

# How to Influence Public Policy



multiple sclerosis  
international federation

# The Federation's Aims

Established in 1967, the Multiple Sclerosis International Federation links the work of national MS societies worldwide. We are committed to working together and with the international research community to eliminate MS and its devastating effects. We also speak out on a global level for those affected by MS.

Our priorities are:

- To support Member MS Societies in their goal of enabling full integration of people with MS and their carers to live their lives to their fullest potential
- To stimulate global shared research into a cure for MS and the alleviation of its symptoms
- To stimulate the active exchange of information on best practice amongst Member Societies and the wider MS community
- To provide support for the development and increased effectiveness of new and existing national MS societies



# How to Influence Public Policy

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# Introduction

I have great pleasure in introducing the International Federation booklet 'How to Influence Public Policy'. The booklet will be an important tool in preparing effective advocacy campaigns that will further develop the role national MS societies play in combating the effects of MS.

The booklet was developed by the Federation Secretariat with the generous support of those who gave presentations at the panel discussion 'Advocacy and its Implications for the MSIF' at the Federation Board Meeting November 2000: Tom Kuhn, President of the Edison Electric Institute and NMSS Board Member; Susan Sanabria, NMSS Vice President Advocacy Programs; and Glynn McDonald, Policies and Campaigns Manager, UK MS Society.

The panel discussion proved to be a great success in highlighting the importance of advocacy and involved both the Federation Board and Member Society CEOs. In addition, many thanks to those CEOs and Member Society staff who responded to the request for case studies which illustrate the principles involved. The inclusion of these case studies certainly highlights how different countries and cultures all face similar problems with similar solutions.

Happy reading and good luck with your campaign!



Peter Schweitzer  
President

In the USA health insurance companies (HICs) proposed to increase co-payment for weekly self-administered injections from 20% to 50% (e.g. an increase from \$1,700 a year for weekly injections to \$4,250). Immediately people affected made contact with their local MS branch/chapter which held a meeting of 5 people, including a lawyer and a person with political connections. They quickly agreed that they should join forces with other affected groups in an alliance and once this had been done developed a set of strategies which included: a letter writing campaign targeting the media, the HICs, local and national government, legislators and potential allies; a petition campaign with 20,000 signatures; getting as many people on TV and radio as possible; organising protest demonstrations in front of HICs; conducting a public forum and inviting the media. Whilst the advocacy effort was underway alliance members, HIC and government representatives worked out a solution. The HICs agreed to keep the co-payments at 20% and a bill was passed prohibiting HICs from charging different co-payments. In addition the branch/chapter developed a Government Relations Committee to handle similar issues in the future.

Martin Doorey, National MS Society, USA

# Campaigning steps

There are seven basic steps to running a successful campaign. These steps apply whether your campaign is national or local, big or small. They are:

- 1 Setting a campaign aim:** deciding what issue you are going to campaign on and what you want to achieve.
- 2 Doing your homework:** collecting facts, figures and information in support of your position on the issue.
- 3 Campaign strategy:** deciding on your campaign strategy and what methods you are going to use to highlight your cause.
- 4 Targeting your campaign:** deciding whom to aim your campaign at for it to achieve its aim(s).
- 5 Managing your campaign:** planning and managing your campaign according to the resources you have available.
- 6 Campaign Tactics:** methods employed by campaigners.
- 7 Measuring success:** assessing your campaign.

One person with MS needed a Roho cushion to ease her discomfort from sitting all day in her wheelchair. It was sent from England by friends, and immediately seized by Customs who demanded a huge duty before they would release it. I saw the head of the Customs Department who was courteous and listened to my explanation of what the uses of such a cushion are. He had never heard of pressure areas and sores or met someone who lived their daily life in a wheelchair. He was interested in the problem, and promised to approach the Minister of Finance to ask that a new Customs tariff be instituted for the importation of items of that nature. He kept his word. It took a whole year for the change to come about, but a letter was sent advising us that a new duty free tariff rating had been accepted in Parliament at the request of the Minister of Finance. The duty was withdrawn, and the lady was allowed to keep her cushion. We were deeply relieved, and also grateful that this recognition had been awarded to the disabled members of society. It also demonstrated that the people in control are also people, who when properly approached will help. But it also takes time and patience and determination.

