



# Multiple Sclerosis International Federation (A Company Limited by Guarantee)

Company Registration Number: 05088553 Charity Registration Number: 1105321

**Report and Financial Statements** 

for the Year Ended

31 December 2014

# Multiple Sclerosis International Federation Report and Financial Statements for the year ended 31 December 2014

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The trustees present their report and financial statements for the period ended 31 December 2014. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued 2005 in preparing the annual report and financial statements of the charity.

**Company Number** 

5088553

**Charity Number** 

1105321

**Registered Office** 

Skyline House, 200 Union Street, London SE1 0LX

#### **Board of Trustees**

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) Mario Battaglia (Italy)

Mai Sharawy (Egypt)

Guillaume Courault (France)

Chairman

Vice Chairman

Secretary

Treasurer

Pedro Carrascal (Spain)

Debra Cerasa (Australia)

Sophie Galland-Froger (France)

John Golding (Norway)

Dimitra Kalogianni (Greece)

Peter Kauffeldt (Denmark)

Daniel Larouche (Canada)

Michelle Mitchell (UK)

Graham McReynolds (USA)

Antonella Moretti (Italy)

Dorothea Pitschnau-Michel (Germany)

Dorinda Roos (Netherlands)

Eli Rubenstein (USA)

Yves Savoie (Canada)

Martin Stevens (UK)

Alan Thompson (UK)

Marie Vaillant (Canada)

Charles van der Straten Waillet (Belgium)

Maria-José Wuille-Bille (Argentina)

Cynthia Zagieboylo (USA)

The Council, MSIF's supreme governing body, elects a Nominating Committee. The Nominating Committee invites MSIF member societies (and all Board and Committee members), past Board members, members of the international MS movement and relevant others to nominate candidates. They review submissions, interview candidates when necessary and meet 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.

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.

New Trustees receive written induction information upon appointment and attend an induction within the first six months of appointment and are sometimes allocated a mentor from among the longer-serving Trustees.

Chief Executive Peer Baneke

Bankers Coutts & Co.

440 Strand

London WC2R 0QS

CCLA Investment Management Ltd

COIF Charity Funds 80 Cheapside London EC2V 6DZ

Auditors Kingston Smith LLP

Devonshire House 60 Goswell Road London EC1M 7AD

Solicitors Collyer-Bristow LLP

4 Bedford Row London WC1R 4DF

# **Governing Document**

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.

### **Risk Management**

The Trustees have examined the major governing, operational and financial risks which the Federation faces and confirm that systems have been established to lessen these risks. The potential risks and management of them are regularly reviewed by the Trustees.

# The Objects of the Charity

The objects for which the charity was established are to support and relieve persons affected by multiple sclerosis and allied conditions worldwide by:-

- 1) Promoting, stimulating and encouraging scientific research worldwide for the public benefit by the dissemination of information and knowledge into the causes of and cure and treatment for multiple sclerosis and allied conditions with the aim of eliminating multiple sclerosis;
- 2) Providing information, advice and support to further the development and work and promote the efficiency and effectiveness of voluntary national multiple sclerosis organisations or the formation of such
- 3) Educating the general public about multiple sclerosis by, amongst other things, collecting and disseminating scientific and educational information relating to multiple sclerosis;
- 4) Aiding, supporting and relieving persons who are affected by multiple sclerosis and allied conditions, to encourage them in every way possible to achieve their full potential as members of society by improving their quality of life;
- 5) Such other charitable purposes as the Trustees shall in their absolute discretion from time to time

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.

#### Review of Activities and Public Benefit

The activities carried out in each area are set out below.

In setting our activities plan for each year we have regard to the Charity Commission's general guidance on public benefit. The trustees always ensure that the programmes are in line with our charitable objects.

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, members of their families and others affected by it.

# Facilitating, Coordinating and Leading International Collaboration in MS research

MSIF has continued to develop its role among the international MS research community.

With some of our member organisations we supported the International Pediatric MS Study Group, which now has 140 members form nearly 40 countries. During 2014, they provided feedback on two pharmaceutical company proposed paediatric trial protocols. The study group input, primarily with respect to safety concerns, resulted in important amendments to the protocols. Two trials have now been launched and recruitment for each is underway. In September 2014, together with the Italian and American MS organisations, we supported the group's global member's symposium in Boston, USA. This was a well-attended (72 IPMSSG members from 19 countries) and well-received educational programme featuring presentations from experts in paediatric research and clinical care and global networking opportunities for attendees, which we hope to lead to collaboration in this challenging area of MS research.

We continued to work with several of our member organisations and key members of the medical and scientific community around the world through the Progressive MS Alliance to give new impetus to research into and to expedite the development of treatments for progressive MS, which is presently poorly understood and for which treatment options are extremely limited. In June 2014 we launched a comprehensive new website for the Progressive MS Alliance (PMSA), (www.progressivemsalliance.org). The Alliance had an unprecedented global response to the first round of grants with 195 applications form 22 countries. These were peer reviewed by the Alliance's international Scientific review committees and funding recommendations led to 22 projects being approved, announced during a media event in Boston at ECTRIMS in September. The Alliance then turned to focus on preparing the second request for proposals incentivising international collaboration in large grants to drive research formed in key areas of progressive MS - launched later in 2014. A forum was held in December to explore how the healthcare industry could contribute and participate in the research. The Alliance also convened a workshop that led to the development of rehabilitation research strategies for progressive MS which will begin with a 6 month feasibility study leading to a large multicentre clinical trial using combined interventions. It is a major achievement that, for the first time, an international grant-giving and review mechanism has been established that will take decisions on behalf of several MS organisations to jointly fund and promote

We also provided financial support for an international collaboration in stem-cell research.

