



multiple sclerosis  
international federation

# MSIF

## ANNUAL REVIEW 2012



# WELCOME TO THE 2012 ANNUAL REVIEW

## A JOINT MESSAGE FROM OUR CHAIRMAN AND CEO

Nobody should be alone with MS. This is why MS organisations exist and why those organisations chose to come together and build a strong global organisation. Collaborating as an international movement, we are stronger in our search for MS treatment and a cure. We learn from each other and support the growth of MS organisations in emerging countries.

In 2012 we started connecting people with MS in China, and appointed our first staff member to work on capacity building in the Middle East, so that one day, all people in the region will have support from an MS organisation.

We used our global framework to develop a global fundraising strategy, uniting our efforts and appealing to donors at a truly global level. The first goal is to boost research on progressive MS.

We must aim high and collaborate for worldwide MS research and support; if we stand together, no country, no region, and no person needs to be alone with MS.



Weyman T Johnson  
MSIF Chairman



Peer Baneke  
MSIF CEO

*FRONT COVER: People in  
Germany marking World MS Day  
2012 with a balloon release.*

## WHAT WE DO

The Multiple Sclerosis International Federation (MSIF) is the world's only global network of MS organisations. We have 44 member organisations around the globe, as well links to many other smaller organisations. Together we lead the fight against MS and work to improve the quality of life of people affected by MS wherever they live.

We bring together the work of MS organisations to help people affected by MS around the world. Along with our members, we campaign for increased international awareness of MS, provide information and support to people affected by MS, and support international research to discover better treatments and ways to manage the disease.

## KEY PRIORITIES

We know that at least two million people worldwide have MS. Many have little support from their governments. So we aim to:

- **support** existing and fledgeling national MS organisations so that people with MS have local support in their country or region
- stimulate and facilitate **international cooperation in research** into the cause and cure of MS and the development of better treatments and rehabilitation
- **communicate** free and independent information about MS, and the experiences of people living with MS
- **raise awareness** about MS and **advocate** to improve the quality of life of people with and affected by MS.

**“WE WOULD LIKE TO THANK YOUR GREAT ORGANISATION FOR GIVING US THE OPPORTUNITY AND SUPPORT TO HELP THE EGYPTIAN MS COMMUNITY”** MS CARE IN EGYPT



# GLOBAL MS MOVEMENT

## WHO WE CONNECT WITH

The Multiple Sclerosis International Federation consists of 44 member organisations from around the globe: 33 full members, 11 associate members and one supporting organisation.

