



multiple sclerosis  
international federation



ANNUAL REVIEW

2010



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## Who are we?

The Multiple Sclerosis International Federation (MSIF) was established in 1967 as an international body linking the work of national MS societies around the world.

## Our vision

A world without MS.

## 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 by facilitating international cooperation between MS societies, the international research community and other stakeholders.

### Chairman and President

Sarah Phillips, UK

**Vice-Chairman** Mario Battaglia, Italy

**Treasurer** Robert Hubbard, Australia

**Secretary** Weyman T Johnson, USA

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Dorinda Roos, Netherlands

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Yves Savoie, Canada

Alan Thompson, UK

Steven Umin, USA (retired January)

Charles van der Straten Waillet, Belgium





*2010 has been another successful year for MSIF.*

*We expanded our reach across the globe and made contact with new MS groups and organisations, strengthened our development strategy in the Arabic-speaking region, and established strong networks in the international research community. Thousands of individuals affected by MS visited our social media networks and website, took part in World MS Day and downloaded our free publications.*

*We continue to thrive in our role to lead the global MS movement.*

Sarah Phillips  
OBE, DL, Chairman and President



*In 2010 many member organisations strengthened the global fight for a world without MS. For example, in Cairo, people with MS worked with a fast food chain to raise awareness on World MS Day, the Canadian, US and Italian MS societies supported the International Pediatric MS Study Group, and the Dutch MS Research Foundation supported the construction of a MS centre in Turkey.*

*Whether you live with MS in Berlin, Babahakala or Buenos Aires – you need support. Global solidarity, impact through international cooperation, and leading the fight for a world without MS – this is what being part of MSIF is all about.*

Peer Baneke  
Chief Executive

#### **Honorary Life Board Members**

Leon Cligman, France  
Alistair M Fraser, Canada  
Robin Inchyra, UK  
Jürg Kesselring, Switzerland  
David L Torrey, Canada

#### **Secretariat Staff**

Peer Baneke, CEO  
Ayesha Ali, Campaigns and Communications Manager  
Paul Browne, Medical and Scientific Research Officer (from November)  
Zoe Burr, Head of International Development  
Lisa Carpendale, Finance Manager (maternity cover)  
Dhia Chandraratna, Head of Research  
Barnaby Dumbell, IT Manager  
Sarah Finch, Advocacy and Communications Manager  
Jo Pennell, Finance and Administration Manager  
Jude Rudolf, Fundraising Manager (from November)  
Lucy Summers, Publications Manager  
Ruth Whitbread, Fundraising, Communications and Advocacy Manager (until September)

# RESEARCH

MSIF stimulates and facilitates global cooperation in research into the cause and cure of MS and the development of better treatment and rehabilitation for people with MS.

## 2010 Highlights

- Our McDonald Fellowships enabling three **researchers from developing countries** to embark on projects in MS centres of excellence. We also offered 12 researchers Du Pré Grants for short visits to established MS research centres

- Past recipients of our research awards and senior MS researchers from our International Medical and Scientific Board meeting at

an alumni meeting in October in Sweden to present their research and **share ideas**

- Working with our global committees and member societies to develop a statement on chronic cerebrospinal venous insufficiency (CCSVI), which was endorsed by the European Committee for Treatment and Research in MS. We continue to **facilitate the exchange of information** on CCSVI

## Aims for 2011

- An update of our Atlas of MS website, which contains data on epidemiology and resource availability in more than 110 countries

- To make an international inventory of MS databases

- Awarding four International Research Meeting Grants to enable **greater global cooperation in MS research**



*Dr Lekha Pandit, a member of IPMSSG, with a 17-year-old MS patient*

“The IPMSSG has made a positive impact to the clinical practice of doctors caring for children worldwide. This represents an important effort to better understand childhood-onset MS”

*Dr Tanuja Chitnis  
IPMSSG Chair, USA*

## The International Pediatric MS Study Group (IPMSSG)

Children with MS represent only 2-5% of the MS population and there is little research in this area. MSIF facilitates the work of the IPMSSG, a group of 150 leading paediatric neurologists, scientists and healthcare professionals,

whose aim is to **optimise worldwide care, education and research** in childhood MS.

In 2010, two flagship research projects were agreed: the development of a clinical database, and a multinational study on environmental exposures and MS in children. This study will follow 800 children to examine

the relationship between environmental risk factors and the risk of developing MS.

A **global consensus statement about paediatric MS treatments** was also formed, with recommendations for future research. This will help inform and guide clinicians, pharmaceutical companies and regulatory agencies.



## MS in focus language editions

We were delighted to produce two Russian-language composite editions of our flagship magazine, *MS in focus*.