We awarded 10 Du Pré Grants and, with the support of NMSS, 5 McDonald Fellowships in 2014 which fostered the skills of young scientists and actively encouraged them to remain in the MS field. In order to develop a lifelong relationship between Du Pré Grant and McDonald Fellowship alumni and MSIF we held the sixth International Research Alumni Meeting at the same time as the combined ECTRIMS ACTRIMS conference in September, in Boston, USA.

We worked with a team at the Institute of Neurology in London to identify the latest developments in MS research in peer-reviewed publications, which we communicated to the global MS community in our regular email newsletter MS Research News. As a result of changes in our communications strategy approved by the MSIF board in April 2014, MS News changed from weekly to monthly and has been written and edited for a lay audience and translated into Spanish and Arabic — ensuring it is accessible to as many people affected by MS around the world as possible. In order to further communicate research in an accessible way, we held a live question and answer webinar event with international experts on MS in November 2014 on the topic of Progressive MS. Up to the end of January 2015 this was watched approximately 3,000 times by people in 80 countries.

# Capacity building and supporting the development of effective national MS societies

National MS organisations are best placed to directly support people with and affected by MS and play a significant role in improving their quality of life in their country context.

Where national MS organisations exist we supported them in their work. Where such organisations are fragile or don't exist, in particular in emerging countries, we worked with relevant individuals and groups to stimulate and strengthen their development.

In 2014 we further developed our work with people affected by MS and Neuromyelitis Optica (NMO) in China to promote the development of local support groups and increased MS awareness. In 2014 we partnered with a local organisation, the China Organisation for Rare Disorders (CORD) with a view to achieve our objective through their work. CORD achieved partial success through producing and distributing two issues of the new Listen magazine by Chinese people affected by MS/NMO. However, changes in staff at CORD and emergence of a new group of people affected by MS and NMO, MS home (MSZJ), made it more productive to work directly with this group. We agreed with CORD that we would not renew the partnership at the end of 2014, whilst staying in contact. We provided CORD with a training workshop on organisational development, which they very much appreciated.

We are keen to assess the extent to which our investments in China since 2011 have contributed to more local activity and to the emergence of MS Home. We will be conducting a review to assess this in 2015, along with a schedule of visits, training and mentoring opportunities to support MSZJ and other groups which may emerge, on its path to sustainability and independence.

In the Arabic-speaking region we have established both regional- and country-focussed programmes. Across the region we facilitated information-sharing in Arabic via:

- · a Facebook group and, webinars,
- A quarterly Arabic e-newsletter, Tawasool, which had contributions from 12 organisations in 11 countries in the region
- · Translation of an issue of MS in focus on 'bladder and bowel' into Arabic,
- · Translation of our monthly e-newsletters for the MS movement for research updates and our website.

The communication is valued by the organisations in the region '... the newsletter will enable MS organisations to improve their performance due to familiarising (sharing) the experiences with each other...' Mr Ahmed Zarouk, Former President of the Tunisian MS Association.

We worked with emerging organisations in the region providing technical advice via conference calls, sharing resources and online meetings on topics such as fundraising, relationships with healthcare companies and organising World MS Day activities. We provided small grants to some emerging organisations to help them get not-for-profit registration and produce information and awareness leaflets

The country-focused programme, now in its second year, provides in-depth organisational development support to help emerging MS organisations become more sustainable and effective. For this, we provided focussed strategic and coaching support and organised workshops for MS organisations in Palestine, Lebanon and Egypt on topics including communication, administrative file management, and, most successfully, MS counselling training. The counselling trainings led in just 2 months, to two organisations establishing group counselling sessions for people affected by MS in their country using what they had learned from the training. We also started to see results from previous year's training in strategic planning and fundraising - with the organisation in Lebanon raising over 4000 USD in two fundraising events and in Egypt, a strong appreciation for the direction the process has brought to the organisation: 'The strategy has revealed what we have done before, what we are doing now and what we need to do better in the future.' Dr Mai Sharawy MS Care Society Form

MSIF supported the growing francophone group (Canada, France, Tunisia, Lebanon, Morocco, Belgium) to hold a meeting in Manchester in 2014 to explore ways to further their collaboration. Work exploring partnership work with Greece and Tunisia has continued.

