

Building the global movement End MS!



multiple sclerosis
international federation

Annual Review 2009

Awards

Our Evelyn Nicholson Award for International Caregiver and our James D. Wolfensohn Award for International Person with MS recognise people who have made outstanding contributions in the field of MS.

Dale Kempen from South Africa won the 2009 Nicholson Award. Dale supports 81 families, as well as looking after her husband who has progressive MS.

The 2009 Wolfensohn Award winner was Ninfa Monarres Madrid from Mexico (pictured below). Ninfa, who has MS, is a leading player in the Mexican MS movement and was nominated for her achievements at local, national and regional levels.



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David Torrey (Canada, retired November 2009)
Steve Umin (USA, retired January 2010)
Charles van der Straten Waillet (Belgium)

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Jo Pennell, Finance and Administration Manager (maternity leave)
Lucy Summers, Publications Manager
Ruth Whitbread, Head of Advocacy, Communications and Fundraising
Thank you to former staff members Helen Regan and Paul Rompani.

Cover: Aida Alić, 32, starred in a poster campaign for World MS Day 2009 run by AMSEL, a chapter of the German MS society.

AKTION MULTIPLE SKLEROSE ERKRANKTER (AMSEL)



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Balloon launch for World MS Day 2009 in Argentina

Welcome



What a fantastic year 2009 was for strengthening the international MS movement. We held our first World MS Day, our first International Research Coordination Meeting and the first Paediatric MS Symposium. We launched a development programme for the Arabic-speaking region, welcomed new members and formalised the principle of Supporting Organisations, opening up the benefits of networking more widely. In 2010 we look forward to continued expansion and to working with new partners towards our goal to end MS.

Sarah Phillips OBE, DL, Chairman and President



In 2009 we strengthened the Secretariat, and worked on projects spanning research, development, advocacy and communications. Central to everything we do is the partnership with our members. World MS Day in May proved an effective way of uniting the movement and showing what we can achieve together. Looking ahead, we will work on the global economic impact of MS, with a special focus on employment. We will co-host a Living with MS Day in Sweden. And work is already under way to make the second World MS Day, on 26 May 2010, even bigger and better than the first.

Peer Baneke, Chief Executive

Research

MSIF works to stimulate and facilitate research into the cause and cure of MS and the development of better treatment and rehabilitation for people with MS.

- The Heads of Research from the MSIF Member Societies with the largest research programmes met leading MS researchers at MSIF's first International Research Coordination Meeting in July. The meeting agreed research foci for MSIF: paediatric MS, stem cells and MS registries.

- Forty members of the International Paediatric MS Study Group, a global network of neurologists, scientists, and healthcare professionals, met at the first Paediatric MS Research Symposium in April, co-hosted by MSIF and the MS societies of Canada, Denmark, Italy and the US. As a consequence, a research project on environmental factors is now seeking funding for a collaborative study involving more than 40 countries.

"Only an international approach, comparing cohorts from different countries with different clinical habits, will give us clues to understand MS in childhood and define its difference with MS in adults. I really look forward to the start of common projects."

Marc Tardieu, paediatric neurologist, France



Left to right: Elizabeth McDonald (MSIF International Medical & Scientific Board), Peer Baneke (MSIF), Prof Prineas, Sarah Phillips (MSIF)

MSIF presented our prestigious Charcot Award for lifetime achievement in research on MS to Professor John Prineas of Australia. The destruction and repair of myelin has been a central theme in Professor Prineas' long career.

- In 2010, we will publish data on the global economic impact of MS, and translate and distribute an information resource on stem cell therapies, written by the UK MS Society in cooperation with other countries.



Participants at the Research Coordination Meeting (left to right): Dhia Chandraratna (UK), Elizabeth MacDonald (Australia), Chris Polman (Netherlands), Alan J. Thompson (UK), Jerry Wolinsky (USA), Peer Baneke (UK), Xavier Montalban (Spain), Mario Battaglia (Italy), Per Soelberg Sorenson (Denmark), Marjanka Luijckx (Netherlands), Gabriele Seestaedt (Germany), John Richert (USA), Lee Dunster (UK), Jon Temme (Canada), Olivier Heinzlef (France)

Supporting young researchers

We continue to support young scientists' development and encourage them to remain in the MS field through grants and awards.

- In 2009 we launched the MSIF Young Researchers Award at the European Committee for Treatment and Research in MS (ECTRIMS). The first award was given to Volker Siffrin from Germany (pictured right), for his work on imaging of neuronal damage in an animal model of MS.



- We awarded a McDonald Fellowship to Klinty Torres-Hernandez from Mexico. Klinty will spend two years in Germany, researching the cell biology of MS.
- Du Pré Grants enabled 14 researchers to travel to work on short term MS projects in Australia, Canada, France, Germany, Italy, UK and the US.
- Award recipients from previous years met at a special alumni event held at ECTRIMS – a great opportunity for young researchers to network and meet with leaders in the field.