The articles were **selected by the All-Russian MS Society** as being the most important for Russian-speaking people with MS around the world.

We also completed the French translation of all the back issues of the magazine, and now each new edition is produced in English, French, German, Spanish and Italian.

“People with MS in Russia will see how issues have been solved elsewhere to improve their quality of life and make each day meaningful. These editions are a powerful answer to such challenges”

*Pavel Zlobin*  
All-Russian MS Society

# 725,000

There were almost three quarters of a million downloads of *MS in focus* across eight languages during 2010

“I look forward to new issues of *MS in focus*. It has **lots of good information**. It is reassuring to read about issues I have, knowing **I am not alone** in having them”

At the end of 2010, we were the **39th** most viewed non-profit **Twitter** site of all time

To date, our **YouTube** channel has received more than **300,000** views

## 2010 Highlights

- Reaching more than **15,000 people with or affected by MS in 145 countries** with our weekly e-newsletter
- Utilising social media to **communicate to more people affected by MS globally** – more

than 42,500 people “liked” MSIF’s Facebook page during 2010

- Our survey of *MS in focus* readers, which revealed that 96% would recommend the magazine to other people

## Aims for 2011

- To produce all back and future issues of *MS in focus* in Arabic, in consultation with a work group from the region
- To launch a new, more interactive MSIF website in May 2011

# COMMUNICATION

Explaining MS and its impact is at the heart of our work. We particularly aim to reach people in countries where there is no MS society.



## French collaboration

The Tunisian MS Association (ATSEP) were provided with financial support by MSIF to attend the annual Francophone MS Group's meeting, which was held in Luxembourg in October 2010. This introduced ATSEP to the **collaborative work of MSIF members**.

The Group consists of the MS societies of Belgium, Canada, France, Luxembourg and Switzerland, who meet annually to discuss their **joint approach to MSIF projects**, such as the translation of MSIF resources like *MS in focus* and our website, and their participation in World MS Day events. ATSEP



gained invaluable **advice on best practice** and fundraising. Potential opportunities for further information exchange, job shadowing and training in Tunisia were also discussed.

*Mohamed Ben Mahmoud (seventh from left) from ATSEP meets with members of the Francophone MS Group for the first time.*

## Aims for 2011

- Continue to develop our relationships with Arabic-speaking MS organisations through the development of Arabic-language materials and an advocacy seminar
- To expand our development work in the Pan-Asian region, with an initial focus on MS in China
- Continuing to encourage national MS societies in under-represented regions to engage with us and work towards a truly global membership

“For FELEM, becoming the first MSIF Supporting Organisation fills us with pride. We feel this will give a new impulse to the MS movement in Spain and in the world.”

*Sandra Fernández Villota,  
Spanish Federation for the  
Fight against MS*

## 2010 Highlights

- The Spanish Federation for the Fight against MS (FELEM) becoming our first ever Supporting Organisation
- Our **national support network growing** to include MS organisations in Chile, Lithuania, Vietnam and Yemen



*Jeiab Al-Gallabi, President of the MS Patients' Society – Aden, Yemen*

# DEVELOPMENT

Supporting MS organisations around the world, and assisting them to share ideas and expertise, is central to MSIF's work.

# ADVOCACY

We work with MS societies, individuals and groups to support campaigns improving the quality of life of those affected by MS.

## 2010 Highlights

- More than 13,000 people taking part in our 2010 **international survey on work and MS**
- Our World MS Day film “Beautiful Day” being shown on **thousands of screens** in public places across Germany, as well as on national television in Cuba, Germany and Spain
- Launching a dedicated World MS Day website in **ten languages**
- Releasing a report on the Global Economic Impact of MS and **leading training sessions** for MS societies and researchers on how to calculate the **national costs of MS**



*MS Argentina marked World MS Day with an information day.*

More than  
**42,500**  
people  
became fans of  
the World MS Day  
Facebook page

## Aims for 2011

- To produce an advocacy toolkit about work and MS, as well as an online petition and a survey on employers’ perspectives
- To host an international advocacy workshop for MS organisations in May 2011, alongside the publication of a practical guide to advocacy and influencing decision makers
- World MS Day 2011 will build on the success of the 2010 campaign and have more of an advocacy focus. Follow developments on [www.worldmsday.org](http://www.worldmsday.org)



## World MS Day

We coordinate and lead this international day for action, which brings together the **global MS movement** of individuals, groups and organisations, who are **all fighting to improve the quality of life of people with MS**.

In 2010, there were events and activities in more than 67 countries around the world, reaching hundreds of thousands of people.