In September, MSIF's fundraising team convened a fundraising workshop for 30 staff and volunteers from MS organisations from 19 countries to share experiences, methods and approaches to successful fundraising. This is part of MSIF's global fundraising strategy to build the individual and combined fundraising of MS organisations in order to draw more attention to MS and support essential research to find treatments and services for improving the quality of life of people affected by MS nationally and

### Communicating knowledge, experience and information about MS

Explaining MS and its impact is at the heart of our work. We particularly aim to reach people in countries where there is little support available. We use the latest information and communication technology to publish and disseminate quality material and relevant information about MS. In 2014 we reviewed and refined our information and communications strategy and as a result launched our website with new features and designed so that it is accessible on all types of devices (phone/desktop/tablet) and content is written with a lay audience in mind and translated professionally into Spanish and Arabic – as well as many other languages via google translate. We also launched a visual identity and logo that works better online and in print to communicate who we are and what we do. The new orange symbol, derived from the nerve cell, signifies the dynamic movement we represent and uses orange as a colour to unify amongst many of

English is our official language, but language should not be a barrier to communication. Our website is now translated into Spanish and Arabic – with other information translatable via google translate. With competition for scarce resources, we began to rely more on Google Translate, hoping that more people around the world can rely on our information in more languages.

To improve internal communication and efficiency we launched a members area on our website where staff from member organisations can share and access resources and toolkits, recycling, adapting and translating them for their needs in their local context, so that they don't need to 'reinvent the wheel', and save resources. It should help both well and less well-resourced member organisations to benefit from tried and tested programmes and materials developed by other MS organisations rather than paying for costly new developments.

In 2014 we published 2 editions of our free magazine for people affected by MS and health professionals, *MS in focus*, which focused on 'Information and Communication' in January and 'Bladder and bowel' in July. The editorial board commissioned articles from the world's leading experts and practitioners in the MS field. These were produced in an English print version. We also produced online versions with some translations in Arabic, French, German and Italian. These were the last to be sent by post because in 2015 we are reformatting the magazine and aiming to publish it more frequently in an online, downloadable format for our member organisations and individuals to use, distribute and recirculate as required.

We also updated our Making Connections email – refocussing it onto a tool for communication for the MS movement, getting contributions for articles form MS organisations around the world. As such it is our public digest email keeping MS organisations, people with MS and other interested stakeholders up to date on interesting developments in the world of MS.

From October 2014, we started a trial of a new weekly email in a very informal and engaging style from our CEO to individuals reaching out and encouraging them to participate and engage with advocacy and interactive experiences to strengthen the global movement and empower and inform people affected by MS with global developments. It is also an important opportunity for MSIF to ask for people to support our work financially, diversifying our income and increasing our sustainability.

### Advocating globally for the international MS community

MSIF and its member organisations led the sixth World MS Day, which was marked by celebrations and events across the world. The campaign focused on access stories about everything from treatments and services to mobility and leisure. We asked people to think about barriers to access in their life and to make a wish for something that would help overcome those barriers through submitting 'one day wishes'. Much of World MS Day consists of actions at national level by MS organisations, people with MS and other key players. Ninety eight per cent of MSIF's member organisations reported having participated in 2014 World MS Day, with activities taking place in 78 countries (an increase from 66 in 2012 and 68 in 2013).

We developed a creative website where people could highlight their one day wishes for a world without barriers for people affected by MS. More than 3000 inspiring one day wishes were shared from 98 different countries on the website, with over 1,500 more on twitter. We also know that there were thousands on Facebook and thousands more captured both on and offline at national level by our network of MS organisations.

2014 marked the final year of the three year World MS Day strategy and, as such, the results and report of an external poll to track awareness levels in a selection of (mostly) emerging countries was prepared. Unfortunately, the results did not show significant improvement in levels of public awareness of MS in the countries studied. However, the experience and the findings were very useful to feed into our next strategy to continuously learn and improve to help ensure world MS day grows in its effectiveness.

Member organisations continued to advocate for the ratification of the International Convention for the Rights of Persons with Disabilities, and its Optional Protocol, with the National MS Society in the USA continuing to mobilise its membership and play a crucial role in trying to persuade the US Senate to ratify

The issue of the high cost of MS medicines has been raised at several of MSIF's meetings and many of the MS organisations and individuals in MSIF's network in emerging countries have raised those costs as one of their most important challenges. MSIF's Atlas of MS found that none of the disease modifying drugs for MS are reimbursed in low income countries. This issue not only involves the pharmaceutical industry but also the regulators (such as the EMA in Europe and the FDA in the USA), governments, insurers, health professionals and intergovernmental organisations such as the World Health Organisation.

MSIF's Atlas of MS calls on policymakers, health professionals and MS organisations to: Ensure treatments are accessible to all that need them regardless of where they live and work together to make treatments more affordable.

In 2014, we signed The Declaration for Universal Access to Affordable Medicine because it makes a very similar demand, it:

- Invites governments, pharmaceutical companies, international agencies, foundations and innovators to design systems and business models that support universal access to affordable medicine.
- Declares the need for universal access to affordable medicine so that the highest attainable standard of health is available to every human being.

We have signed the declaration, and encouraged the MS organisations and individuals in our network to sign it in order to join forces with many other disease areas and to raise attention for this issue, in particular at the WHO, so that it becomes a major issue of attention at the highest level. The Declaration and the signatures will be presented to Dr Margaret Chan, the Director-General of WHO in the course of 2015.

