



Working towards a world without MS

2008 Annual Review



multiple sclerosis
international federation

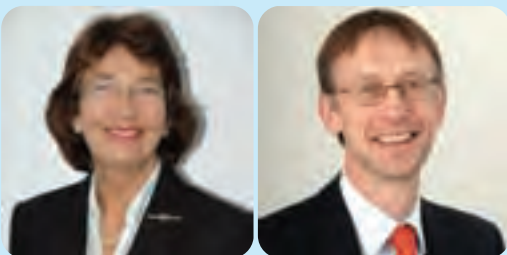
Message from MSIF Chairman and CEO

We are a federation of national MS societies working together on behalf of millions of people affected by MS worldwide.

In 2008 we reviewed and updated our four-year strategy, which has allowed us to increase our support for emerging MS organisations, strengthen international research cooperation and raise awareness of MS through our advocacy and communications initiatives such as the Atlas of MS.

We will build on this in 2009 with the first World MS Day on Wednesday 27 May.

Thank you for your support – your help enables us to make a difference.



Sarah Phillips

Sarah Phillips OBE, DL
Chairman and President

P Baneke

Peer Baneke
Chief Executive

Research

In 2008, to stimulate and facilitate international cooperation and collaboration in research to better understand the nature of MS, to develop better treatment and rehabilitation of people with MS and inform relevant communication and advocacy initiatives, we:

- Awarded seven Du Pré Grants, enabling young researchers to learn new skills through international collaborative research projects. www.msif.org/dupre
- Awarded three McDonald Fellowships to talented researchers from emerging countries. www.msif.org/mcdonald
- Launched the International Research Meeting Grants to enable greater international cooperation in MS research and supported the Gordon Research Conference on “Development and Diseases of Myelin” in May 2008. www.msif.org/research
- Facilitated and part-funded the first Research Symposium of the International Pediatric Multiple Sclerosis Study Group (IPMSSG). www.ipmssg.org
- Appointed Prof Chris Polman as Deputy Chairman of the International Medical and Scientific Board and recruited Dr Dhia Chandraratna as International Scientific Research Officer. www.msif.org/imsb
- Launched a Research Alumni Programme during the World Congress on Treatment and Research in MS in Montreal, Canada, to promote scientific communication and formation of a global MS research network. www.msif.org/alumni



MSIF's first Du Pré Grant recipient, Prof Samuel Komoly (left) with Prof Xavier Montalban (IMSB lead on the Alumni Programme) at the alumni reception in Montreal.

- Developed a Member Society Research Funding database, with data on annual research funding by our member societies, to inform future funding decisions and the development of international collaborative initiatives.



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Development

In 2008, to support and encourage the development of new MS societies and stimulate and support national MS societies in their work to improve the quality of life of people affected by MS, we:

- Worked with volunteers from six MS societies to draft the fifth *How to* guide, *How to Develop a Twinning Partnership* and the development of the MSIF Twinning Programme.
- Provided support and guidance to twinning partnerships between MS societies in the Netherlands and Turkey and in Spain and Argentina.
- Used the MSIF Development Toolkit to support emerging MS organisations in China, Gambia, Indonesia, Kuwait, Nigeria, Qatar, Taiwan, Trinidad and Tobago and Venezuela.
- Surveyed relevant individuals in 18 Arab-speaking countries and worked with our contacts in Egypt, Qatar, Saudi Arabia and the UK to plan our first Arabic Development Seminar to take place in Cairo in 2009.
- Collaborated with member societies, the Consortium of Multiple Sclerosis Centers, Rehabilitation in Multiple Sclerosis and the International Organization of MS Nurses to draft the sixth *How to* guide, *How to Develop an MS Centre*.
- Attended MS events in Belgium, Germany, Iceland, Iran, Mexico, Netherlands, Romania, Turkey, the UK and the USA and at an Executive Committee meeting of the European MS Platform.
- Provided support for the Palestinian MS Society to present at the Developing MS Societies session at our September 2008 Board meeting.

Case study

In November 2008, MSIF Secretariat staff members visited the Iranian MS Society (IMSS) in Tehran. Since the first visit by MSIF in 2002, significant progress had been made with the assistance of our development support. The IMSS now runs a therapy centre which provides occupational and physical therapy for 35 people with MS a day. Other IMSS activities include subsidising

treatment for 3,000 people with MS, distribution of a quarterly journal to 6,000 people nationwide and advising the Iranian Health Ministry on treatment. The society also offers paid employment to people with MS through a clothing manufacturing workshop and runs a residential centre for people with MS outside of the city.

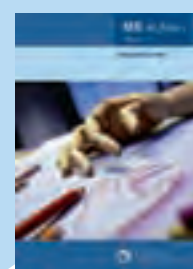


Paul Rompani and Zoe Burr from MSIF (first and second from left) visit colleagues at the Iranian MS Society.

