How to Develop a National MS Society

multiple sclerosis
international federation

The Multiple Sclerosis International Federation (MSIF) was established in 1967 to link the activities of national multiple sclerosis (MS) societies throughout the world.

Mission Statement

MSIF works in worldwide partnership with Member MS Societies and the international research community to eliminate MS and its consequences, and to speak out globally on behalf of people affected by MS.

The term ‘people affected by MS’ includes those people with MS as well as their family members and carers. It will be used throughout the booklet.

MSIF works to achieve this mission through the following key priorities:

- Stimulate global shared research into a cure for MS and the alleviation of its symptoms

- Stimulate the active exchange of information on best practice amongst Member Societies and the wider MS community and

- Provide support for the development and increased effectiveness of new and existing national MS societies

All bearing in mind the complete involvement of people living with MS.

Content

Stages of development:

Introduction

A national network of local self-help groups and associations is essential for the provision of support and services to people affected by MS. However a focused national MS society is better placed than independent local self-help groups or associations to develop effective nationwide projects and programmes.

The provision of universal and broad support and services to all people affected by MS in any country requires resources, planning and leadership which can best be coordinated by a single, national entity.

In 2003 people affected by MS, volunteers and staff members of national MS societies from seven countries formed a Work Group under the Chairmanship of Dr Hans-Peter Fricker, CEO of the Swiss MS Society, to create this booklet.

It identifies five phased stages to the development of an effective national MS society. Of course the scope, scale and rate of development of a national MS society will be dependent upon the economic, cultural, social and possibly legal situation specific to your country. Therefore it must be understood that the stages suggested are flexible and that tasks outlined could be accelerated or delayed accordingly. However, those activities identified in the earlier stages should continue to be undertaken and further developed in the later stages.

Experience has taught us that partnerships between new and existing national MS societies can provide valuable experience, skills and resources to the development process. MSIF will consequently try to identify a suitable partner for the development of your national MS society if you so wish.

‘How to Develop a National MS Society’ Work Group
July 2003

Activities of an effective national MS society

A national MS society* is a country-wide organisation which is established to undertake the following activities:

- Provide information for people affected by MS about all issues affecting their life from the point of diagnosis to later stages.
- Develop and implement national programmes to increase the general public awareness of MS and the need to find a cause and cure.
- Develop and implement projects and programmes to provide, coordinate or stimulate the provision of support and services for people affected by MS.
- Develop and implement programmes to recruit and train volunteers and leaders for the society.
- Publicise the benefits and coordinate the development of Mutual Support/Self Help Groups for people affected by MS.
- Promote social research to develop knowledge and understanding of the national MS situation.
- Promote and, if appropriate, provide public and privately funded scientific research to find the cause, cure and improved treatment of MS.
- Promote, develop and/or sponsor clinics and centres for people with MS.
- Support and work with medical practitioners and clinics to develop a wide ranging scientific and medical programme in MS, aimed at seeking new knowledge, its dissemination and application it for the benefit of people affected by MS.
- In conjunction with a Medical & Scientific Board, or equivalent, develop and implement a programme to inform and educate neurologists, doctors and medical practitioners on MS and its diagnosis, treatment, management and rehabilitation.
- Establish an advocacy programme to influence public policy on issues relating to MS and other disabling diseases. This includes working closely at both national and local levels with health and social service organisations with similar interests.

- Develop and implement fundraising programmes to support all aspects of the society's work.
- Be an active member and participate fully in the Multiple Sclerosis International Federation and regional associations.

The terms 'health care professionals' and 'medical practitioners' include nurses, doctors, neurologists, counsellors, psychotherapists, physiotherapists, occupational therapists, medical/diagnostic services, social workers etc. They will be used throughout the booklet.

*A national MS society may also be called an Association, League, Federation, Foundation, Union or other appropriate title, depending upon the regulations and/or practice of the country concerned.

Structure of a national MS society

National – represents all regions and/or major towns and cities in the country, ideally incorporating a network of local or regional chapters/branches/offices.

Representative – represents people affected by and interested in MS through a structure of individual membership.

Formal – legally and financially institutionalised, for example registered as a legal entity, legally recognised and having regular meetings, rules of procedure, business plans, accounts and audit.

Professional – employs (a) paid staff member(s) devoted to the day-to-day management of the organisation.

Self governing – equipped to control its own activities by establishing a governing body (Board) and relevant Committees or Work Groups, such as a Medical & Scientific Board made up of the country's leading MS health care professionals.

