multiple sclerosis
international federation

Strategic Plan
2012 - 2016

A world without MS!

Introduction

Welcome to the new strategy for Multiple Sclerosis International Federation (MSIF) - the world's only global network of MS organisations. Together we lead the fight against MS and strive to improve the quality of life of people affected by MS wherever they live.

We bring together the work of more than 80 MS organisations to deliver programmes to help people affected by MS around the world. Our members campaign for better practices and policies, build partnerships with communities, civil society, governments and the private sector, provide information and support to people affected by MS, and support international research in MS to discover better treatments and ways to manage the disease.

MSIF consists of its Member Societies (Members), Board, Committees and its Secretariat. It is therefore only as strong as the collaboration and coordination between these groups and the common conviction that the global MS movement is a shared responsibility among all.

This is our common plan for 2012 to 2016, outlining our priorities and commitments for the next five years and how we will deliver them and it has been produced after a comprehensive consultation process. The strategy will enable our network to flourish for the benefit of all who are affected by MS anywhere in the world.

The starting point of the strategy is that MSIF must add value to what individual Members do. The common added values which underlie all we do are: strength in numbers; international collaboration; action at the international level; avoiding duplication of efforts; and sharing of best practice. **Our priorities for 2012 to 2016 are international collaboration in research and capacity building.**

Over the next five years, **capacity building for MS organisations**, particularly in emerging countries, will be one of MSIF's two top priorities. Having piloted different approaches in our regional strategy for Arabic-speaking countries, we now need to build our expertise in this field and step up our efforts. We will embark on further programmes in the Pan Asia region - in particular in China - and in Latin America.

The other top priority will be **global collaboration in research**. Our staff expansion is already taking place and the pace of interaction amongst Members is accelerating. Key areas of collaboration will be in progressive MS, paediatric MS and stem cell research.

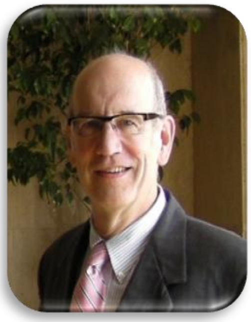
MSIF's campaigning and communication work will continue to be important in their own right, particularly in expanding World MS Day and in our digital and social media presence, reaching out to individuals. We will continue to publish high-quality information about MS and make it widely available and re-usable, for example, with *MS in focus* being developed as a flexible tool for MS organisations in emerging countries and our Members to use. We will aim to gear these activities as much as possible towards supporting the priority areas.

We will also explore the important benefits that can be found in international collaboration in fundraising which should benefit individual Members as well as the movement as a whole.

The ambitious programme set out in this plan will require a clear focus, appropriate investment, and commitment from Members.

With the support of our Members and partners, we are confident that MSIF's exciting plans for the next five years will help towards a cure and improve life for everyone affected by MS around the world.

Weyman Johnson, Chairman
Peer Baneke, Chief Executive



1. Our vision

A world without MS!

2. Our mission

To lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding and treatment of MS, advancing the route to a cause and cure.

In pursuing its mission MSIF will facilitate international collaboration between MS organisations, the international research community and other stakeholders.

3. Our membership

MSIF has 33 Full Members, which have the right to vote and elect its Board. It has a further 10 Associate Members which have the same involvement and rights apart from voting rights. The newest Associate Members to join are the national Russian, Estonian and Tunisian MS societies. In countries where there is a Member, another MS organisation can acquire the status of Supporting Organisation, which is part of the network but with fewer rights than Full and Associate Members. There is one such organisation.

In many emerging countries with which MSIF actively liaises it undertakes capacity building to support Corresponding Organisations, which may become Members at some stage in the future.

4. The world of MS and the external environment

The understanding of MS has improved, but this has not led to a cure. However, new avenues of research (such as genetics, stem cells and individualised medicine) have promise. More pharmaceutical companies are entering the field and there are a large number of possible treatments in the pipeline. Generic and bio-similar products may also be produced in the coming years which may lead to less expensive treatments, particularly in emerging countries.