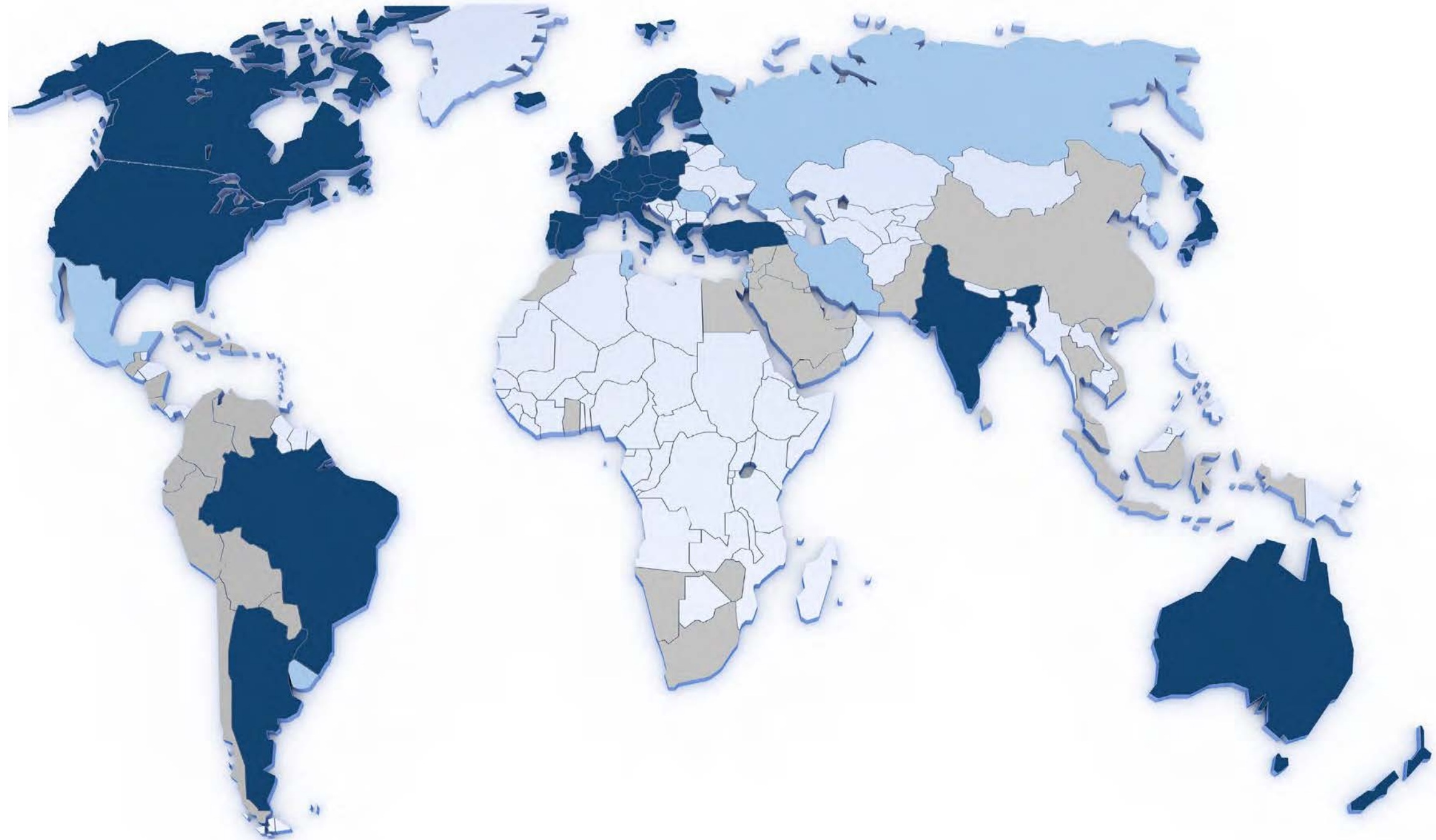
We also connect with and support many other smaller organisations and groups who support people with MS in their country and are working towards MSIF membership.

Together, we form the global MS movement.

### KEY:

- Full members
- Associate members
- Other organisations we connect with

\* Please note: In Spain, there is both a full member and a supporting organisation.



# RESEARCH

## LEADING INTERNATIONAL MS RESEARCH

**A top priority in our strategic plan is global collaboration in research. In 2012 we worked closely with our member societies on our key areas of research into progressive MS, paediatric MS and stem cells.**

Two important meetings took place in 2012 in our key research areas. The Steering Committee of the International Progressive MS Collaborative met to discuss strategies to expedite the development of treatments for progressive MS.

Existing blockages to research progress and potential solutions were identified in "Setting a research agenda for progressive MS: the international collaborative on progressive MS", published in *Multiple Sclerosis Journal*.

Five working groups were set up in key areas to engage the international research community and to address these gaps in research. Their recommendations are being used to shape the long-term strategy of this research initiative.

The International Pediatric MS Study Group (IPMSSG) meeting brought together key stakeholders to analyse the feasibility, methodology and priorities for paediatric clinical trials for new MS medications. The meeting report, "Towards therapeutic trials in paediatric MS", has been published in *Neurology*. The group have also assigned a task force to ensure advances in the treatment of MS in children.