The Atlas of MS 2013 report, film and website/database have continued to prove a useful and relevant resource with the figure of 2.3 million now being widely quoted. The Atlas of MS is the only up-to-date online source of information on the worldwide epidemiology of multiple sclerosis (MS) and the global availability and accessibility of resources for people with MS. People can use the website to analyse and share the full results, maps and database from surveys undertaken in both 2008 and 2013. An MSIF article on the Atlas findings was published in the Journal of Neurology in September 2014.

### **Future developments**

During 2015 we will continue to play a key role in the Progressive MS Alliance, support the International Paediatric Study group, and offer Du Pré Grants and McDonald Fellowships to build the capacity of research in MS in emerging countries. We will convene a meeting of research staff from across the world to explore ways to collaborate internationally in research. We will continue to promote collaborative partnerships and sharing best practice between member organisations and provide training and small grants which will enable smaller MS organisations to increase their knowledge and build their capacity to support their local MS communities.

Communicating information will remain at current levels with a stronger focus on linking web-based and interactive communication and on providing materials in other languages. We will coordinate another World MS Day on 27 May 2015, on the access issues faced by people affected by MS. Learning from our evaluation of previous world MS Days we will make a website that will last for more than one year, include archive material from previous years and create tools that are flexible enough for MS organisations and individuals to use to raise awareness, funds and advocate for changes, wherever they live and whatever their level of resources. The website and materials will be available in Arabic, English, French, Portuguese and Spanish. The 2015 resources will include thank you e-cards for people to share on and offline, acknowledging those who help to break down the barriers to access to treatment, services and transport for

We will finalise and launch the next multi-year strategy for World MS Day.

We will review and report on progress against MSIF's strategic plan and start to develop the next organisational strategic plan.

# Maintain good governance and leadership

The trustees held two meetings, the first in London in April; the second meeting was combined with the combined ECTRIMS and ACTRIMS meeting in Boston. In 2015 we will hold two board meetings, one in London and the second in Barcelona, Spain, together with the council meeting which will elect a new board.

### Transparent finance, personnel and administration structures

MSIF maintained and developed existing relationships with sponsors, including companies within the healthcare industry, individuals and foundations. In addition to the existing post of head of international fundraising, a second full-time post of senior fundraiser was created.

MSIF maintained and developed existing relationships with sponsors, including companies within the healthcare industry, individuals and foundations. In October, we launched a series of digital fundraising activities which we will continue to develop in 2015 in order to diversify our funding sources.

# **Grants 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.

These grants are sometimes given directly to small emerging MS support structures or groups, such as in the Arab Region Country-focused Programme or, in exceptional cases, to intermediary non-governmental organisations or individuals to help them undertake capacity building work to help create a local MS support structure (like in the case of China).

The grants are given for time-limited project work (e.g. production of materials, training and learning opportunities and awareness-raising activities) or for travel to MSIF or other meetings and training events from which they may benefit.

Travel grants to MSIF meetings are normally provided with the requirement that grantees provide part of the costs themselves or find matching funding. Travel grants are awarded on the judgement of MSIF staff.

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 in place to implement the grant effectively).
- organisation type (patient-led/health professional-led)
- · organisations' responsiveness and readiness
- · MS prevalence rate
- accessibility to treatment by people with MS
- the 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, with further instalments dependent on reporting on progress towards objectives and expenditure.

Where travel grants are provided to MSIF Board Members from emerging countries, the MSIF Nominating Committee will be included in the decision making process.

# 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, to groups of researchers or to individual researchers. The grants to individuals have a strong emphasis on researchers from emerging countries and as such 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 research in a top research institute in a different country (the Du Pré Grant and McDonald Fellowships)
- support for international research meetings (Meeting Grant)
- · awards in recognition of life time achievements or outstanding research contributions (Charcot 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 researchers from MSIF's International Medical and Scientific Board (IMSB).

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

Criteria used to decide on grants may include:

- · scientific merit of the proposals
- relevance to MSIF's research 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.

# Reporting, evaluating, learning and Impact

MSIF upholds the importance of evaluating projects regularly to learn and continuously improve the effectiveness of its work. It is challenging to measure the impact of its projects, as this is something that is achieved over many years and via a multiplicity of variables. However, MSIF's director of programmes is working to strengthen its reporting system through setting measurable indicators and results. We will then collect and analyse project-based quantitative and qualitative data, as well as ensuring evaluations and surveys and reporting against the indicators and milestones set in the strategic plan, to continuously strive to ensure that our activities are meeting our objectives, achieving our mission and therefore making a difference to people affected by MS. An example of an evaluation report produced in 2014 is the external report on the awareness raising impacts of the last 3 years of world MS day. In 2015, we will conduct a review of our pilot project in China to inform future strategic decision making.

#### Quantitative data

MSIF regularly collects quantitative data from a number of sources:

- website download and page visit statistics, for example the number of MS in focus magazines downloaded each month;
- numerical survey results;
- number of subscribers to printed publications and the various e-newsletters;
- number of annual applications for the Du Pré research grants and McDonald fellowships;
- number of contacts maintained with MS organisations, individuals affected by MS and scientists throughout the world:
- number of MS organisations and individuals taking part in events, such as World MS Day;
- increased organisational assessment score of MS organisations taking part in the country focussed capacity-building programme.