Communication

In 2008, to enhance and complement MS societies' efforts to increase awareness, knowledge and understanding of MS and of the needs of people with MS and how to improve their quality of life and be a resource for those people affected by MS who do not have an MS society to support them, we:

- Published two editions of *MS in focus* in English, Spanish and German; issue 11: stem cells and remyelination and issue 12: spasticity, both with record downloads. www.msif.org/msinfofocus
- Celebrated that more than 1.4 million copies of all issues of *MS in focus* had been downloaded since publication.
- Published the French versions of issues 1-5 of *MS in focus*, along with issue 8 in Dutch.
- Produced monthly profiles of people with MS from a variety of countries in Arabic, English, French, German, Italian, Russian and Spanish. www.msif.org/profileofthemonth
- Launched a Polish version of our 'mini' World of MS (WoMS) website. www.msif.org/pl
- Comprehensively updated the online edition of our *Multiple Sclerosis: The Guide to Treatment and Management* on our website.
- Planned the development of a new PDF publication, *MS: The Basics*, containing core information about MS in 15 languages.



Issue 12 of *MS in focus*

Advocacy

Case study

"Neurological information is not available in a cohesive way in Ireland. Therefore, the internationally recognised Atlas of MS is very important in providing evidence to back up MS Ireland's media and lobbying work." Taragh Donohoe, Communications Manager, MS Ireland

In 2008, to support MS societies and people affected by MS to have and exert influence on laws, policies and decisions, in order to improve the quality of life of people affected by MS we:

- Published the *Atlas of MS* with the World Health Organization, which led to widespread media coverage on television (including BBC World), radio and the Internet in 17 countries. www.msif.org/atlasofms
- Supported Global Dinner Party events in Australia, Canada, Estonia, Germany, India, Namibia, Netherlands, Poland, Spain, Switzerland and the USA which raised more than £48,000 for international research into paediatric MS. www.msif.org/gdp
- Awarded the 2008 Evelyn Nicholson Award for International Caregiver to Elisabeth Golding of Norway who used her award money to enable two members of her local MS society to take a respite break. www.msif.org/nicholson
- Co-hosted the Montreal 08 Living with MS Day event where 450 international attendees heard presentations from people with MS and healthcare professionals. www.montreal08.net
- Translated the *Principles to Promote the Quality of Life of People with Multiple Sclerosis* into Russian.
- Promoted ratification of the International Convention on the Rights of Persons with Disabilities.
- Worked with our member societies to develop the first World MS day. www.worldmsday.org
- Commissioned RTI International to work with us on the development of our Global Economic Impact of MS project, which will be launched at the end of 2009.



Examples of media coverage in Ireland as a result of the *Atlas of MS*.



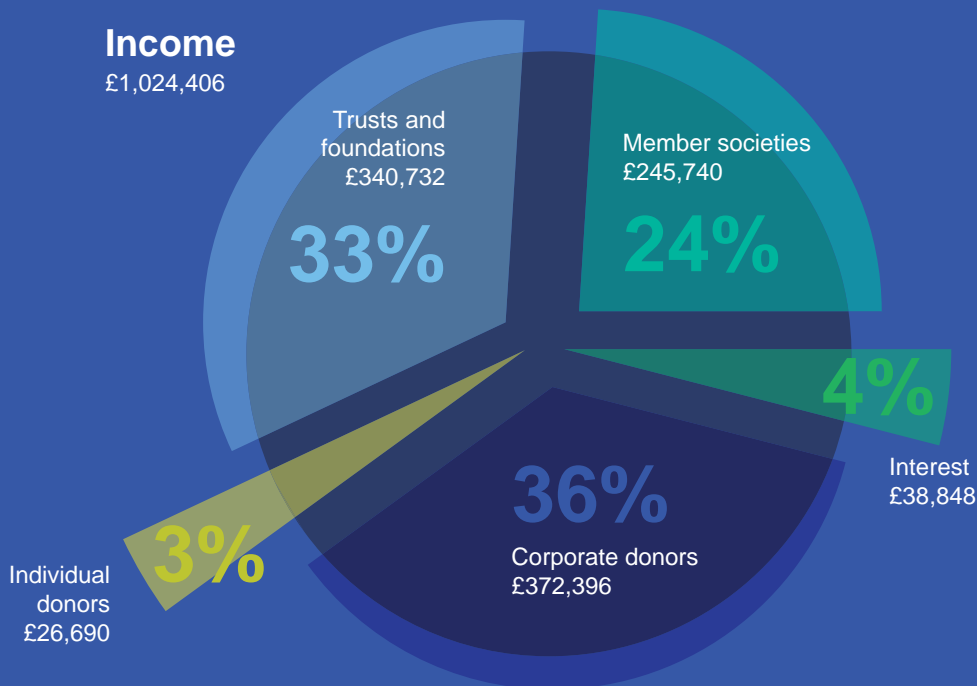
Elisabeth Golding receives the 2008 Evelyn Nicholson Award from MSIF Chairman, Sarah Phillips.