Voluntary – involves some degree of voluntary participation in particular a committed volunteer Board of Directors/Trustees.

Private – institutionally separated from government and fundamentally a private institution in basic structure.

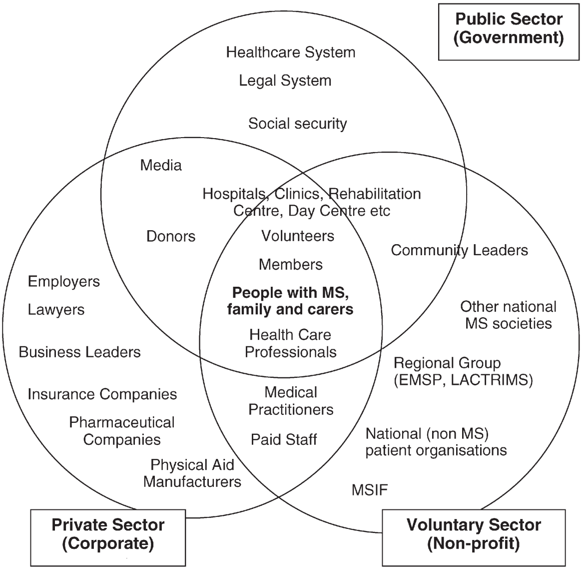
Independent – independent of political parties, private companies and government.

Non-profit distributing – not returning profits to Board, staff or members but 'investing' surplus funds back into the activities of the organisation.

Stakeholders of a national MS society

Stakeholders are those individuals and organisations that have an interest in the national MS society who should be involved and/or considered in its various operational activities.

The complexity of the diagram below highlights the complexity of running a fully functioning, mature national MS society!



Stages of development for a national MS society

Stage 1 – Early days/First steps

Key Activities:

- Gather information about the availability and accessibility of health professionals, medical practitioners, treatment, rehabilitation and other support services.
- Print a basic information leaflet about MS and your plans to develop the national MS society.
- Establish and publicise a permanent contact name, address, telephone/fax number and email for the planned society.
- Identify people affected by MS in your country.
- Find individuals with the range of skills, time and commitment to help establish the society and initiate an email group.
- Identify other voluntary organisations (like the Lions Club, Red Cross/Crescent etc) that can help your society develop.
- Identify relevant training services available on subjects such as NGO development, fundraising etc.
- Identify relevant Non Governmental Organisations (NGOs) and local/national government social/health departments.
- Identify and make contact with individuals in the media, health, business and community sectors etc.
- Contact MSIF to identify MS societies in countries near to your own or in countries that speak the same language.
- Hold an organisational meeting with key individuals who will lead the society and plan a public meeting.
- Prepare guidelines on how to develop Mutual Support/Self Help Groups (see MSIF publication).
- Plan courses for newly diagnosed people with MS/affected by MS.
- Consider local and national public policy issues such as cost of, availability of and access to treatment and rehabilitation.
- Initiate a study about the needs of people with MS to inform your first advocacy campaign.

- Develop individual and corporate membership structures.
- Develop a membership constitution highlighting the benefits, duties and responsibilities of the members.
- Consider activities requiring funding.
- Identify potential funding sources.
- Identify people or organisations that can propose and coordinate fundraising campaigns.
- Gather easily accessible national MS epidemiological data.
- Identify experts in the diagnosis, care, treatment, rehabilitation and management of MS.
- Begin to develop the society's purpose, goals, aims, objectives and Mission Statement.
- Identify a volunteer administrator to work with the Board once it has been established.

Commentary:

It is important that you realise why you want to develop a national MS society, how it will benefit people affected by MS in your country and what needs to be done. You will have to convince others!

The most important issues for people affected by MS are access to information, treatment, rehabilitation and support, whether financial or psycho/social. A small developing national MS society may find it easier to tackle each of these issues in turn, rather than all at once. This often means that the first tasks to be undertaken are the provision of information and bringing people affected by MS together, often through Mutual Support Groups.

"My group can't replace the support I get from my family, but it is so great to talk about things I'm going through that my family just can't understand."

How to Develop a Mutual Support Group
MSIF publication

Multiple Sclerosis.
Will anyone with MS
please communicate
with patient.
T272 Times

Print a brief leaflet with your contact details saying that you would like to meet with others who are affected by MS. Doctors may be willing to pass it onto people with MS or display in their hospital or clinic. In addition display it in other locations like pharmacies or even in cinemas and shops – as some people with MS do not contact their doctor or neurologist often.