## LOOKING AHEAD

- ➔ First scientific meeting on progressive MS
- ➔ 2013 Charcot Award at ECTRIMS
- ➔ Launch of IPMSSG research project on environmental risk factors in childhood MS



### 2012 MSIF Du Pré Grant recipient Darshpreet Kaur (far right) describes the impact of her MSIF research grant:

"The grant helped me travel to France to work on the REACTIV project. This helped me understand the methodologies for evaluating and rehabilitating cognitive impairments in MS. Since my return to India I have created awareness of cognition and rehabilitative techniques among health professionals and MS patients. This great opportunity has opened doors to a novel way of rehabilitation by empowering brain power!"





# CAPACITY BUILDING

## STRENGTHENING MS ORGANISATIONS

**Our capacity-building 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.**

The team grew in 2012 with a China-based consultant in post from May and a Regional Capacity Building Officer, with a focus on the Arab region and Pan Asia, in post from October. The growth of the team has further improved our understanding of the organisations and individuals we engage with, enabling us to plan for and carry out more in-depth, needs-based work in the regions.

### GLOBAL REPRESENTATION

In April 2012, the Tunisian MS Association became an MSIF Associate Member and the first member from the Arab region. This is a significant step for Tunisia and the region, as their membership will allow them to participate in and influence the development of global projects and

**5,100+ PEOPLE BELONG TO MS ORGANISATIONS IN THE ARAB REGION**

programmes as well as contribute to the direction and priorities of MSIF's work.

We gave grants to enable delegates from Argentina, Egypt, Estonia, India, Tunisia and Turkey to attend our Board and Committee Meetings in 2012, ensuring that the discussions and decisions made were representative of the global MS movement.

### LOOKING AHEAD

- ➔ Focus on building the capacity of three organisations in the Arab region
- ➔ Support activities identified by people with MS in different Chinese cities

### Connecting people with MS in China

In 2012, we hosted an event in Beijing for people affected by MS or NMO, MS health professionals, and people from other 'rare' disease organisations. This meeting emphasised the need for all groups to work together to enable a future MS support structure to thrive, and demonstrated how individuals could get involved.

*Peer Baneke (right), MSIF's CEO, meets people from other Chinese charitable organisations at the meeting in Beijing.*



# ADVOCACY & CAMPAIGNING

## UNITING THE GLOBAL MS MOVEMENT FOR MS AWARENESS

**In 2012 we embarked on a new strategic aim in advocacy and campaigning to raise public awareness and understanding of MS to improve the quality of life of people with MS.**

The World MS Day 2012 “1000 Faces of MS” campaign actively sought to raise awareness of MS among new audiences via a creative and thought-provoking campaign across digital and traditional media.

**2,000,000** TOTAL NUMBER OF PEOPLE REACHED BY WORLD MS DAY DIGITAL CHANNELS DURING MAY 2012

It was a great success, with 52,000 visits to the World MS Day website during the month of May, and 2,500 people creating a postcard about what living with MS meant to them.

### ATLAS OF MS

In 2012, MSIF launched a programme to update the Atlas of MS database and

website, which currently contains MS epidemiological and resource accessibility data from 112 countries and which has proven to be a valuable tool for researchers, MS organisations and the general public. The update will ensure that the Atlas continues to contain the latest information.

An online survey on the epidemiology and resources available to people with MS was produced and distributed and is now being analysed.

### LOOKING AHEAD

- ➔ World MS Day 2013 will focus on the challenges facing young people with MS
- ➔ Updated Atlas of MS website will be launched at ECTRIMS 2013 in Copenhagen, Denmark

### Reaching new audiences

MS Stichting in the Netherlands translated and used the World MS Day materials for a highly successful campaign, utilising outdoor advertising space (including bus stops) in 232 sites across the country, as well as a radio commercial which raised awareness of MS and won best radio campaign of the month. These combined to ensure new national audiences were reached and were connected to the campaign.