#### Qualitative data

More important is the knowledge that MSIF projects are making an impact; strengthening MS organisations, raising awareness and funds, stimulating international collaboration in research and helping improve the quality of life for people affected by MS. To do this, MSIF collects and analyses information such as:

- Comparison of organisational self-assessments made at the beginning and end of capacity-building programmes to show improvements in prioritised areas such as governance, project management, fundraising, marketing, finance and human resource management.
- Externally conducted evaluations, such as that for World MS Day, assessing if knowledge and awareness of MS has increased in a selection of countries that participate in World MS Day.
- Reports by consultants on the project results and effectiveness of MSIF programmes, for example of our recent work in China.

Qualitative data (continued)

- End-of-project internal process evaluations, such as that of the recent research webinar—seeking to establish how project management can be improved in the future.
- Surveys and tests of award recipients and participants in training or attendance at conferences or board
  meetings, designed to assess increased knowledge, continued participation and involvement in MS
  research, and/or their commitment to put knowledge and experience gained from these awards and
  events into practice to make a difference to the lives of people with MS in their countries.

In particular, MSIF takes into account and actively encourages the involvement of people with and affected by MS in its programmes and seeks feedback to improve the effectiveness of the programmes to meet their needs (achieve impact) as follows:

- By actively encouraging individuals and families, MS society staff and volunteers, scientists and health
  professionals to participate in relevant surveys, for example the recent review of MSIF's communications
  newsletters, website and publications and the annual evaluation survey of World MS day. The collection
  and review of thank you-notes and other feedback received to the info@msif.org email address.
- · Feedback from individual participants in MSIF meetings and project work groups.
- · Reports of positive outcomes due to an MSIF project.

Quantitative and qualitative feedback received by MSIF is stored and analysed and, where possible, suggestions for improvements are considered. Annual reports are prepared for all programme areas and major funders, with six-monthly updates provided to the board and all members through the CEO report.

#### **Financial Review**

Income received during the year was higher than in 2013 due to an increase in voluntary income for restricted funds from MS Societies in relation to Progressive MS and McDonald Fellowships. Unrestricted income rose with an increase in individual donations. Expenditure increased from 2013, largely in relation to additional McDonald Fellowship grants being awarded and grants made to the Progressive MS Alliance. The increase in professional fees relates to the value of pro bono legal support, launch of our new website and visual identity and continued support in development in the Arab speaking region and China.

### Reserves Policy

The Trustees' policy on unrestricted reserves is that such reserves should be sufficient to fund the annual overhead costs of the charity, currently in the range of £550,000 to £650,000. As at 31 December 2014 unrestricted reserves amounted to £888,924. However, due to the current economic environment, the Trustees believe this level to be acceptable. This policy ensures the future security of the charity against fluctuations in income in the short-term.

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

#### Note of Appreciation

We would like to thank the people affected by MS, national MS society staff and volunteers, scientists and other professionals, donors and sponsors - both corporate and individual - for their generosity and support, without which we would not be able to continue our activities.

# Small company rules

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 and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

# Multiple Sclerosis International Federation Statement of Trustees' Responsibilities for the year ended 31 December 2014

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.

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 and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

On behalf of Trustees

Weyman Johnson

Chairman

Date: 24: April 2015

# Independent Auditor's Report to the Members of Multiple Sclerosis International Federation

We have audited the financial statements of Multiple Sclerosis International Federation for the year ended 31 December 2014 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (Effective April 2008), United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities.

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 Part 16 of the Companies Act 2006. Our audit work has been undertaken for no purpose other than to draw to the attention of the charitable company's members those matters which we are required to include in an auditor's report addressed to them. 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.

### Respective Responsibilities of Trustees and Auditors

As explained more fully in the Trustees' Responsibilities Statement (set out on page 12), the trustees' (who are 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.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors.

### Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition we read all the financial and non-financial information in the Annual Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

# Opinion on the financial statements

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 2014 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 applicable to Smaller Entities; and
- have been properly prepared in accordance with the requirements of the Companies Act 2006.

### Opinion on other matters prescribed by the Companies Act 2006

In our opinion 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.

# Independent Auditor's Report to the Members of Multiple Sclerosis International Federation (continued)

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

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' report and from preparing a strategic report.