Put an advertisement in your local and national newspapers giving people with MS the opportunity to make contact. This was the method used by Sylvia Lawry in 1945 who established what became the US National MS Society. Ms Lawry then played a major role in establishing MSIF some years later.

"You have to use every opportunity to get the people with MS out of their isolation."

Gabriele Seestaedt, DMSG, Germany

It is recommended that for the first year emphasis be placed on a public information campaign, addressed not only to the public but also to certain selected sectors, such as corporate, government and non governmental organisations (NGOs) etc. You should try to use all the media for this purpose, including press, radio, television and the internet. This public information campaign should:

- Publicise the MS problem in your country, the consequences of MS and the daily reality of living with MS.
- Report the establishment of the MS society that proposes to do something about it.
- Include the names of those leading the society.
- Put emphasis on the Action Plan (programme of activities the society wishes to undertake).

Involve as many people as possible in the development of the society, even if it means working with similar groups from the same area, as ultimately it will speed up the development process. Empower people and every now and then ask for feedback from everyone involved in the development process to ensure 'buy in' and support.

Laurenţiu Lazăr, UNOMS, Romania

Develop an Action Plan (programme of activities the society wishes to undertake), which details the major aims and objectives of the society over the next year or two and highlights particular projects to be undertaken. Do not write a sophisticated Action Plan. It will be hard to work with and could negatively affect the development process. Your plan can be simple, structured and focused on "SMART" objectives (Short, Measurable, Achievable, Realistic and Time bound). A short SWOT (Strengths, Weaknesses, Opportunities, Threats) analysis can be helpful.

The experience, skills, resources and access to the general public of existing national voluntary organisations, like the Lions Club, Rotary, Red Cross/Crescent etc, make them an attractive source of support and advice.

The membership constitution should offer members open, transparent and equal access to the decision making process of the society. The development of standards of membership offers members the opportunity to improve the quality of the work they do for the society and motivate them to improve over time.

People affected by MS should always be included and involved in the society's governance and leadership.

Sue Tilley, Chair
Persons with MS International Committee

Stage 2 – The society takes shape

Key Activities:

- Refer people affected by MS to relevant professional services.
- Encourage professionals to refer people with MS to you.
- Develop knowledge of ‘gaps’ in national support services.
- Translate existing information on the most important aspects of MS from developed national MS societies and print leaflets.
- Develop society website, magazine and/or newsletter.
- Establish and advertise a telephone helpline.
- Identify community leaders in the public & private sector.
- Recruit Board Members and volunteers from among people affected by MS, business and community leaders, and the general public.
- Initiate email group for members and develop email group for the Board and regional network.
- Agree at the public meeting to set up a national MS society.
- Plan the date and location of regular meetings welcoming new members and updating on society development.
- Advertise public meeting in newspapers, local radio, TV hospitals, clinics, libraries etc.
- Encourage and support Mutual Support Groups to develop around the country.
- In conjunction with the Medical & Scientific Board develop a training programme for health professionals.
- Apply for independent training programmes for the Board Members and other key volunteers.
- Develop local and national public policy campaign.
- Provide employment, financial, pension and insurance advice.
- Implement individual membership model.
- Develop a database of society stakeholders (see page 6).
- Develop a membership promotion programme.
- Develop a fundraising plan.
- Implement small fundraising events.
- Identify relevant pharmaceutical companies.
- Prepare project proposals and apply for grants.
- Plan a national epidemiological study.
- Establish a Medical & Scientific Board (MSB).

- Agree the society's purpose, goals, aims, objectives and Mission Statement.
- Elect/appoint Officers, Treasurer and Committee Chairs
- Register with federal, regional and/or local governments, as necessary.
- Hire part-time paid manager/CEO (Chief Executive Officer)
- Obtain accessible office space.
- Try to find office devices to facilitate networking and develop contacts at national level (e.g. computer, fax, printer etc).

Commentary:

Ideally the Board of the society should represent local and national interests and include people with MS as well as family and others with close relations to people with MS.

In addition the Board should include influential business and civic leaders with proven abilities to provide advice, contacts and financial stability. This would include prominent representatives of the education, legal, voluntary, public and private sectors. The people responsible for the recruiting of these leaders should select from this group a Steering Committee (or an Organising Committee) charged with preparation of a governing document (Statutes/By-laws/Constitution) that set out the purposes of the society and the structure and systems it will adopt.