# COMMUNICATION

## SHARING INDEPENDENT AND FREE INFORMATION ABOUT MS

**Communicating knowledge, experience and quality information about MS is at the heart of our work, in particular for people with MS in countries with limited local support or information.**

In 2012 we continued to produce our magazine, *MS in focus*, with an update of the “Fatigue in MS” edition, and also the “Is it MS?” edition about diagnosis and the uncertainty of MS as it progresses.

**“I REALLY ENJOY THE RESEARCH E-NEWS. I ALWAYS LEARN SOMETHING NEW TO PASS ON TO MY SUPPORT GROUP.”** SHARON, USA

We were delighted to publish the magazine in a new language – Mandarin Chinese – with seven key topics chosen by a workgroup from the country. This adds to the English, Spanish, French, Arabic, German, Dutch and Italian translations of the magazine already published.

Our two e-newsletters were re-designed in 2012 and now reach more than 9,000 people each week for research news, and 12,000 for our monthly round-up of international MS news. Sign up free at [msif.org/subscribe](http://msif.org/subscribe)

Using our fatigue survey results we created a simple but striking film in multi-languages, which had 28,434 views on YouTube in 2012. We also increased our social media presence, with increased ‘likes’ and connectivity on Facebook and Twitter with the MS global movement.

### LOOKING AHEAD

- ➔ In early 2013 we launched a new and improved website
- ➔ The translation of a further seven editions of *MS in focus* into Chinese

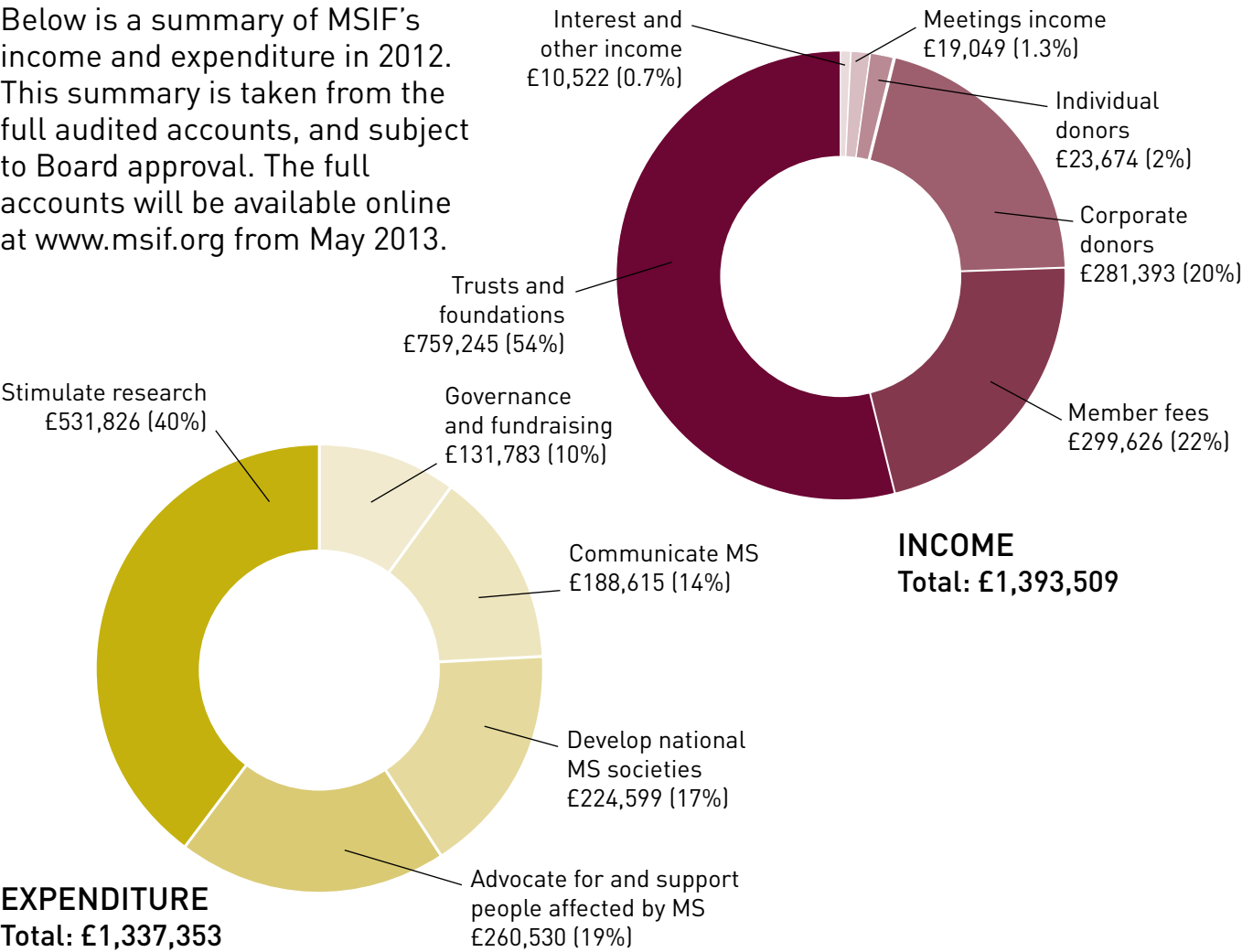
#### 20th edition of *MS in focus* magazine published in 2012

