lifetime achievement in outstanding research into the understanding or treatment of MS. The winner gives the Charcot Lecture at ECTRIMS. Their travel costs, and expenses are covered, up to a maximum of £5,000. A grant of £1,500 is awarded to the winner.

**Strategy & research coordination:** Facilitate, co-fund, cooperate and support common action by national MS organisations in relation to international research programmes/conferences. This involves the International Research Staff Network, International Medical and Scientific Board (IMSB) and liaison with the international MS research community.

**Data Sharing:** The programme of work encompasses our support for an international initiative to establish a global consensus around patient reported outcomes, and also our participation or collaboration in any internationally relevant initiatives about sharing research/patient/clinical data relevant to MS.

**Increasing resources:** This programme of work aims to support encourage and support our member organisations to raise more funds for research. The most prominent part of this programme is the global Kiss Goodbye to MS campaign that focuses mostly on raising funds for research.

**Progressive MS:** Activities and support related to progressive MS as well as to the Alliance with sixteen of our member organisations to expedite the research into treatments for progressive MS.

### **Improving access to treatment**

This programme aims to improve access for people with MS to all forms of healthcare, medical treatment and MS drugs around the world, that are effective, affordable, and of reliable quality.

**Treatment information:** Attend meetings and calls to contribute to the development of international guidelines on MS and provide funds to translate resulting materials.

### **Supporting informed decision making**

**Resource development:** Repurpose and translate information materials for adaption and use around the world.

**Digital communications:** Any digital communication, including keeping MSIF's website up to date with free, trusted information about research, treatment and other aspects of MS, as well as MSIF's and our member's activities, for use by member organisations and other groups and individuals throughout the world. Prepare, send and translate (into Spanish and Arabic) MSIF's e-newsletters: Making Connections and Research News.

**Skills Networks:** Building the MSIF movement's capacity in communications, care and services through establishing and strengthening networks of relevant staff and volunteers from MS organisations and bringing them together to share skills and experience, proving training and development with the potential to develop international collaborative projects or replicate and adapt high quality projects in multiple countries.

**MSIF communications:** Funds for communications about the organisation itself, such as banners or materials and attendance at international conferences.

### **Changing policies and practices:**

**World MS Day:** World MS Day (30 May) is an opportunity for people worldwide to join the global MS movement and participate in events and activities to raise awareness of MS as a global issue.

**Atlas:** The Atlas of MS presents data on the global, regional and national epidemiology of MS, and the resources available for the treatment, management, rehabilitation and support of people with MS in every country with a significant prevalence of MS. Individuals, groups and organisations use it as a tool to illustrate the results of comparative analysis of epidemiology and resource data across geographical areas.

**Awards (Nicholson & Wolfensohn):** The James D Wolfensohn Award is given every two years to a person with MS in recognition of their valuable contribution to the fight against MS. The Evelyn Nicholson Award, given every two years, recognises people who are, or who have been, volunteer caregivers to people with MS and who have demonstrated outstanding commitment and devotion in the support of a loved one. Nominations for both these awards are submitted by MSIF member organisations and MSIF’s Person’s with MS Committee selects the winner. Every two years people with and affected by MS gather to give direct input into the work of the Global MSIF movement at the People with MS Forum facilitated by MSIF.

**Advocacy:** Includes the Quality of Life Principles is a framework that sets out what is required for people with MS to have the best possible quality of life.

### **Constantly Improving the MSIF movement**

**Global and other countries:** building capacity, by supporting member organisations, amongst others through coaching, visits, exploring new partnerships and providing travel grants for attendance at meetings.

**Regional Programmes - Arab Region:** Build capacity, by initiating or supporting the development of MS organisations in Arabic speaking countries.

**Regional Programmes - Latin America:** Build capacity by supporting the development of MS organisations in Latin America.

**Regional Programmes – Asia:** Build capacity, by initiating or supporting the development of emerging MS support structures and groups and MS organisations in Asia, including through small grants for workshops, world MS Day activities and newsletters.

**Skills networking:** To provide opportunities for the membership to learn about each other’s areas of work and share best practice.

**Kiss Goodbye to MS:** an international campaign that enables people around the world to raise funds for vital research into MS and support people living with MS today.