Communications

Explaining MS and its impact is at the heart of our work. We use the latest technology to publish and share relevant information about MS. We particularly aim to reach people in countries where there is little support.

- In 2009, we published two editions of our flagship magazine, *MS in focus*, on *Tremor and Ataxia* and *Disease Courses in MS*. French, Spanish, German and Italian editions were published, along with our first ever Arabic edition. The refreshed Editorial Board met face to face in November, to plan future editions and new directions for the magazine.
- Readership of our publications continues to grow. In 2009, total downloads of all editions of *MS in focus* passed 1.9 million, with downloads in 2009 alone reaching 500,000. Meanwhile, 15,000 people subscribe to *Making Connections*, our weekly e-newsletter.
- In 2010, we will audit members' information needs and initiate a programme of promoting resources between members. We will continue to develop our online communications and will relaunch our website. We will expand the translation and online publishing of *MS in focus* to reach new audiences.



Development

Strong and effective national MS societies are essential to people with and affected by MS. Supporting their development is key to MSIF's work.



Delegates at the Arabic Development Seminar in Cairo, Egypt in February 2009

- We launched a development strategy for the Arabic-speaking region, with a seminar attended by stakeholders from 13 countries and the participation of the World Health Organization.

"I am very glad that MSIF presented us with the opportunity to meet and harness our energy towards the MS cause in our region. You don't know how important this event was... It will help us move forward in providing the proper services for the MS community in Lebanon."

Maha Maalouf Kassouf

President, MS Society of Lebanon

- MSIF supported two twinning partnerships in 2009, between MS societies in India and the US, and Cuba and Spain.

- We published *What is an MS Centre?*, sharing best practice on the support an MS centre can provide.

- In 2010, we will work with colleagues in Russia and other countries to assess their need for printed information on MS, and will publish Russian editions of *MS in focus*. We will develop our strategy in the Arabic-speaking countries and build on our contacts in the Pan-Asian region.

- We welcomed two new members in 2010: **The All-Russian Public Organisation of Disabled People with MS** joined MSIF as an Associate Member, representing a huge extension to the global network.

- **The Swedish Association for Persons with Neurological Disabilities** gained Full Membership. We also supported emerging MS organisations in several countries, including Chile, Georgia and Morocco.



Bollywood actor Milind Soman, pictured with US fundraiser Zoe Koplowitz, raised funds and awareness when he ran the New York Marathon to mark the twinning of the US and Indian MS societies.

Advocacy

MSIF works with MS societies, individuals and groups worldwide to support campaigns to improve the quality of life of people affected by MS.

- Member societies continued to lobby their countries to adopt the International Convention for the Rights of Persons with Disabilities. 82 countries have ratified the Convention.
- We published our *Principles to Promote the Quality of Life for People with MS* in Chinese and Arabic.

- Our World MS Day Facebook group, which highlights international campaign opportunities, has attracted 20,000 fans.
- In 2010 we will conduct a multi-language online survey to gather experiences of how MS has affected people's employment. And we are looking forward to an even bigger World MS Day.



worldMSday

The first ever World MS Day, on 27 May 2009, was a huge success. Planned to raise awareness of MS and unite and broaden the global MS movement, the day saw more than 200 activities in 67 countries. The campaign film *Beautiful Day*, launched in nine languages, was used to raise awareness at events, online and on television.



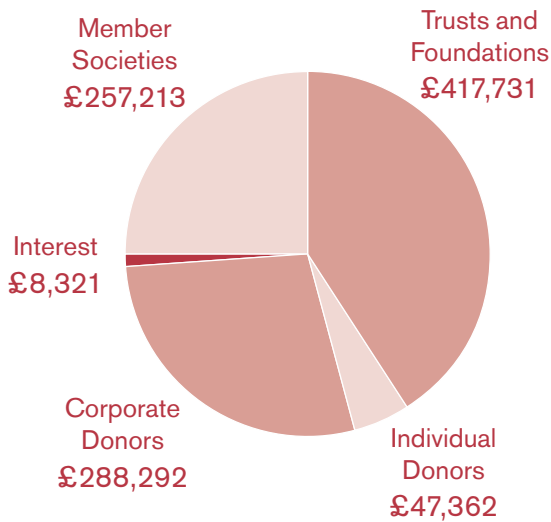
"Thank you very much for the wonderful video with U2's song Beautiful Day. It made me feel happy inside and a bit sad also. And it made me stronger. I hope the world listens to us and helps to find a cure."