*Members of the Korean MS Society held marches and gave out information on World MS Day 2010.*



# FUNDRAISING

Helping to finance the global fight against MS.

Our vision is a world without MS. To achieve this, we rely on the generosity of individuals and organisations - we do not receive any financial support from governments - to fund our programmes. These include:

- facilitating **global cooperation in research** into the cause and cure of MS
- communicating and educating at a global level **about MS and its impact** on people and society
- advocating at all levels to **improve the quality of life** of people affected by MS
- supporting the development of national MS societies to **drive the global movement** in the fight against MS.

We would like to thank the following for their generous donations in 2010. This support

has made a real difference to the lives of people with or affected by MS around the world.

## Trust and foundation donors

MSIF Foundation  
Points of Light Foundation  
Vanneau Trust  
Wolfensohn Family Foundation

## Corporate donors

Bayer HealthCare  
Pharmaceuticals  
Biogen Idec International GmbH  
Demos  
Genzyme Corporation  
Merck Serono  
Novartis Pharma AG  
Pharma Genesis  
TEVA

## Individual donors

M Arjen  
H Drane  
JM Gregory



*Volunteers raise funds for a regional MS society in Serbia.*

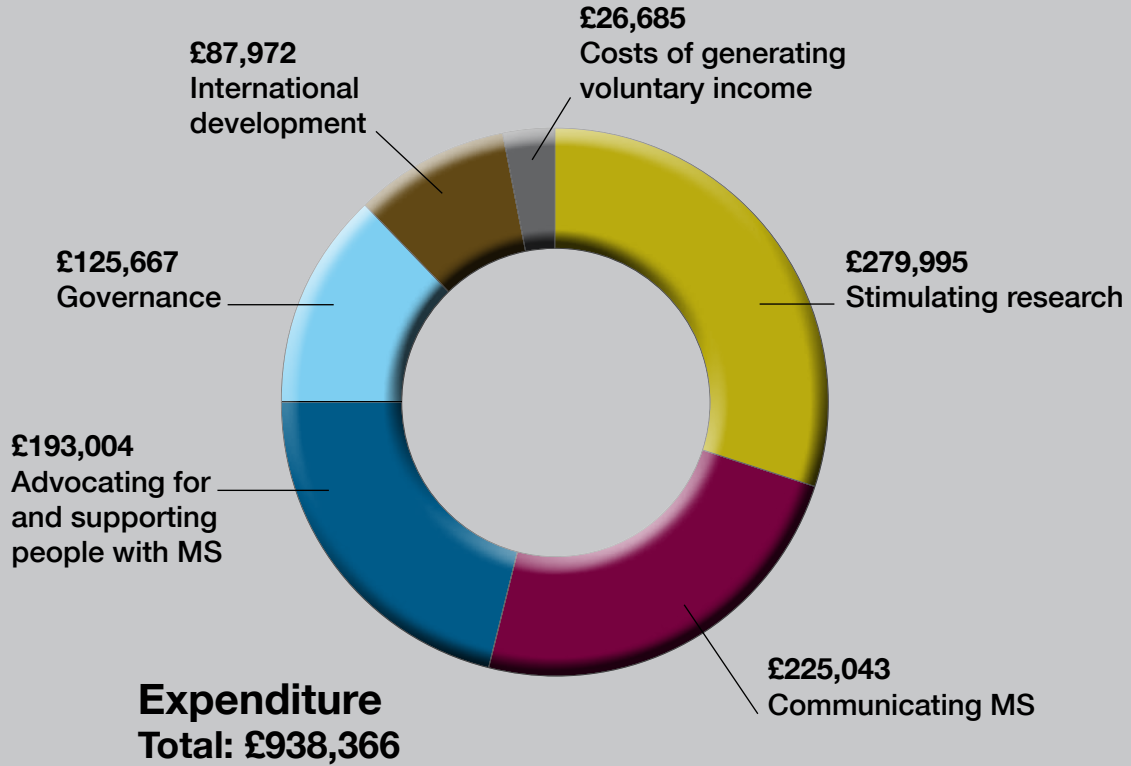
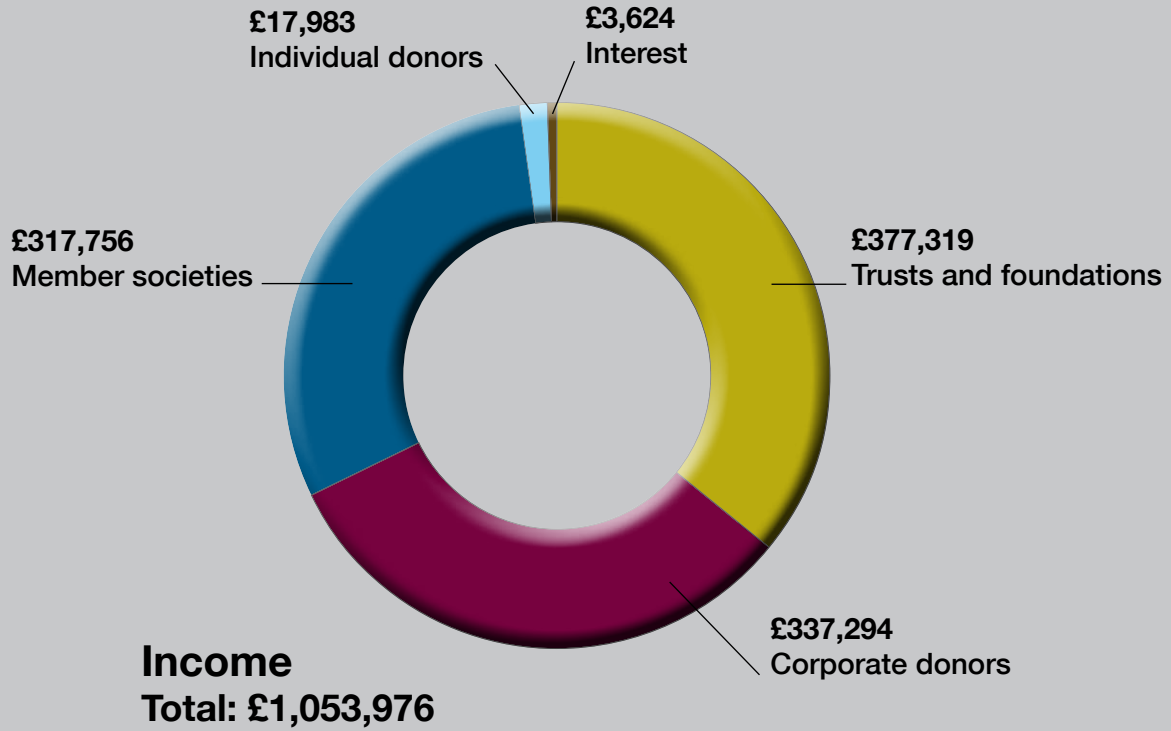
L Harvey  
P and J Jolley  
S Kharazi  
F Klassen  
J Kusters  
G and C Marston  
MSIF Board members  
A and D Parry  
Teignmouth Methodist Church  
Ladies Thursday Group, UK