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Nicholas Brooks

Senior Statutory Auditor

For and on behalf of Kingston Smith LLP, Statutory Auditor

Devonshire House 60 Goswell Road London EC1M 7AD

Date: \$ / \$ / / \$

# Multiple Sclerosis International Federation Statement of Financial Activities for the year ended 31 December 2014

	Note	Unrestricted Funds £	Restricted Funds £	2014 Total Funds £	2013 Total Funds £
Income and Expenditure					
Incoming Resources					
Incoming resources from generated fund Voluntary income Meeting Income Bank Interest Incoming resources from charitable action Membership dues Total incoming resources	2	19,667 21,084 2,318 307,441 350,510	1,299,743 612 - - - 1,300,355	1,319,410 21,696 2,318 307,441 <b>1,650,865</b>	1,196,427 16,600 4,258 289,805 1, <b>507,090</b>
Resources expended					
Costs of generating funds					
Costs of generating voluntary income		79,294	4,344	83,638	78,354
Charitable activities Stimulate research			706.040	706 040	E33 100
Develop national MS societies		68,565	736,340 241,070	736,340 309,635	533,199 280,248
Communicate MS		35,671	253,974	289,645	217,792
Advocate for & support people affected by	MS	19,634	185,901	205,535	260,191
Governance costs		58,302	2,005	60,307	67,477
Total resources expended	3/4	261,466	1,423,634	1,685,100	1,437,261
Net incoming resources before transfers	6	89,044	(123,279)	(34,235)	69,829
Transfers between funds		-	-	~	-
Other recognised gains and losses			· · · · · · · · · · · · · · · · · · ·	-	_
Net movement in funds for the year		89,044	(123,279)	(34,235)	69,829
Total funds brought forward		799,880	203,458	1,003,338	933,509
Total funds carried forward	44	000.004	90.470	060 402	4 002 220
at 31 December 2013	11	888,924	80,179	969,103	1,003,338

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

The accompanying notes on pages 17 to 24 are an integral part of these financial statements.

# Multiple Sclerosis International Federation Balance Sheet as at 31 December 2014

		201	4	20	13
	Note	£	£	£	£
Fixed Assets Tangible fixed assets	6		3,706	·	7,411
Current Assets					
Debtors Cash at bank & in hand	7 8	169,430 1,067,776 1,237,206		102,305 1,104,694 1,206,999	
Creditors' amounts falling due within one year	9	(271,809)		(211,072)	
Net current assets			965,397		995,927
Total Net Assets	10	=	969,103	- =	1,003,338
Funds Unrestricted Funds Restricted Funds	11		888,924 80,179		799,880 203,458
		- =	969,103	- -	1,003,338

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 and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The accompanying Notes on pages 17 to 24 are an integral part of these financial statements.

The accounts were approved by the Board and authorised for issue on 24 April 2015, and signed on its behalf by:

**Guillaume Courault** 

Treasurer

### 1 Accounting Policies

# 1.1 Basis of Accounting

These Financial Statements have been prepared under the historical cost convention and in accordance with the provision of the Companies Act 2006, the Statement of Recommended Practice (SORP 2005) "Accounting and Reporting by Charities" and applicable accounting standards.

The following principal accounting policies have been consistently applied in preparing the financial statements.

# 1.2 Incoming Resources

Income is recognised in the accounting period to which it relates. Membership dues and legacies are accounted for on a received basis. Donated services are valued at the advised commercial rate.

### 1.3 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.

### 1.4 Grantmaking Policy

Grants are awarded by the Board to both individual and institutional recipients on the basis of their work.

### 1.5 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.

### 1.6 Fixed Assets

Depreciation is provided on fixed assets in excess of £1,000 to write off the cost during their estimated useful lives which is currently over 3 years.

### 1.7 Foreign Currencies

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 Voluntary income	Unrestricted Funds £	Restricted Funds £	Total 2014 £	Total 2013 £
BiogenIdec	-	75,000	75,000	65,400
BiogenIdec*	-	571	571	12,142
Genzyme*		140,469	140,469	<b></b>
Genzyme	<u></u>	33,367	33,367	191,363
Latham & Watkins LLP (donated service)	-	66,833	66,833	41,230
Medtronic Foundation	•	-	•	25,000
Merck Serono	-	173,494	173,494	178,646
MSIF Foundation	2,536	-	2,536	-
MS Societies	-	173,729	173,729	-
Novartis	<b>.</b>	33,748	33,748	24,991
Synthon	-	-	-	8,147
Teva	-	-	u u	6,145
Vanneau Trust	_	579,000	579,000	625,870
Legacy	1,000	••	1,000	10,000
Other	16,131	23,532	39,663	7,493
	19,667	1,299,743	1,319,410	1,196,427

Personal donations from Trustees during the period amounted to £4,036.

# 3 Resources Expended

	Grants Paid £	Direct Costs £	Support Costs £	Total 2014 £	Total 2013 £
Costs of generating funds					
Costs of generating voluntary income	-	36,535	47,103	83,638	78,354
Charitable activities			•		
Stimulate research	417,445	101,497	217,398	736,340	533,199
Develop national MS societies	41,568	86,895	181,172	309,635	280,248
Communicate MS	_	141,085	148,560	289,645	217,792
Advocate for & support people					
affected by MS	500	96,335	108,700	205,535	260,191
Governance costs	-	38,567	21,740	60,307	67,477
	459,513	500,914	724,673	1,685,100	1,437,261

Grants payable comprises:

	Grants to Insitutions £	Grants to Individuals £	Total £
Stimulate research	129,980	287,465	417,445
Develop national MS societies	15,978	25,590	41,568
Advocate for & support people affected by MS	-	500	500
	145,958	313,555	459,513

Grants to individuals during the period include Du Pre Grants amounting to £46,144, of which £17,000 was accrued and £10,000 was still payable as at the year end date and is included in Other Creditors, and £240,000 for McDonald Fellowship winners, of which £120,000 was accrued and £30,000 was still payable as at the year end date and is included in Other Creditors.