## **13 Future Commitments**

At 31 December 2019, MSIF had total minimum lease payments under operating leases as set out below:

	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
<b>Equipment</b>		
Less than one year	700	700
One to five years	875	1,575
<b>Land and Buildings</b>		
Less than one year	83,374	27,995
One to five years	253,091	380,093
	<b><u>338,040</u></b>	<b><u>410,363</u></b>

## 14 Related Party Disclosures

Name of Entity	Nature of Relationship	Membership Dues Received 2019 £	Membership Dues Received 2018 £
Ligue Nationale Belge de la Sclérose en Plaques, Belgium	Joint Trustee and Chairman	8,145	6,360
MS Society of Canada	Joint Trustee	32,693	32,683
MS Society Denmark	Joint Trustee	10,489	9,373
MS Care, Egypt	Joint Trustee and Chairman	12	12
Ligue Francaise contre la Sclerose En Plaques, France	Joint Trustee and Treasurer	6,544	6,544
MS Society India	Joint Trustee and Chairman	-	495
MS society Italy	Joint Trustees and Chairman	32,693	32,693
Stichting MS Research, Netherlands	Joint Trustee	6,360	3,503
Esclerosis Multipla Espana, Spain	Joint Trustee	586	352
National MS Society, USA	Joint Trustees and Chairman	110,004	110,004

Name of Entity	Membership Dues Accrued 2019 £	Membership Dues Accrued 2018 £
EMA, Argentina	-	351
Associação Brasileira de Eslerose Múltipla, Brazil	-	703
Union of Estonian Multiple Sclerosis Societies	19	19
MS Society Greece	293	293
MS Society Guatemala	12	12
MS Society Iceland	895	-
MS Society India	550	-
MS Society Israel	352	-
Multiple Sclerosis Society Malta	18	-
MS Society New Zealand	703	-
MS Society Portugal	948	-
MS Society Turkey	626	-
UK MS Society	-	27,244

<b>Name of Entity</b>	<b>Nature of Relationship</b>	<b>Grants Received 2019 £</b>	<b>Grants Received 2018 £</b>
Scleroseforeningen, Denmark	Member	8,039	14,137
Neuroliitto, Finland	Member	429	275
Ligue Française contre la Sclérose En Plaques, France	Joint member Progressive MS Alliance	-	8,985
Ligue Française contre la Sclérose En Plaques, France	Member	1,305	934
Fondation pour l'Aide à la Recherche sur la Sclérose En Plaques, France	Joint member Progressive MS Alliance	103,466	-
Fondation pour l'Aide à la Recherche sur la Sclérose En Plaques, France	Member	63,448	64,000
DMSG Germany	Member	32,045	-
MS Ireland	Joint member Progressive MS Alliance	12,842	1,313
MS Ireland	Member	1,316	3517
MS Society Italy	Member	33,850	-
Stichting MS Research, Netherlands	Member	2,107	12,106
Stichting MS Research, Netherlands	Joint member Progressive MS Alliance	42,312	44,080
Ms Society New Zealand	Member	376	
MS Forbundet, Norway	Joint member Progressive MS Alliance	-	23,015
Esclerosis Multipla Espana, Spain	Joint member Progressive MS Alliance	78,244	48,017
Esclerosis Multipla Espana, Spain	Member	-	2,098
MS Society, UK	Member	10,000	28,522
National MS Society, USA	Member	113,433	5,623

<b>Name of Entity</b>	<b>Nature of Relationship</b>	<b>Grants Paid 2019 £</b>	<b>Grants Paid 2018 £</b>
Progressive MS Alliance - National MS Society, USA	Joint member	260,210	146,884
ALCEM, Argentina	Member	-	1,000
Ligue National Belge de la Sclerose en Plaques, Belgium	Member	-	1,001
Unie Roska ceská MS společnost, Czech Republic	Member	-	620
MS Society, Greece	Member	1,000	-
ASOGEM, Guatemala	Member	2,000	-
MS Society, India	Member	9,062	6,481
Associazione Italiana Sclerosi Multipla, Italy	Member	-	39,628
ALSEP, Lebanon	Member	600	1,500
Stichting MS Research, The	Member	-	437
Polskie Towarzystwo Stwardnienia Rozsianego, Poland	Member	900	1,270
MS Society, Portugal	Member	600	-
MS Society, New Zealand	Member	-	1,000
Esclerosis Múltiple Uruguay	Member	900	-