Lorna Robinson, Zimbabwe MS Society

# Setting a campaign aim

Before embarking on your campaign you need to decide what you want it to achieve. For example, would your society like to see more respite care provided for carers or more funds provided for research into the causes and a treatment for MS?

A good starting point is to define the issues which most concern people with MS, carers, and members of your society. You can do this in a number of ways:

- Send a questionnaire to these groups asking them for their views on the issues which most concern them.
- Discuss campaigning at your annual general meeting.
- Discuss with other organisations, such as carers groups, to see whether you have some shared concerns and objectives.

When setting a campaign aim it is important to ensure that:

- Your campaign has a positive message or puts forward a constructive solution to a problem you have identified. Governments and politicians react better to this sort of positive approach.
- Your campaign aims are realistic and achievable. In terms of resources it is often better to focus on one or two issues.
- Everybody in your organisation is clear about the issue on which you are going to campaign and what your aims and objectives are.

An issue of parking outside a particular shopping centre has come to my attention because that shopping centre's management has neither provided parking bays for disabled people nor are steps being taken to rectify matters. In fact an inordinately long time is being taken to comply with municipal by-laws. The matter continues to be a problem and will remain so until it has been satisfactorily addressed.

David Phillimore, South Africa National MS Society

# Doing your homework

For a campaign to be successful it is essential that you spend time early on collecting facts, figures and other information to support your argument. People who you want to join your campaign and those who you are seeking to influence will expect you to be able to provide evidence to support your case.

Here are some sources of information that may be helpful in your research:

- **Government and politicians**
- **Libraries / Internet**
- **Universities / Research Institutes**
- **Health and social care professionals**
- **Other non-profit organisations / coalitions**

People with MS and their carers are an important source of information. In addition to developing statistics from the survey or questionnaire of people with MS and carers you conducted in setting your campaign aim, you could also make others understand what you are trying to achieve by quoting the letters and voices of people with MS and carers describing the difficulties they face. Your research at this stage can also be helpful in deciding who you should target your campaign at, what your campaign strategy should be and what campaign methods/tactics you should use.

Questions your research might therefore address include:

- finding out what current government policy is;
- how public policy is formed;
- whether it is necessary for the law to be changed to achieve your aims;
- what needs to happen for your campaign to be successful; and
- whether there have been similar campaigns on your issue in the past and whether you can learn from these.

Having done your homework you should now be in a position to develop a 1 to 2 page statement outlining your position

In 1996, with the European Social Fund and the French Ministry for Employment and Social Affairs, we organised a survey 'MS and Employment' to emphasise the positive factors resulting from the maintenance of people with MS at work. As a result a booklet summarising the results of this work is still distributed to staff-managers who are prepared to consider this attitude favourably.

Eric Palluat de Besset, French MS Society

# Campaign strategy

When deciding on your campaign methods and strategy you should bear the following general points in mind:

- **Devise a timetable for your campaign**

Have some idea of where you want your campaign to go and when. Often this is determined by what is happening in your country's government.

- **Have a focus for the start of your campaign**

You could hold an event such as a conference or public meeting where all sides of the argument can put their case forward and which will attract some publicity.

- **Exploit every opportunity**

Good campaigners are opportunists and maximise opportunities when they come along as a chance to get their campaign message across.

- **Be flexible**

Campaigners should expect the unexpected and be able to adapt their campaign strategy accordingly.

- **Be visible**

The more visible your campaign is and the more publicity it gets, the more likely you are to achieve your aims.

Important points to remember when deciding your campaign methods and strategy:

- **know your opposition;**
- **know where the issue will be decided;**
- **know who will decide the matter;**
- **know what they need to be persuaded; and**
- **select tactics and people to target.**

Members were urged to write to their Members of Parliament (MP) so that every MP was aware of the controversy surrounding Beta Interferon, which was only being prescribed by certain local health authorities. Then we held a mass rally at the House of Commons. Every branch and region was asked to make an appointment for the same day to see their local MP and ask them what they were willing to do about it. We wanted to make sure that every MP was aware of the effects of not being able to access the drug. A petition with 21,000 signatures was given to the Prime Minister whilst about 100 people gathered in Whitehall. The UK MS Society also issued a full-page irreverent and political newspaper advertisement. The advertisement not only increased awareness of the campaign, but also led to an increase in membership.