Grants to organisations/institutions includes £26,000 of grants accrued in 2014 to be paid in 2015. £16,000 of the accrual is for institution host fees in relation to the fellows they host, and £10,000 for an Iternational Conference on Cell Based Therapy. A material grant of £91,305 was paid to the Progressive MS Alliance. The remaining balance is made up of smaller individual grants.

<sup>\*</sup> Income received from the MSIF Foundation

4 Breakdown of Resources Expended by Activity

	Generating Voluntary Income	Stimulate Research	Dev. C	Communicate MS	Adv. & Sp.	Total Charit. Activ.Govemance	overnance	Total 2014	Total 2013 Ĉ
Direct Costs	ı		1	1	1	1	1	1	4
Conferences & Meetings	10,742	23,418	5,281	910	2,041	42,392	18,190	60,582	58.684
Travel & Accommodation	8,364	10,813	28,841	1571	5,838		8,470	63,897	68,968
Professional Fees	15,900	66,573	52,419	111,814	84,622	m	11,907	343,235	217,449
Printing & Publications	332	693	172	24,442	2,262		, 1	27,901	50,881
Online Communication Costs	1,197	ſ	182	2,348	1,572		ı	5,299	38,249
Grants (note 3)	•	417,445	41,568	. 1	500	45	ı	459,513	281,922
Sub Total	36,535	518,942	128,463	141,085	96,835	921,860	38,567	960,427	716,153
Support Costs	0 0 0	4000	, c c c c c c c c c c c c c c c c c c c	0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	0,00	200 700	0	000	й 4.
Stall Costs (Hote 3)	900,80	102,090	132,244	124,042	9,540	280,70b	18,210	9/8'90a	007,166
Education & Training	311	1435	1195	980	717	4,638	143	4,781	3,159
Rent, Rates & Insurance	4,494	20,740	17,287	14,178	10,374	67,073	2,074	69,147	113,626
Premises Maintenance	894	4,138	3,450	2,823	2,065		414	13,784	17,066
IT Support & Maintenance	869	4,013	3,343	2,741	2,006	12,972	401	13,373	17,099
Office Expenses	346	1,593	1,329	1,088	797	5,153	159	5,312	6,669
Financial Expenses	364	1,678	1,398	1,148	839	5,427	168	5,595	8,202
Depreciation (note 6)	241	1,111	926	760	556	3,594	111	3,705	4,087
Sub Total	47,103	217,398	181,172	148,560	108,700	702,933	21,740	724,673	721,108
Total Expenditure	83,638	736,340	309,635	289,645	205,535	1,624,793	60,307	1,685,100 1,437,261	1,437,261

Auditors Fees during the period amounted to £4,700 + VAT. Auditors' Other Services during the period amounted to £1,259. (December 2013 - Auditors Fees £4,560 + VAT. Auditors Other Services - £213)

Support costs are apportioned on the basis of staff time

2014	2013
£	£
527,918	462,840
59,246	51,649
-	(1,863)
21,812	38,574
608,976	551,200
	£ 527,918 59,246 - 21,812

The average number of employees during the year was 12. (2013 - 12) One employee received total taxable emoluments of between £90,000 and £100,000 during the year and defined contributions to a pension scheme (2013 one £80,000 - £90,000). No other employees received total taxable emoluments exceeding £60,000 (2013 - £Nil).

No Trustee received any remuneration from the charity in the period. During the period four Trustees received travel expenses totalling £7,106 from the charity (2013 - two trustees received £998).

6 Fixed Assets		Equipment £
Cost brought forward at 1 January 2014 Additions		40,104
Disposals Cost/depreciation carried forward at 31 December 2014		(4,400) <b>35,704</b>
Depreciation brought forward at 1 January 2014		32,693
Depreciation for the year  Disposals		3,705 (4,400)
Cost/depreciation carried forward at 31 December 2014		31,998
Net Book Value at 31 December 2014		3,706
Net Book Value at 31 December 2013		7,411
7 Debtors and Prepaid Expenses  Other Debtors Prepayments VAT Reclaimable	2014 £ 129,662 23,405 16,363 169,430	2013 £ 59,312 27,271 15,722 102,305
8 Cash and Cash Equivalents  Bank Accounts Cash	2014 £ 1,067,414 362 1,067,776	2013 £ 1,104,538 156 1,104,694

# 9 Creditors: Amounts falling due within one year

	2014	2013
	£	£
Other Creditors	69,661	118,258
Taxation and Social Security Creditor	16,714	15,461
Accruals	185,434	77,353
	271,809	211,072
	***************************************	

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

	Fixed Assets Current Assets Current Liabilities		Unrestricted £ 3,706 1,157,027 (271,809) 888,924	Restricted £ - 80,179 - 80,179	Total £ 3,706 1,237,206 (271,809) 969,103
11	Restricted Funds	Balance 01.01.14 £	Resources Incoming	Resources Outgoing	Balance 31.12.14 £
a.	Research Fellowships & Grants	£ 25,228	£ 311,866	£ 337,001	£