The MS population is changing with earlier diagnosis and an increasing proportion of women being affected. Our *Atlas of MS* has established that MS is present around the world.

New MS organisations have formed and there is potential for growth in many emerging countries where economic development has been strong (for example India, Brazil, Russia and Turkey). This is supported by improved diagnosis leading to more people from these countries being diagnosed with MS. The digital media revolution has brought about many challenges, such as a tendency from pharmaceutical companies to link up directly with individual persons affected by MS. However, it also brings great opportunities. Websites such as Facebook, Twitter and YouTube have been used by the People with MS Community, moving away from MS organisations and more traditional institutional platforms and support structures. MS organisations have also embraced those media, with MSIF reaching nearly 500,000 viewings on Youtube and having 50,000 World MS Day Facebook friends.

In the short term, the global economic crisis is likely to lead to less government spending on medical research, and cuts to spending on public welfare, putting health and social services under pressure. This, in turn, leads to a greater need for the support of people with MS by MS organisations. Some Members report that their income is diminishing.

There is an increased financial strain on government schemes to reimburse or subsidise MS treatments, which is likely to lead to a reduced willingness to pay the high prices for those treatments. Governments, as a result, may increasingly restrict the choice of medicines available.

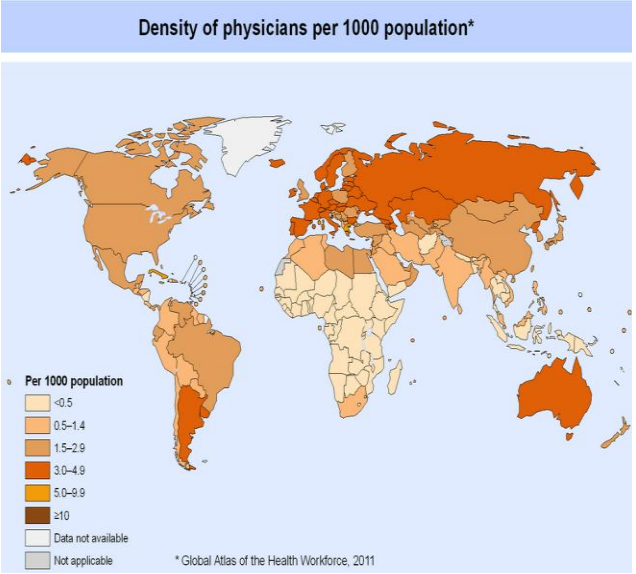
5. Key challenges for the MS community

Tackling the disease

While understanding of the disease is growing continuously, there are no treatments for the large group of people with progressive MS. We need to understand the underlying disease mechanisms of progressive MS and improve treatments that impact on symptoms and the disease course. Better global integration of all involved is needed, tapping into and better linking all possible expertise to find a cause, a cure and treatments: involving scientists, MS organisations, pharmaceutical companies, regulators and governments. Larger, more impactful and international research projects are required.

Increasing awareness, protection and support

Greater awareness of MS would help with research, fundraising and providing support and understanding for people with MS. There are upwards of 2 million people with MS in the world. However, compared to other diseases, such as diabetes (350 million) or dementia (36 million) the figures are small. This makes it more difficult to create awareness.



* Global Atlas of the Health Workforce, 2011

It is therefore also more of a challenge to create support for all people with MS wherever they live - because in many countries, the numbers of people with MS are small and fewer doctors have the experience to be able to provide a diagnosis or the capacity to organise an MS support organisation is smaller. Also public health services/provision, especially in emerging countries, have traditionally focused on mortality, rather than on chronic diseases.

However, the rights of people with MS need to be protected in relation to their quality of life (access, employment, health insurance etc) and in relation to medical trials. Advocacy needs to affect all who can play a role: local, regional, national and global authorities, as well as the pharmaceutical industry. As many member organisations are already doing, we need to link forces with other relevant actors, particularly in the neurological and disability fields to help advocate on common issues. As a larger proportion of women than men has MS, special involvement of women's organisations may reap benefits.