*The MS Association of Turkey held a city bike ride as part of their 2010 World MS Day activities.*





This summary is taken from the full audited accounts, and subject to Board approval. The full accounts will be available on [www.msif.org](http://www.msif.org) from May 2011.



# FINANCIAL SUMMARY

Above is a summary of our 2010 income and expenditure.

# THANK YOU

MSIF would like to thank the hundreds of people around the world who play an active part in our many projects. Without them, we could not achieve our goals.



*Claudia Opazo of the Chilean MS Patients' Association presents the country's President, Michelle Bachelet, with a gift as part of their 2010 Green Ribbon Campaign.*

## **Global Economic Impact of MS project**

David Bates, UK  
Amanda Honeycutt (RTI)

## **Secretariat of the International Pediatric MS Study Group**

Deborah Hertz, USA  
Jon Temme, Canada  
Mario Battaglia, Italy

## **MSIF project interns**

Holly Garraway, UK  
Ayman Uweida, UK

## **Persons with MS Executive Committee**

Allen O'Connor, Ireland (Chairman)  
Claudio Conforti, Italy (Vice-Chairman)  
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Reni de Boer, Netherlands  
Guy De Vos, Belgium  
Trevor Farrell, Australia  
Héctor García Caballero, Mexico  
Martin Stevens, UK

## **Translators and language checkers**

Amal Abdulrahman (Arabic)  
Hana Al-Hussain (Arabic)  
Rania Aly (Arabic)  
Ghada El-Sherbini (Arabic)  
Nicolas G Kerbage (Arabic)  
Fatima Saeed (Arabic)  
Mai Sharawy (Arabic)  
Wendy Cheng (Chinese)  
Yaou Liu (Chinese)  
Xian-hao Xu (Chinese)  
Satu Nurkkala-Lämsä (Finnish)  
Jean-Marie Eral (French)