Sue Tilley, UK MS Society

# Targeting your campaign

Aiming your campaign at the right people makes all the difference. Remember, it is who you know as well as what you know that matters.

Your research at the beginning of your campaign will have told you a great deal not only about how public policy is formed and what you need to do to achieve your aims, but also about those people in positions of influence that you need to talk to and persuade. These people will be the 'targets' at which your campaign will be aimed.

Your targets may include: government ministers, officials and advisers; national and local politicians across the political spectrum; other organisations; health and social care professionals; the media; and the general public.

For instance, if your campaign is aimed at improving the provision of respite care it is more than likely that your country's health minister will be one of the key targets of your campaign, whereas the foreign minister would not be.

We have already mentioned how important it is for a campaign to be visible to attract widespread support in the community and be more influential with public policy-makers. The media can play a crucial role in getting your message across to carers, the general public and your targets. Remember, politicians read newspapers as well.

Spend some time getting to know those newspapers, TV and radio programmes, and journalists who are more likely to deal with issues of concern to you. Send them press releases and information about your campaign and follow-up any material you send with a telephone call.

500 “younger” people with MS (under the age of 60) were kept in social isolation in old people’s homes among 80-plus aged people with Alzheimer’s etc. We introduced the problem in meetings with the media and the responsible spokespersons of the six political parties that were expected to support the annual state budget. In addition we hosted a lunch in our secretariat with the Minister of Social Affairs. The issue attracted much publicity, and the state budget consequently set aside approximately US\$25 million for the next six years in order to further the construction or alteration of future suitable housing.

Peter Kauffeldt, Denmark MS Society

# Managing your campaign

Running a campaign will have implications for your organisation in terms of both human and financial resources. These have to be set against other priorities your organisation may have such as providing information and advice to people with MS and their carers; providing help and support to people with MS; and raising funds.

Limited resources are a common problem faced by all campaigners. Ensuring that your campaign aim is realistic and achievable can help avoid a situation where your campaign runs out of steam because of lack of resources.

But your campaign can also be made more manageable by:

- Setting up a small committee (three or four people) to manage your campaign.
- Having a campaign organiser to manage your campaign.
- Sharing out campaign tasks such as envelope filling among people in your organisation so that one or two individuals don't have too much to do.

Having a campaign committee and campaign organiser means you also have more control over your campaign.

MSIF has found that campaigning is often made easier by forming alliances with other organisations. They enable you to pool resources and demonstrate to others that you have widespread support in the community and therefore make you more visible.

Esclerosis Múltiple Argentina (EMA) is one of the 114 registered non-profit organisations that are a member of the 'Forum of the third sector'. Each member pays a fee to be included in the Forum's campaigns. An issue that affected EMA was when the government planned to withdraw non-profit organisations' tax-free status. In this instance each member was sent a letter by the Forum that they were to print on their headed paper, sign and send to the relevant government department. This combined action led the government to reverse their decision thus saving EMA and other members much money, over both the short and long term. The alliance is not unique in Argentina and EMA had the option of researching which one best served our needs or establishing our own.

Nadine Vila Moret, Argentina MS Society

# Campaign tactics

Common campaign methods employed by campaigners:

## **Face to Face Contact**

A good short-term goal for any campaign is to seek a meeting with those people you have identified as targets. This puts your concerns on their agenda and establishes an on-going dialogue. You need to find a politician who will support your cause and this is best done in the first stage of any campaign.

Nickie Cassidy's MS symptoms made it difficult for her to stand for long periods of time, but she found it hard to persuade passengers to give up their seats on her bus to work every day. Nickie discussed this situation with a local politician and demanded that "somebody do something" to address the issue. The politician replied: "You're someone, aren't you? If you want to know how, I will help." With guidance from the politician, Nickie joined forces with the local branch/chapter and a local disability organisation. She persuaded her council to introduce a new law that provided priority-seating cards to local transit passengers with disabilities. The municipality received an award for the bylaw, which has since been adopted by other municipalities in Canada.