Providing advice in the digital age

With an increasing number of organisations or individuals who can reach out to people with MS, it is a challenge to help those people find reliable sources of information. Equally, the number of treatments is increasing. We need to ensure that the need for quality information and advice for individuals with MS is met and is not hindered by overwhelming amounts of information.

Fundraising

All these challenges require more fundraising. The global movement needs to look beyond national borders and the traditions of purely nationally organised fundraising; the delivery of this presents additional internal and external challenges to MSIF.

6. Our aims, strategies and objectives

MSIF's different areas of work impact on each other. For example, stronger Members will raise more money for research. Researchers from emerging countries[1] who receive MSIF grants will support capacity building. With more effective information tools and more widespread translations, MS organisations from emerging countries will be able to reach more people with MS and grow. World MS Day will be an important tool for capacity building, with stronger MS organisations in emerging countries making it an even more global and vibrant event and strengthening international solidarity in the global movement.

The sections below outline the aims, strategies, objectives, actions and key outcome indicators for each of our five strategic areas. Achievement of our aims relies on involvement of the Members in the activities and their preparation. It needs consultation, active advice or participation in committees. All this requires time of staff, volunteers and board members – and other resources. We will measure our success at the end of this Strategic Plan period through selective key outcome indicators. Specific timing of some outputs and outcomes are given in section 9.

Key aims of our strategic plan 2012 - 2016

Research

Together with our Members active in research, to facilitate, coordinate and lead international cooperation and collaborative initiatives to better understand the nature of MS, to develop better treatment and rehabilitation of people with MS and inform relevant communication and advocacy initiatives.

Capacity building and emerging countries

Initiate, support and encourage the development of new MS organisations. Support emerging structures and stimulate and support existing national MS organisations in their work to improve the quality of life of people affected by MS.

Advocacy and campaigning

Raise public awareness and understanding of MS by uniting the global MS movement though campaigning and advocate for the interests and rights of people affected by MS, in order to improve their quality of life.

Information and communication

Enhance and complement (particularly emerging) MS organisations' efforts to provide information which meets the needs of people affected by MS. Be a resource for people affected by MS who do not have access to an MS organisation.

Fundraising

Grow the fundraising income of the MS movement to improve the quality of life for all people affected by MS.

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[1] For purposes of MSIF grants, emerging countries are those with a low, lower middle or upper middle income as defined by the World Bank.

Research

Aim

Together with our Members active in research, to facilitate, coordinate and lead international cooperation and collaborative initiatives to better understand the nature of MS, to develop better treatment and rehabilitation of people with MS and inform relevant communication and advocacy initiatives.

Strategy

Through strengthened cooperation with Members that have research funding programmes, and with our advisors from the medical and research community, we will stimulate, support and, where we are best placed, lead international collaboration in areas of greatest need and promise. Through this, we will aim for larger and more international research projects in key areas such as progressive MS, paediatric MS and stem cell research and, where relevant, help to develop methodologies or standards at international level.

By improving connections between our research and capacity-building work in emerging countries, we will aim for stronger relations with specific research centres, strengthened medical/research output, both in terms of skilled medical/research professionals, care for people with MS and increased funds for MS research in those countries and globally.   Equally, by increasing awareness of MS we will aim to increase political and public support for MS research.

As pharmaceutical companies undertake key activities in all our strategic fields, we will strengthen our leadership role on behalf of our Members and the MS movement.   We will make use of the expertise, research capacity and resources of the pharmaceutical industry, ensure the independence of MS organisations, and where necessary, promote the rights and interests of people with MS in relation to industry.

Objectives

1. **Substantial progress in the key fields of paediatric MS, progressive MS, stem cells and databases/registries**

   Action: Support or coordinate international collaborative projects between MS organisations and researchers to make progress in key areas; facilitate funding, particularly of logistical support; where appropriate, play a leadership role.