If possible a prominent and/or famous person should be found as Patron. The role of Patron is usually passive in that he/she simply allows his/her name to be used by the society as a means of increasing reputation, standing, prestige and trustworthiness.

A person with a financial background should be found for Treasurer to prepare accounts and assist the Board in preparing for audit.
A person with MS who speaks English should be identified to communicate on an international level.

The country's leading neurologists, doctors, nurses and medical practitioners should be encouraged to establish a Medical &

Scientific Board (MSB), which will help guide the society's works, keep it abreast of current medical research at home and abroad and develop and assess the policies and programmes for research and patient services.

Seek the endorsement of the national medical society or nearest equivalent established groups and thus be assured of the cooperation of medical schools that subscribe to them.

To convince governments and policy makers it is important that your arguments are 'evidence based'. It is important to start to compile preliminary epidemiological statistics on the number and location of people with MS in your country. Encourage the newly established MSB to take this on as its first project. The involvement of the MSB will also help the society to be seen as acting professionally which will encourage the government to take you seriously.

Experience shows that the success of the funding and programming activity stems from having a well-structured subscription paying membership, open to all citizens. Membership subscriptions are not only a form of participation but also provide a modest but stable financial base.

Set a date for the launch of the first public awareness campaign. Prepare for widespread distribution leaflets which:

- Describes the new society, its Patron, Officers and Board.
- Explains the structure of the society, its purposes and plans.
- Provides information about MS and the needs of PwMS.
- Explains how individuals can help and/or donate.

In general you should be able to secure the support of the media (local and national newspaper, radio, TV and website) without cost to your society as they are always looking for interesting new stories. If possible, identify a national celebrity with MS who could appeal on TV or radio.

Small fundraising events include undertaking an everyday activity but getting people to sponsor you for how many or how much of the activity is completed. Examples of such small but effective fundraising methods include a sponsored walk, run, swim, bicycle ride, read etc. You could stage an event and charge admission such as a party, picnic, fashion show, play or art exhibition or your members could produce things to be sold, the profits from which go to the society. To show your appreciation to volunteers, sponsors etc every fundraising event should be followed by a small social event such as a party or picnic.

Set a date for the launch of the first major fundraising campaign. It is important to define how donations are processed in your country before appealing for them. The Fundraising Committee/Work Group should determine whether tax advantages for gifts to the society are possible and if not influential members of the board may wish to consider an approach to appropriate government agencies to determine how such tax advantages might be secured.

The first public meeting will have greater impact if you invite a well-known or prominent local or national figure, especially from the public sector. This will improve access in the future.

The Board, staff and branch members should be offered regular training opportunities. When the society is small and young misinterpretation of the mission, goals, objectives and governance can easily develop. Training will not only provide knowledge and skills but will also develop a representative and democratic organisational culture.

Stage 3 – The society functions

Key Activities:

- Plan the promotion and development of MS specific services (e.g. MS Day Centre, Residential Centre).
- Translate and print existing information on *all* aspects of MS.
- Develop audio-visual materials (cassettes, video).
- Involve community leaders from the public/private sector.
- Start organising volunteering programme and services.
- Build international partnership on specific objectives.
- Hold regular society meetings and open days.
- Prepare press releases on important topics, issues and developments.
- Encourage Mutual Support Group leaders to develop local/regional branches and chapters.
- Plan branch/chapter visits.
- Develop volunteer training programme.
- Develop MS awareness amongst health professionals
- Identify training opportunities for society Board and staff.
- Work closely at both national and local levels with health and social service organisations with similar interests.
- Implement corporate membership structure model.
- Consider major fundraising events and methods.
- Implement national epidemiological study with MSB.
- Develop MSB Work Groups to undertake short-term projects.
- Develop team-building programmes.
- Develop internal evaluation programme.
- Hire full-time paid manager/CEO (Chief Executive Officer) and appoint new part-time paid staff.

A society of today is not that of the past. I believe that today, support groups, helping newly diagnosed and providing services, are the goals.

Dr Leonor Gold, Esclerosis Múltiple Argentina

Commentary:

Once the Board, Committees and MSB have been established, Work Groups can be developed to undertake specific projects.

Simultaneously with the planning and execution of the public information campaign a fundraising Work Group or Committee should study the kinds of major methods and events most likely to produce results.