Helen Wagle, Canadian MS Society

## **Letter-writing**

Letters are written to those people you are seeking to influence. A letter-writing campaign is a good way of involving people in your campaign.

## **Petitions**

Petitions demonstrate that your campaign has widespread support in the community. Getting people to sign your petition engages them in discussion about your concerns and encourages them to become involved. You can also use it as a focus for publicity when you hand it in to your country's parliament or government.

## **Press and media launches**

Hold a press conference to launch your campaign. Suggest to your national broadcast and print media that they should run a feature about your concerns coinciding with the launch of your campaign. You might also want to hold a public meeting to launch your campaign. Ensure that all sides of the argument are represented and invite the media along to cover the event.

## **Celebrities and 'gimmicks'**

It can be very helpful to your campaign if you can get famous people to speak out in support of your cause. They may be willing to do interviews for the media. Another way of getting media coverage is to stage an event.

# Measuring success

In measuring the success of your campaign you should remember the following points.

Campaigning is a long process. You need time and patience. While your campaign might not have achieved all its aims and objectives in the time that you had planned, you will undoubtedly have achievements to look back on and build upon, such as a more open public debate about your concerns and dialogue with government.

Greater awareness and understanding of MS and the needs of people with MS and their carers is a by-product of all our campaigns.

Remember the maxim 'if at first you don't succeed, try, and try again'.

Finally, there are three essential qualities that all campaigners must have to be successful. To be:

- **Positive:** to believe that they will succeed in the end and to put forward constructive solutions.
- **Persistent:** to never give up.
- **Patient:** to campaign in the knowledge that public policy is very rarely changed overnight, but that by being positive and persistent they can achieve their ultimate aims and objectives.

Our successful 1999 campaign to extend the reimbursability of Beta Interferon to 2,000 patients with relapsing-remitting MS involved a number of strategies including an evaluation of historical activities; contact with Institutions and government Ministries; an assessment of information need; identification of opinion leaders and journalists; and organisation of meetings with relevant institutions. In addition we generated press office activity with TV appearances, 10 radio interviews with the President of the Italian MS Society and persons with MS and more than 30 newspaper articles.

Antonella Moretti, Italian MS Society

In 1998 some political parties launched a referendum to restrict research and production of drugs in the field of gene and biotechnology. The promising development of medication against MS would thereby be prevented.

We could not remain silent and put the referendum to public vote. We issued a 2-page text explaining the interests of people with MS and stating the principal arguments against the referendum. We restricted the number of official speakers to the Chairman, the Chairman of the Medical Advisory Board and the Chief Executive. In our own magazine and at our annual general assembly we stated not only what our arguments were, but also why we took a stand in the first place. In press conferences, TV debates, advertisements etc. we tried to appear as much as possible together with representatives from similar organisations in order to raise pressure, but also in order not to be “shot down” alone by our opponents.

We received a number of letters and phone calls to the Chief Executive criticising us for going into politics instead of serving the people with MS. Others reproached us for doing the business of, and being used by, the pharmaceutical companies; there was also some investigation by critical journalists as to the amount of our sponsorship by the pharmaceutical industry.

Five members (out of 18,000) left the society on the grounds of our political action and some considered that we were too much oriented towards the traditional “school” of medicine, rather than towards complementary medicine.

We also received phone calls and letters of praise for departing from our “virgin” political attitude; special donations, some of considerable amount, to support our campaign; a substantial increase in the number of public appearances of MS and the MS Society in broadcasts and printed press raising our profile; the gratitude not only of the pharmaceutical industry, but a number of politicians who had not really recognised our existence before and who are now available to us for other issues.

A majority defeated the issue. Our Board’s conclusion after the vote was that we did not only reach our goal, but that the society had gained both profile and respect without losing substantial support.

With public political action this is possible if you can explain clearly and plausibly to everyone, also to opponents, what’s at stake for the persons with MS and that you are doing this in their interest.

Hans-Peter Fricker, CEO, Swiss MS Society



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## MSIF Member Societies

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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

United Kingdom

United States of America

Zimbabwe

(\*Associate Member)

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