2. **Broadened involvement in MS research by supporting new entrants to the MS research arena, in particular from emerging countries, and enhanced support of people affected by MS.**

   Action: Focus the McDonald Fellowships and Du Pré Grants on emerging countries.

3. Increased coordination of research by MSIF and its Members and the scientific community

Action: (Biennial) international research coordination meetings involving key members of MSIF's International Medical and Scientific Board and Members with substantial involvement in research. Coordination of common positions, such as in relation to newly proposed treatments or hypotheses.

4. Increased strategic targeting of Member and MSIF Research Funding

Action: Coordinate or facilitate pooling of research funding and seeking funding from donors interested in global initiatives, informed by the MSIF Database of Research Funding.

Key outcome indicators

- Acquisition of project grant and publication of an international study on environmental factors in paediatric MS (Objectives 1, 3 and 4).
- Consistently high satisfaction ratings of MSIF coordination from members of the International Pediatric MS Study Group (Objective 1).
- Establishment of a Progressive MS Collaborative and publication of a position paper
- Major scientific meeting focusing on progressive MS.
- Publication of five papers by MSIF fellows/grantees in high-quality journals and involvement in MS organisations of 10 2008-2016 alumni (Objective 2).
- Participation of 10 Members and/or other funding-NGOs in pooled funding of research-related activities over the period (Objectives 1, 3 and 4).

Capacity building and emerging countries

Aim

Initiate, support and encourage the development of new MS organisations. Support emerging structures and stimulate and support existing national MS organisations in their work to improve the quality of life of people affected by MS.

Strategy

Our strategy is based on the conviction that everybody affected by MS, wherever they live, should have access to information, support and advice from an MS organisation.

In emerging countries many organisations lack skills, experience and resources; they may not yet be able to build accountable structures and are often fragmented and sometimes open to the influence of some companies. In these countries, the need for MS support structures is high, due to limited state healthcare provision, low numbers of health professionals with MS knowledge and under/mis-diagnosis. Those organisational structures that do exist are mostly concentrated in urban areas and information in native languages is also often extremely limited.

We will listen to those who take initiatives to set up support structures and will provide resources to reinforce their efforts based on our best knowledge and experience.

We will build up the MSIF Secretariat's capacity to coordinate regional strategies, including activities for several countries within a region and a focus on individual countries with potential for developments. We will link up the supporting capacity of the MSIF research fellowships and grants to tap their potential as a development catalyst.

We will coordinate the sharing of experiences between Members and other MS organisations, in particular through twinning and other opportunities such as global conferences or meetings on particular topics. We will bring together MS organisation representatives from similar groups of countries to focus on strengthening particular skills; fundraising and strategic programme development will be a crucial element of this. We will provide materials which can be freely used by MS organisations and people affected by MS alike, in different languages, in particular *MS in focus*.

Objectives

1. New MS organisations in countries without one

Action: Identification of key activists and provision of training, advice and support, including financial, enabling them to establish and build an MS support structure. Programme to be piloted in China.

2. Stronger MS organisations in emerging countries

Action: A proactive regional approach including MSIF staff with a regional focus, based in London or the relevant region. Regional and linguistic groups to be brought together to share best practice and strengthen organisational capacity through regular, targeted training opportunities.

Extensive use of World MS Day to create awareness and mobilisation.

Support programmes for one or two countries with extensive MS populations and major organisational development and fundraising self-reliance potential, such as India, Brazil or Turkey.

Exchange of skills, knowledge and best practice through twinning, targeted materials translation, and the development of a multi-faceted toolkit.

3. A competent and professional membership

Action: A 2013 World Conference on MS, to be hosted in Berlin by the German MS Society (DMSG) in collaboration with MSIF. Investment in Members, guided by a Membership Audit, which will take stock of the capacity, developments and ongoing needs of the Membership.