Examples of major fundraising methods include:

- Subscriptions and/or donations from members.
- Direct mailing to potential donors (advanced level).
- Grants from national and local government.
- Grants or gifts from companies and corporations.
- Grants or gifts from charities, trusts or foundations.
- Grants or gifts from religious organisations.
- Gifts from wealthy individuals.
- Sponsorship from business and industry.
- Sponsorship from drug companies without a commitment to endorse or promote any particular company's product or treatment more than another's.

Consider the practicality of public fundraising via direct mail, by personal visits and talks etc to sectors of the public. Collection boxes in the street and workplace can also serve as a way of educating the public about MS in addition to raising funds.

In the beginning it will naturally be difficult to organise MS society branches and chapters of appropriate volunteers throughout your country. Therefore concentrate on the main city (or cities if you can). You should however develop a plan to gradually include branches in other well-populated areas, whether on a provincial, district or state basis.

The development of a visit agenda for branch/chapters/member organisations would increase the speed of development and help the local members to build powerful relations with the community.

A team-building programme will help to keep all branches and members focused and committed. Meetings involving external facilitators can be very effective in identifying and responding to individual and group personal and professional needs.

You should note, and be sensitive to the fact, that local organisations may already exist, and have existed long before you considered establishing a national MS society. You will need to emphasise the benefits of people affected by MS speaking with one strong voice on a national level and integrate local organisations into the national framework.

Local volunteer based branches should be organised as closely as possible to the model of your own national society. Have each of these branches represented on the Board so that they become part of the overall national structure. Once the organisation grows with a number of local branches a regional approach could then be considered.

Governance and management structures, meetings, publicity, fundraising, business plans, training, etc., are all important aspects of developing an effective national MS society. But we must always remember that they are all MEANS to an end, not ENDS in themselves. While giving them all due attention, we must not let ourselves be distracted from our real and much more important objective – to provide positive support for all those affected by MS, encouraging and enabling them to attain their full potential as members of their nation's society by improving their conditions and quality of life.

Mick Bond, UK

Stage 4 – The society develops

Key Activities:

- Coordinate the provision of MS Day Centres, Residential Centres, Hospitals, Holiday Homes, Respite Centres, Nursing Homes, Rehabilitation Centres, Accommodation, Transport facilities etc.
- Review information material and website.
- Develop programmes to recruit and train volunteers and future leadership for the society.
- Organise the first national MS meeting.
- Develop public education programme.
- Develop network of branches and communicate regularly.
- Hold workshops for medical professionals.
- Hold workshops for volunteers.
- Identify other non profit organisations in health or other fields with a view to forming an alliance.
- Provide legal assistance and advice to people with MS.
- Develop/implement membership recruitment campaigns.
- Implement major fundraising events.
- Promote research to find the cause, cure and improved treatment of MS.
- Review membership of the Board and its methods of election/appointment to ensure representation.
- Hire a number of paid staff in charge of information & communications, fundraising, finance, services etc.

Over 50 staff members provide the wide range of professional services the 10,000 people with MS and their families ask of us. However, what would we do without the daily presence of over 1,300 volunteers organised in 42 groups all across the country?

Hans-Peter Fricker, Swiss MS Society

Stage 5 – The mature society

Key Activities:

- Review and revise services provided, in the light of changing needs of users.
- Commission articles.
- Implement and expand programmes to recruit and train volunteers and future leadership for the society.
- Organise and host national, regional and international meetings, seminars and conferences for various audiences.
- Develop regular input to national and local media (TV, radio) to increase public awareness, as the society gets better known.
- Establish minimum standards of support provided by these groups across the country, monitor their achievements, and help those not achieving the standards.
- Review and expand workshops both for health professionals and for volunteers in the light of experiences gained.
- Coordinate representation to government on behalf of people with MS.
- Develop and implement fundraising programmes to support all aspects of the society's work.
- Fund research to find the cause, cure and improved treatment of MS.
- Hire paid staff in regional/local branches chapters.
- Apply for MSIF Associate Membership.

At this stage of the society's development it is important to think about training volunteers (especially those who will be involved in visiting and giving welfare advice/support to people with MS).

The society will also be in a position by now to promote specialist areas of support and services such as the training and accreditation of MS nurses or separate services for the different groups of people in your country.