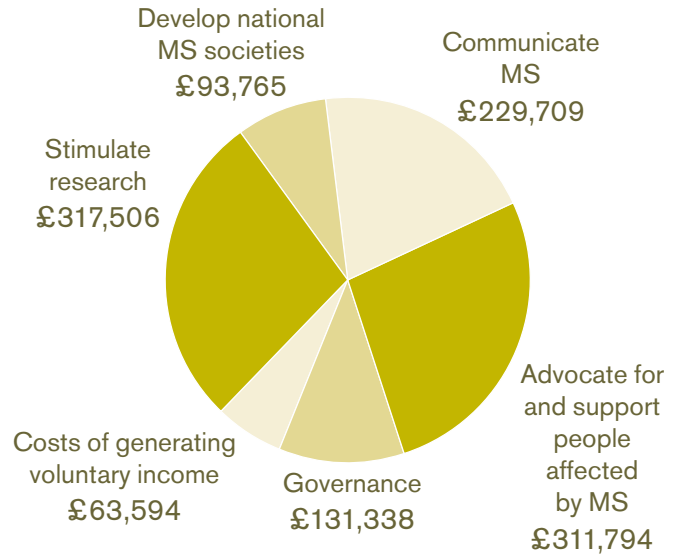
Campaigning in Saudi Arabia (top), Chile (middle) and Portugal (bottom).

Financial summary

Income: £1,018,919



Expenditure: £1,147,706



This summary is taken from the full audited accounts, and subject to Board approval. The full accounts will be available on www.msif.org from May 2010.



Fundraising in Denmark

We would like to thank the people affected by MS, national MS society staff and volunteers, scientists and other professionals, and sponsors – both corporate and individual – for their generosity and support, without which we would not be able to continue our work.

Donors: Trusts and Foundations

Hertie Foundation
 Hilton Foundation
 Points of Light Foundation
 Vanneau Trust
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 Mr and Mrs Sharp

MSIF Board members
 Rotary Action Group for MS Awareness

“MSIF does such important work and I know that they will make the very best use of any gift, large or small.”

Ed Kangas, Former Chairman and CEO of Deloitte Touche Tohmatsu

Member Societies

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

Corresponding Organisations

Armenia	Ghana	Pakistan
Bahrain	Georgia	Palestinian Authority
Barbados	Guatemala	Paraguay
Bolivia	Haiti	Peru
Bosnia & Herzegovina	Indonesia	Qatar
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Colombia	Jordan	South Africa
Croatia	Kuwait	Sri Lanka
Cuba	Lebanon	Syria
Dominican Republic	Malaysia	Tunisia
Ecuador	Montenegro	UAE
Egypt	Morocco	Venezuela
Estonia	Namibia	Zimbabwe
	Nicaragua	



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Thank you

MSIF is grateful to the many individuals and groups that gave us the benefit of their skills and experience in 2009.

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 Jon Temme (Canada)
 Alan J. Thompson (UK)

2009 Profile of the month

Thank you to those who shared their stories of how MS has affected them. The profiles, published online in seven languages, inspire and inform readers worldwide.

Aida Alić (Germany)
 Kent Andersson (Sweden)
 Claus Thuesen Beck
 (Denmark)
 Wendy Cheng (China)
 Ahmed Darwish (Egypt)
 Reni de Boer (Netherlands)
 Ali Ahmad Hijawi
 (Palestinian Authority)
 Mandi Kingsbury
 (New Zealand)
 Adrijana Nikolić
 (Montenegro)
 Jyoti Ronghe (India)
 Lori Schneider (USA)
 Pavel Zlobin (Russia)

Pictured, left to right: Lori Schneider became the first person with MS to climb Mount Everest in May 2009; Claus Thuesen Beck, whose sister has MS, cycled 6,000km across the US to raise money for the MS cause; Kent Andersson is Treasurer of the Swedish Association of Neurologically Disabled; Dubai-based fashion designer Mandi Kingsbury campaigns and raises funds through her ProtestMS label.





Aida Alić, a Bosnian living in Germany was diagnosed with MS at the age of 22. As she came to terms with her diagnosis, she received help from AMSEL, a chapter of the German MS Society.

In 2009, AMSEL asked her to star in their poster campaign for World MS Day. Aida says, "I had fallen into a bottomless emotional chasm as my MS had worsened. Then came the poster campaign. My portrait was on a poster ten metres high and on postcards in cafes and public places. People recognised me in the street. Everyone told me how they admired me for being so open about the disease. After taking part in the campaign I became more involved in my daughter's day-care centre and did simple work like photocopying. Suddenly I was living again!"



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- \$16/€11/£10 could keep a person affected by MS in touch with progress in the global fight against the disease through our website and e-news service.
- \$50/€33/£30 could help us support new MS societies in countries where there is little assistance or treatment for people with MS.
- \$208/€138/£125 could help us to connect the world's top researchers in childhood MS.

Please complete the form overleaf



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London SE1 0LX, UK.

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- local contacts in my country

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- \$208/€138/£125
- other amount: _____

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- Make an international bank transfer to MSIF.
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Please use the reference **Annual Review** and your name.
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Thank you!

We welcome any comments you might have about this Annual Review or about the work of MSIF.

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.....
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- We would like to keep you up to date with our work. Please tick if you would prefer not to be contacted.