4. Increased engagement with the wider MS community

Action: Development of other mechanisms for engagement with non-members, individuals and those professionally engaged with MS. Consider MSIF membership for regional organisations.

Key outcome indicators

- A self-reliant MS organisation in China with at least one paid staff member in place, who is involved in MSIF's projects and programmes including World MS Day participation (Objective 1).
- Two MS organisations from the Arabic-speaking region to reach MSIF Associate Membership standard (Objectives 2 and 3).
- Six twinning partnerships to have taken place or to be underway between MSIF Members and MS organisations in emerging countries, with MSIF funding matched by the MSIF Member partners (Objectives 1, 2 and 3).
- 60% of the 2013 Membership is represented at the Berlin World Conference on MS (Objective 3).
- 30% increase in total income or number of registered individual members or supporters by the MSIF Member in one country-focused capacity building project (Objective 2).
- An increase in awareness of MS of 10% in selected key indicator countries (Argentina, Egypt, India, Ireland and Estonia) (Objectives 2 and 4).

Advocacy and campaigning

Aim

Raise public awareness and understanding of MS by uniting the global MS movement though campaigning and advocate for the interests and rights of people affected by MS, in order to improve their quality of life

> “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”
>
> **WHO Constitution, 1946**

Strategy

Advocacy must take place at national and local levels to ensure benefits for people affected by MS. However, a great deal can and must be done to create an international rights framework which can be used to strengthen advocacy at the national level. MSIF will continue to work with the World Health Organization (WHO), UN agencies, and to liaise with the European MS Platform (EMSP). MSIF will develop a leading global role in relation to the pharmaceutical industry on behalf of its Members.

World MS Day – now firmly established and steadily growing in impact – will be a tool for global awareness raising and advocacy (with varying emphasis on either or a combination of both). While it will gain its maximum benefit if all Members, other MS organisations and individuals around the world participate, MSIF will emphasise the campaign’s role in strengthening awareness, activism and mobilisation in low- and middle-income countries.

Objectives

1. Increased global awareness of MS amongst the public and policy makers

Action: Coordinate World MS Day, including a theme and resources, with a particular focus on the needs of low- and middle-income countries.

Strengthen links with the WHO and cooperate with other intergovernmental organisations and international non-governmental organisations as appropriate.

2. Increased policy impact and opportunities for MS organisations through international epidemiological and socio economic comparative research and international action

Action: Update the *Atlas of MS* including data about access to drugs and treatment, health services, and service provision.

Coordinate additional research, as necessary, to achieve advocacy and campaigning project objectives.

Continue to use and promote the *Principles to Promote the Quality of Life* in appropriate advocacy and campaigning projects such as the *Atlas* and World MS Day.

Represent and advocate for rights of people affected by MS towards international entities such as the healthcare industry and intergovernmental organisations.

Key outcome indicators

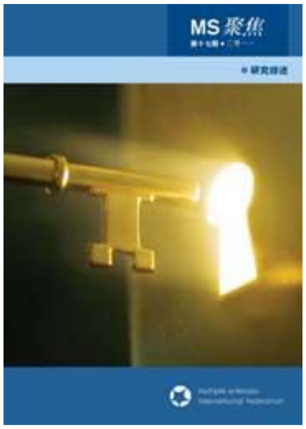
- A 10% increase in awareness of MS in 5 selected key indicator countries (Argentina, Egypt, India, Ireland and Estonia) Objective 1
- The *Atlas of MS* provides up-to-date epidemiological data from more countries to all stakeholders and interested parties: the *Atlas* is quoted in more than 15 scientific publications.
- All Members and their chapters participate in World MS Day, and 60% have a national campaign.
- MS organisations in emerging countries will grow through increased public awareness, exposure and mobilisation, as indicated by outcome measures under the Capacity Building Aim.

Information and communication

Aim

Enhance and complement (particularly emerging) MS organisations' efforts to provide information which meets the needs of people affected by MS. Be a resource for people affected by MS who do not have access to an MS organisation.