This series provides comprehensive, independent, free and high-quality information about a range of topics related to MS, including symptoms, MS research and daily living with MS. The total number of copies downloaded from our website during 2012 reached an amazing 934,806!

# FINANCIAL SUMMARY

## DETAILS OF OUR INCOME AND EXPENDITURE

Below is a summary of MSIF's income and expenditure in 2012. This summary is taken from the full audited accounts, and subject to Board approval. The full accounts will be available online at [www.msif.org](http://www.msif.org) from May 2013.



# FUNDRAISING

## A GLOBAL APPROACH

Fundraising must be seen in a global context. Globalisation has changed the landscape for charitable organisations, donors and people affected by MS. Increasingly, foundations seek to fund efforts that will have an international impact. The rise of social networking means that people seek solutions, innovations and change where it exists and not within the confines of their own organisation or country. The MS movement is poised to meet

the fundraising opportunities this provides. MSIF has therefore embarked on a global fundraising strategy. Through working together, MSIF and its members can attain funding and support that would otherwise not be realised. We will learn best practices and share innovative ideas, become stronger individually and collectively in our fundraising, and increase the amount raised to meet the expectations of people with MS all over the world.

# CORPORATE DONORS AND TRUSTS

## THANK YOU FOR YOUR SUPPORT

We rely on the generosity of trusts, foundations and organisations to fund our programmes so we can make a difference to the lives of people with MS around the world. We would like to thank the following for their donations in 2012:

- |              |         |                       |
|--------------|---------|-----------------------|
| Biogen Idec  | Teva    | Vanneau Trust         |
| Merck Serono | Synthon | MSIF Foundation       |
| Novartis     | Genzyme | Wolfensohn Foundation |
| Sanofi       |         |                       |



# THANK YOU!

## WORKING TOGETHER TO HELP PEOPLE WITH MS

Our programmes would not be possible without the support of many volunteers from around the world. Each of the following has given their expertise, time and energy to the global MS movement:

**NOMINATING COMMITTEE** Lou Maroun, Chair (Bermuda/Canada), Eli Rubenstein (USA), Martin Stevens (UK), Dorothea Pitschnau-Michel (Germany), Charles van der Straten Waillet (Belgium), Peter Kauffeldt (Denmark), Mario Battaglia (Italy) **PEOPLE WITH MS ADVISORY COMMITTEE** Martin Stevens, Chair (UK), John Golding (Norway), Sophie Galland-Froger (France), Pille-Katrin Levin (Estonia), Guy De Vos (Belgium), Mindy Alpert (USA) **FINANCE AND AUDIT COMMITTEE** Rob Hubbard, Treasurer (Australia), Ed Kangas (USA), Antonella Moretti (Italy), Eli Rubenstein

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