Commentary:

At regular intervals, and certainly not less frequently than once a year, the Executive Committee or Board should undertake an evaluation of what has happened up to date and review its plans for the future. It is always worthwhile to have such a future plan or strategy which comprehends all phases of the society's activities, such as its:

- administration procedures within the office
- efforts at organising throughout the country
- programme in which it engages
- performance of the staff

The basic plans should be reviewed, revised and updated in the light of the experience gained and the results achieved. Financial records should be maintained in the society's offices and an annual audited report of the society's receipts and expenditure made.

Almost 10 years ago, MS Society of Canada volunteers and staff worked over a number of months to examine the future direction of the organisation. Scrutinising everything from the role of volunteers, current operating policies and the overall mission, the MS Society developed a re-focused mission statement, some measures to determine when it would achieve the mission and a planning document called The Way Forward. This document has served us well over this past decade. We revisited the document a few years ago and refined it somewhat, but as a whole we use it when setting budgets, drafting business plans and measuring how well we have done.

Alistair M. Fraser, MS Society of Canada

Annex – Potential support and services provided by an effective national MS society

Information

- Telephone helpline (publicise in newspapers, booklets, doctors' practices, hospitals, pharmacies etc).
- Information booklets about all aspects of MS.
- Audio-visual materials (cassettes, video).
- Society website/magazine/newsletter.
- Meetings/open days/exhibitions.
- Events/activities in towns to inform the public; appearance in the local TV.
- Newspaper articles, advertisements etc

People affected by MS

- Mutual Support/Self-Help Groups.
- Holidays/summer camps.
- Sport activities.
- Respite care.
- Home visits.
- Financial support/grants.
- Transport services (e.g. minibus/car).

Awareness, Education and Training

- Courses for newly diagnosed people with/affected by MS.
- Training of social workers/health professionals (doctors, nurses, therapists etc).
- Public education (e.g. presentations to schools).
- National/Regional Conferences/Seminars for various audiences.

Advocacy/Campaigning at national and local levels

- Representation to government on behalf of people with/affected by MS.
- Legal assistance/advice.
- Employment advice.
- Financial, pension and insurance advice.
- Representation on accessibility issues (office buildings, transport etc).

Services by professionals (provide, train or refer)

- MS Nurses
- Counselling/Psychotherapy.
- Physiotherapy/Occupational therapy.
- Medical/diagnostic services.
- Social workers.

Promote/Support Medical/Social research

- National epidemiological study.
- National standards/available resources study.

Support facilities

- MS Day Centre/Residential Centre.
- Hospital.
- Holiday Home/Respite Centres/ Nursing homes.
- Rehabilitation Centres.
- Houses/accommodation.
- Transport facilities (e.g. minibus).

The ‘How to Develop a National MS Society’ Work Group members are:

Hans-Peter Fricker	Switzerland
Mick Bond	UK
Torben Damsgaard	Denmark
Mariella von Klenck	Germany
Laurențiu Lazăr	Romania
William Lonergan	Ireland
Gabriele Seestaedt	Germany
Nadine Vila Moret	Argentina
Paul Rompani	MSIF International Development Manager

MSIF would like to thank the Work Group members for the considerable time and energy invested in the development of the booklet.

Edited by Paul Rompani from an original concept developed by Charlie Goodyear (USA) and Paul Rompani.

Other booklets in MSIF’s ‘How to’ series include:

How to Develop a Mutual Support Group
How to Influence Public Policy

For further information please contact:

Multiple Sclerosis International Federation
3rd Floor Skyline House
200 Union Street
London SE1 0LX
United Kingdom
Tel: +44 (0) 20 7620 1911
Fax: +44 (0) 20 7620 1922
Email: info@msif.org
Web: www.msif.org

MSIF Member Societies

May 2003

Argentina
Australia
Austria
Belgium
Brazil
Canada
Chile *
Cyprus *
Czech Republic
Denmark
Finland
France
Germany
Greece
Hungary
Iceland
India
Iran *
Ireland
Israel
Italy
Japan
Latvia *
Luxembourg
Malta *
Mexico *
Netherlands
New Zealand
Norway
Poland
Portugal
Romania *
Slovakia *
Slovenia
South Africa
Spain
Sweden
Switzerland
Turkey
UK
USA
Zimbabwe

(*Associate Member)

MSIF would like to thank the MS Society of Great Britain and Northern Ireland for their generous grant.

MSIF is a non-profit charitable organisation 501(c)(3) IRC chartered in the State of Delaware, USA, in 1967.