Strategy



MS organisations around the world aim to provide reliable information to people affected by MS. MSIF particularly reinforces organisations in emerging countries through the production of information from an international perspective, such as *MS in focus*, signposting materials produced by other MS organisations and by translating such information as required. Information from *MS in focus* is also used by established organisations, such as those in Italy, Spain, France and Australia and by individuals around the world. However, in producing it, the needs of emerging countries will become more central. For this we rely on the input from staff and volunteers from Members and other organisations and on voluntary contributions from many medical practitioners and researchers.

Digital media will play an increasingly important role in our work and that of our Members, making it easier to connect with individuals anywhere in the world. Recognising that globalisation also affects MS organisations, we will explore how these media can be used to link MS organisations around the world and connect the global MS movement. A more harmonised global branding of the MS movement would be explored in the context of a wider development of international collaboration and closer connection of activities of MSIF and MS organisations.

Our information and communication activities will be particularly geared to support our research and capacity building objectives and be closely integrated with World MS Day and other advocacy activities.

Objectives

1. **Increased knowledge about MS and relevant treatments, in particular among people affected by MS**

   Action: Continue to produce *MS in focus* and other relevant MSIF publications; develop their content and format for relevant use by Members and MS organisations from emerging countries.

   Develop a useable and accessible library of quality information about MS, made up of the best core materials from the MSIF Membership.

   Continue and develop e-newsletters for all our audiences.

Attend relevant international meetings to promote knowledge about MS and MSIF.

2. Increased engagement from individuals affected by MS

Action: Expand the use of electronic and social media in an integrated way and promote links between Members and MSIF.

Provide forms of ad hoc and ongoing engagement, including those supporting our advocacy aims, such as petitions, surveys and, for individuals around the world, referring them to national MS organisations where appropriate.

Further explore how to build on these communication tools to engage with young people.

3. Build awareness of MSIF's work and role, particularly in countries without MS organisations, and with specific audiences

Action: Develop key messages about MSIF and the work of the MS movement.

Review the MSIF brand and explore harmonising the brand across the Membership.

Promote our programmes and goals as widely as possible through our website, publications, e-newsletters, meetings, social media sites and Members.

Key outcome indicators

- Content of *MS in focus* is used by 30% of MSIF Members and Corresponding Organisations.
- MSIF's e-newsletters and social media reach 50% more people than in 2011.

Fundraising

Aim

Grow the fundraising income of the MS movement to improve the quality of life for all people affected by MS.

Strategy

Globalisation has not only brought change to the business world, it is also changing the landscape for corporations, foundations, donors and people affected by MS.

Increasingly, foundations are seeking to fund efforts that will have an international impact on the health and well-being of individuals and communities. Strong, integrated approaches are expected in projects and plans to meet the challenges affecting the human condition including multiple sclerosis.

The advent of social-networking tools has also allowed both donors and people with MS to become borderless. People seek solutions, innovation and change wherever it exists and not within the confines of their own community, country or continent. Accordingly, people will embrace and financially support those organisations that are able to effectively demonstrate an ability to harness the collective strength of worldwide knowledge and experience. And for those that fail to meet this challenge, they will ignore and seek or create institutions that will meet this challenge.

The MS movement is poised to meet the opportunities that a global fundraising strategy would achieve. Through working together, MSIF can attain funding and support that will otherwise not be realised. We will learn best practices and innovative ideas from each other. We will become stronger individually and collectively in our fundraising efforts. Most importantly, together, we will meet the hopes and expectations of people with MS all over the world.

Objectives

1. Deliver an integrated MS movement global fundraising growth strategy
2. Increase collaboration to fundraise more effectively
3. Develop and manage a diverse global fundraising portfolio
4. Monitor and evaluate national and international fundraising activities
5. Deliver a consistent message platform for global fundraising initiatives
6. Strengthen the skills and provide development opportunities for fundraisers across the MS movement through a global fundraising network
7. Deliver an internal communications programme to stimulate fundraising discussions, celebrate success and share fundraising knowledge
8. Allocate required resources (time, staff and money) to develop and deliver the global growth strategy

Key outcome indicators

- A more coherent understanding of fundraising as part of an international movement, cooperation, collaboration and increased working together across the Membership.
- A more balanced fundraising portfolio, an increase in income which will allow diversification of Vanneau funding and growth in MSIF's international programmes and increase in reserves.