#### **Prior Year Related Party Disclosures**

<b>Name of Entity</b>	<b>Nature of Relationship</b>	<b>Membership Dues Received 2018 £</b>	<b>Membership Dues Received 2017 £</b>
Ligue Nationale Belge de la MS Society of Canada	Joint Trustee	6,360	6,175
	Joint Trustee	32,683	31,741
Greek MS Society	Joint Trustee and Treasurer	-	348
MS Care, Egypt	Joint Trustee	12	11
Ligue Francaise contre la Sclerose En Plaques, France	Joint Trustee and Treasurer	6,544	6,544
MS Society India	Joint Trustee and Chairman	495	550
Stichting MS Research, Netherlands	Joint Trustee	3,503	3,500
Esclerosis Multipla Espana, Spain	Joint Trustee	352	341
National MS Society, USA	Joint Trustees and Chairman	110,004	110,004

## Prior Year Related Party Disclosures Continued

Name of Entity	Membership Dues Accrued	Membership Dues Accrued
EMA, Argentina	351	-
Associação Brasileira de Esclerose Múltipla, Brazil	703	683
Union of Estonian Multiple Sclerosis Societies	19	23
MS Society of Greece	293	-
MS Society, Guatemala	12	-
MS Society India	-	550
Multiple Sclerosis Society of Malta	-	21
Polskie Towarzystwo Stwardnienia, Poland	-	892
UK MS Society	27,244	-

Name of Entity	Nature of Relationship	Grants Received 2018 £	Grants Received 2017 £
Scleroseforeningen, Denmark	Member	14,137	-
Neuroliitto, Finland	Joint member Progressive MS	-	52,438
Neuroliitto, Finland	Member	275	548
MS Forbundet, Norway	Joint member Progressive MS	23,015	47,687
MS Forbundet, Norway	Member	-	1,221
Stichting MS Research, Netherlands	Member	12,106	10,000
Stichting MS Research, Netherlands	Joint member Progressive MS	44,080	43,952
Ligue Française contre la Sclérose En Plaques, France	Joint member Progressive MS	8,985	105,455
Ligue Française contre la Sclérose En Plaques, France	Member	934	1,014
Fondation pour l'Aide à la Recherche sur la Sclérose En	Joint member Progressive MS	-	104,362
Fondation pour l'Aide à la Recherche sur la Sclérose En	Member	64,000	32,000
MS Ireland	Joint member Progressive MS	1,313	8,575
MS Ireland	Member	3,517	3797
MS New Zealand	Member	-	562

## Prior Year Related Party Disclosures Continued

Name of Entity	Nature of Relationship	Grants Received 2018 £	Grants Received 2017 £
Esclerosis Multipla Espana, Spain	Joint member Progressive MS Alliance	48,017	87,244
Esclerosis Multipla Espana, Spain	Member	2,098	3,436
MS Society, UK	Member	28,522	1,611
National MS Society, USA	Member	5,623	33,278

Name of Entity	Nature of Relationship	Grants Paid 2018 £	Grant Paid 2017 £
Progressive MS Alliance - National MS Society, USA	Joint member	146,884	454,032
ALCEM, Argentina	Member	1,000	-
Ligue National Belge de la Sclerose en Plaques, Belgium	Member	1,001	-
Asociación de Lucha contra la Esclerosis Múltiple, Brazil	Member	-	1,263
Unie Roska česká MS společnost, Czech Republic	Member	620	500
Union of Estonian Multiple Sclerosis Societies	Member	-	500
MS Society, Greece	Member	-	1,051
MS-félag Íslands, Iceland	Member	-	500
MS Society, India	Member	6,481	-
Associazione Italiana Sclerosi Multipla, Italy	Member	39,628	-
MS Society, Japan	Member	-	4,832
ALSEP, Lebanon	Member	1,500	-
Stichting MS Research, The Netherlands	Member	437	-
Polskie Towarzystwo Stwardnienia Rozsianego, Poland	Member	1,270	-
MS Society, New Zealand	Member	1,000	-
Esclerosis Múltiple Uruguay	Member	-	500

## **15 Company Limited by Guarantee**

Every full voting member undertakes to contribute such amount as may be required (not exceeding £10) to the company's assets if it should be wound up while it is a full voting member or within 1 year afterwards, (2019 32 members (2018 - 32 members)).