Monique Jansen (French)  
 Michelle Jones (French)  
 Pascale Schweikert (French)  
 Jacques Steffen (French)  
 H  l  ne Thamrin (French)  
 Christiane Tihon (French)  
 G  nter Lampert (German)  
 Tina Me   ner (German)  
 Stefanie Mohr (German)  
 Nicole Murlasits (German)  
 Sarah Nash (German)  
 Gabrielle Seestadt (German)  
 Margot Sepke (German)  
 Stefanie Werthmann (German)  
 Bipasha Gupta (Hindi)  
 Ruchika Pandey (Hindi)  
 Kanya Puspokusumo  
 (Indonesian)  
 Claudio Conforti (Italian)  
 Cecilia Longo and family (Italian)  
 Lu  sa Sacchetti Matias  
 (Portuguese)  
 Vanda Fernandes Mendes  
 (Portuguese)  
 Anna Bogolyubov (Russian)  
 Mikhail Kurapov (Russian)  
 Anastasia Milovanova (Russian)  
 Yan Vlasov (Russian)  
 Pavel Zlobin (Russian)  
 Alina Braden (Spanish)  
 Crist  bal Calleja Guill  n  
 (Spanish)  
 Pedro Carrascal (Spanish)  
 Yanna Rodriguez (Spanish)  
 Carolina Smith (Spanish)

#### **MS in focus Editorial Board**

Michele Messmer Uccelli, Italy  
 (Editor)  
 Francois Bethoux, USA  
 Guy De Vos, Belgium  
 Martha King, USA  
 Elizabeth McDonald, Australia  
 Dorothea Cassidy Pfohl, USA  
 Silvia Traversa, Italy  
 Pablo Villoslada, Spain  
 Nicki Ward-Abel, UK  
 Pavel Zlobin, Russia

#### **Arabic-Speaking Regional Network Work Group**

Iman Al-Madi, Jordan  
 Rania Aly, Egypt  
 Hesham Azmi, Qatar  
 Ali Hijjawi, Palestinian Authority  
 Maha Maalouf Kassouf,  
 Lebanon  
 Mai Sharawy, Egypt

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 Chris Polman, Netherlands  
 (Deputy Chairman)  
 Alastair Compston, UK  
 Reinhard Hohlfeld, Germany  
 Fred Lublin, USA  
 Xavier Montalban, Spain  
 Carlo Pozzilli, Italy  
 Ernest Willoughby, New Zealand

#### **Du Pr   Grant Work Group**

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 (Chairman)  
 Hans Lassmann, Austria  
 Catherine Lubetzki, France  
 Howard Weiner, USA  
 Hartmut Wekerle, Germany

#### **World MS Day Work Group**

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 Crist  bal Calleja Guill  m, Spain  
 Reni de Boer, Netherlands  
 Shawna Golden, USA  
 Weyman T Johnson, USA  
 Adam Michel, Germany  
 Geeta Mirchindani, India  
 Mar  a Jos   Wuille-Bille,  
 Argentina

#### **MSIF GLOBAL NETWORK**

##### **Full Members**

Argentina, Australia,  
 Austria, Belgium, Brazil,  
 Canada, Czech Republic,  
 Denmark, Finland, France,  
 Germany, Greece, Hungary,  
 Iceland, India, Ireland, Italy,  
 Japan, Latvia, Luxembourg,  
 Netherlands, New Zealand,  
 Norway, Poland, Portugal,  
 Slovakia, Slovenia, Spain,  
 Sweden, Switzerland,  
 Turkey, UK, USA

##### **Associate Members**

Cyprus, Iran, Israel, Malta,  
 Mexico, Romania, Russia,  
 South Korea, Uruguay

##### **Supporting Organisations**

Spain

##### **Corresponding Individuals, Groups and Organisations**

Armenia, Bahrain,  
 Barbados, Bolivia,  
 Bosnia and Herzegovina,  
 Bulgaria, Chile, Colombia,  
 Costa Rica, Croatia,  
 Cuba, Dominican  
 Republic, Ecuador,  
 Egypt, Estonia, Georgia,  
 Ghana, Guatemala, Haiti,  
 Indonesia, Iraq, Jordan,  
 Kuwait, Lebanon, Lithuania,  
 Malaysia, Montenegro,  
 Morocco, Namibia,  
 Nicaragua, Pakistan,  
 Palestinian Authority,  
 Paraguay, Peru, Qatar,  
 Saudi Arabia, South Africa,  
 Sri Lanka, Syria, Tunisia,  
 UAE, Venezuela, Vietnam,  
 Yemen, Zimbabwe

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W: [www.msif.org](http://www.msif.org)



*MS Society of India supporters took part in a human chain in ten cities (left, in Chennai) on World MS Day, providing a visually powerful symbol for the global movement to end MS.*