		Balance	Resources	Resources	Balance
	•	01.01.14	Incoming	Outgoing	31.12.14
		£	£	£	£
a.	Research Fellowships & Grants	25,228	311,866	337,001	93
b.	Research Miting Grants	7,769	14,870	22,639	•
c.	Research Support	7,734	41,831	49,517	48
d.	Charcot Award	158	8,068	7,964	262
e.	IMSB	3,501	14,237	17,655	83
f.	IPMSSG	2,762	97,204	86,836	13,130
g.	Stem Cell	422	17,768	17,96 <b>4</b>	226
h.	Progressive MS	54,782	142,073	196,764	91
í.	Regional Programmes - Arab Regio	24,205	131,938	128,926	27,217
i.	Regional Programmes - China	-	107,522	107,522	-
j.	MS in focus	43,900	51,648	79,745	15,803
k.	Making Connections	5,669	34,749	34,291	6,127
1.	MSIF Website	-	97,653	97,058	595
m.	Atlas of MS	27,328	1,239	12,063	16,504
n.	World MS Day	-	173,170	173,170	•
0.	Other	<u>.</u>	54,519	54,519	-
		203,458	1,300,355	1,423,634	80,179

The purposes of the restricted funds are as follows:

a. 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 four fellowships per year.

Grants enable young researchers to undertake short visits to MS research centres of excellence. Each grant is £1,000 - £5,000 to cover travel costs or as a top-up to an existing grant. MSIF makes up to 10 grants per year.

**b.** Established to help support the costs of the organisation of international meetings focused on MS research.

- c. Facilitate, co-fund and cooperate in relation to international research programmes/conferences.
- d. 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.
- **e.** To identify and propose relevant international research projects for MSIF, support and generate exchange of information between the MSIF Board and the MS scientific community.
- **f.** Facilitate and coordinate the work of the International Pediatric Multiple Sclerosis Study Group. The group of neurologists, paediatricians and healthcare professionals aim to optimise worldwide care, education and research in paediatric MS.
- g. Help fund an international collaborative effort to research treatment with stem cells.
- **h.** Collaborative with five of our member organisations to expedite the research into treatments for progressive MS.
- i. Build capacity, by initiating or supporting the development of new MS organisations in Arab speaking countries and Asia
- j. A biannual free magazine aimed at the MS community with an English print version and online versions in English, Spanish, German, Dutch, French and Italian. Its uniqueness resides in its depth of focus on specific themes relevant to MS, selected by its international Editorial Board. Articles are commissioned from the world's leading experts and practitioners in the MS field.
- k. A monthly email newsletter for the organisation's stakeholders with an update on MS research, MSIF
- I. Fund for designing and launching MSIF's new website.
- m. 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.
- n. World MS Day (last Wednesday in 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.
- Other restricted income for communications and donated services for legal advice.

# **12 Future Commitments**

At 31 December 2014, MSIF had annual commitments under operating leases as set out below:

·	2014 £	2013 £
Equipment Expiring between two to five years	1,559	1,559
Land and Buildings Expiring between two to five years	58,725 <b>60,284</b>	58,725 <b>60,284</b>

# 13 Related Party Disclosures

Name of Entity	Nature of Relationship	Membership Dues Received 2014 £	Membership Dues Received 2013 £
Multiple Sclerosis Australia	Joint Trustee	31,918	31,930
Ligue Nationale Belge de la Sclérose en Plaques, Belgium	Joint Trustee	4,048	3,926
MS Society of Canada	Joint Trustees	34,547	34,547
Greek MS Society	Joint Trustee	348	348
Ligue Francaise contre la Sclerose En Plaques, France	Joint Trustees	6,544	6,544
Associazione Italiana Sclerosi Multipla of Italy	Joint Trustee	31,734	31,734
National MS Society, USA	Joint Trustees	110,004	110,004

Name of Entity	Nature of Relationship	Grants Received 2014 £	Grants Received 2013 £
Ligue Nationale Belge de la Sclérose en Plaques, Belgium	Joint member Progressive MS Alliance	62,436	-
Danish MS Society	Member	2,705	-
Stichting MS Research, Netherlands	Member	2,729	-
German MS Society	Member	1,953	-
Associazione Italiana Sclerosi Multipla of Italy	Member	3,917	-
Esclerosis Multipla Espana, Spain	Joint member Progressive MS Alliance	28,586	-
MSIF Foundation - National MS Society USA	Member	143,576	12,142
National MS Society (USA)	Member	71,401	<b></b>
Progressive MS Alliance - National MS Society (USA)	Joint member	12,150	-

# 13 Related Party Disclosures (continued)

Name of Entity	Nature of Relationship	Grants Paid 2014 £	Grant Paid 2013 £
Fondazione Italiana Sclerosi Multipla	Linked to Associazione Italiana Sclerosi Multipla of Italy. Joint Chairman and Trustee	10,000	10,000
International Advisory Committee on Clinical Trials in MS of the National MS Society (USA) & European Committee for Treatment & Research In MS	Member	10,000	<u>.</u>
Progressive MS Alliance - National MS Society (USA)	Joint member	91,305	<u>.</u>