7. Organisational development and membership involvement

Realisation of the aims of the global movement requires developments on several organisational fronts.

Within MSIF and its Secretariat it will require an increase in staff, particularly in relation to capacity building and fundraising, and with that a strengthened management, allowing the CEO to pay more attention to linking up the Membership, stakeholders and external supporters and embodying the strengthened global leadership envisaged in the strategy.

As research-related activities increase, demands for guidance from the volunteer Chair of the IMSB will become too large. Options will need to be explored, including appointment of a senior medical advisor.

With an increased emphasis on emerging countries, the number of Board members from such countries needs to be kept at least at the present level. The role of regional clusters within the MSIF Membership and the relationship with regional MS organisations will need to be clarified.

With more global fundraising, involving many different Members, new forms of cooperation and more new common identities need to be developed to shape common programmes, approaches and income management.

8. Risks and mitigating actions

The economic climate contains many risks. The best mitigating action is for Members to learn from each other, explore new fundraising opportunities and the opening up of new countries for fundraising. With pressure on funding opportunities, a sense of competition between Members and MSIF needs to be avoided. We will need to further develop international fundraising agreements, for example specifying sources and types of funding where MSIF leads, those where countries lead and those where the starting point lies in joint ventures between MSIF and specific Members.

Some pharmaceutical companies use digital media to reach out directly to people affected by MS, rather than engaging with them through MS organisations. MSIF needs to ensure common principles of engagement from Members towards global pharmaceutical companies and common action where needed.

Our ambitious plans require further strengthening of our organisation. We are currently dependent on a small number of dedicated people. We need to reduce the risks associated with this dependency by ensuring we invest in our own organisational capacity in line with our plans for growth.

There is also a risk that MSIF will find that it faces expectations from the Membership to provide new or enhanced services which outstrip the growth of its resources. There is a major challenge in keeping attuned to the needs of Members and in prioritising work so that we can best meet those needs.

9. Timetable and key milestones

2012

- Launch Progressive MS Collaboration
- Flagship Paediatric MS Seminar – trials: pharmaceutical companies and regulators
- World MS Day – Living with MS
- Baseline MS Awareness survey in 5 countries
- First global fundraising project

2013

- Second International Research Coordination Meeting
- Launch Atlas of MS
- International research meeting on progressive MS
- Interim report 'Environmental factors in Paediatric MS'
- Start-up of one-country focused development project
- DMSG-MSIF World Conference on MS - Berlin
- World MS Day – Young People and MS
- Agreement on one MSIF-global corporate (non-pharma) cooperation
- Produce an integrated MSIF global fundraising growth strategy

2014

- Project proposal and funding on environmental factors in Paediatric MS research project
- Start up of second one-country focused development project
- New development focus on Latin America
- World MS Day on Access to treatment
- Follow-up MS awareness survey in 5 countries (expected 10% increase)

2015

- Third International Research Coordination Meeting
- Preparation of new strategic plan
- First year of new three year World MS Day strategy.

2016

- Publication of (interim) results of the study into Environmental Factors in Paediatric MS.
- Adoption of new strategic plan
- Additional income reached for MSIF and its members. The target for this will be decided in the course of 2012 and 2013 as part of the further development of a global fundraising strategy

For more information about MSIF

Telephone: +44 (0) 20 7620 1911

Fax: +44 (0) 20 7620 1922

Email: info@msif.org

Visit: www.msif.org

MSIF is a charity and company limited by guarantee, registered in England and Wales.

Company No: 5088553. Registered Charity No: 110532.

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