Financial information

Full accounts are available at: www.msif.org/aboutus

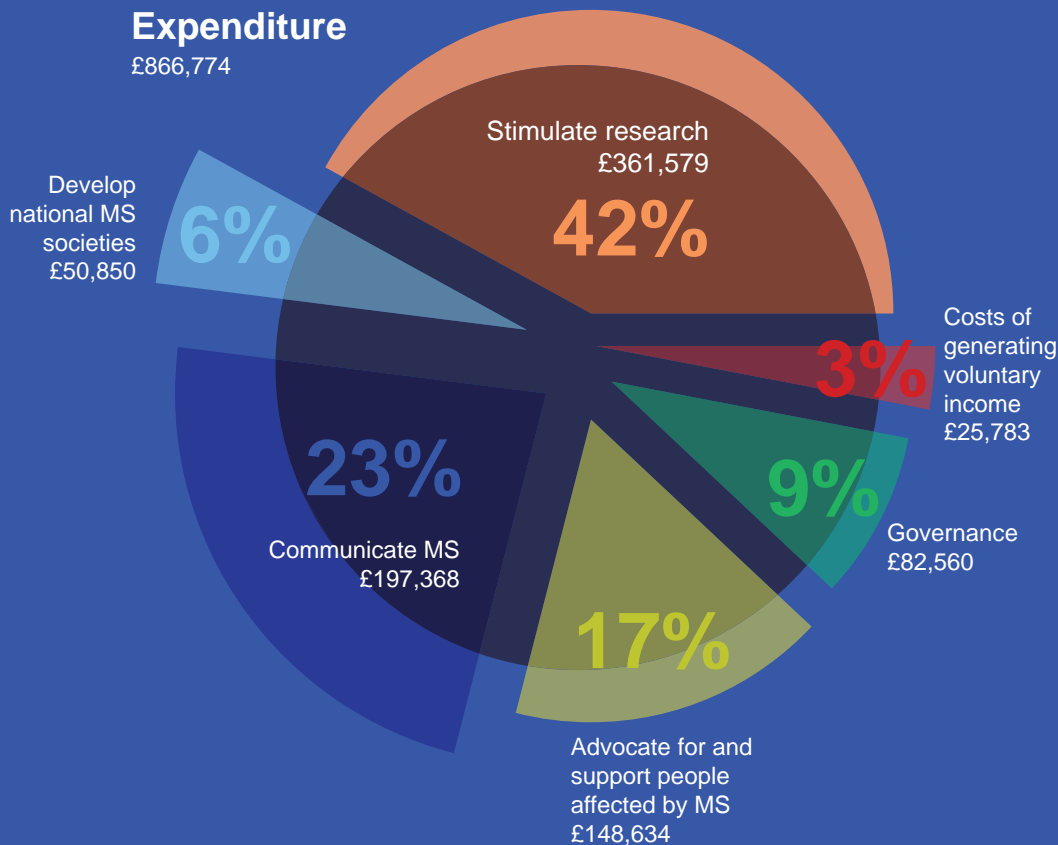
Income

£1,024,406



Expenditure

£866,774



MSIF members

Full Members (32)

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

Associate Members (10)

Chile	Mexico
Cyprus	Romania
Iran	South Korea
Israel	Sweden
Malta	Uruguay

Corresponding (Individuals, Groups and Organisations) (40)

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

Thank you

International Medical and Scientific Board Executive Committee

Alan J Thompson, Chairman	(UK)
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MSIF Research Funding Database

Olga Ciccarelli	(UK)
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MSIF Twinning Programme Work Group

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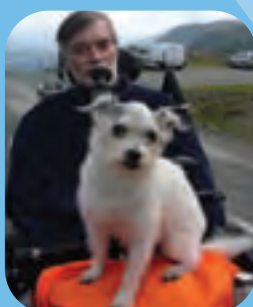
Profile of the Month translators

Louis Adam	(Canada)
Hana Al-Hussain	(Saudi Arabia)
Anna Bogolyubova	(Russia)
Claudio Conforti	(Italy)
Nancy Daoust	(Canada)
Jean-Marie Eral	(France)
Sandra Fernández Villota	(Spain)
Paulette Freichel	(Luxembourg)
Günter Lampert	(Austria)
Nicole Murlasits	(Austria)
Sabinne Paz Vergara	(Spain)
Celina Prieto Pérez	(Spain)
Margot Sepke	(Austria)
Jacques Steffen	(Luxembourg)
Christiane Tihon and colleagues	(Belgium)
Marcell Weiler	(Luxembourg)

Profiles of the Month

January	Maarten Wilbers	(Netherlands)
February	Caitlin Kernaghan	(Canada)
March	Fabiana Pérez Montañés	(Uruguay)
April	Christo Balabanov	(Bulgaria)
May	Kanya Puspokusumo	(Indonesia)
June	Roberta Amadeo	(Italy)
July	Fabiola Claret	(Argentina)
August	Jim Wolfgang	(Canada)
September	Kathleen Wilson	(USA)
October	Kürşat Korkut	(Turkey)
November	Raz Khatibi	(Iran)
December	Henri Goethals	(Belgium)

Some Profiles of the Month



Henri Goethals



Roberta Amadeo



Maarten Wilbers



Kanya Puspokusumo



Fabiana Pérez Montañés

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German:	Dr Gabrielle Seestaedt	(Germany)
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	Jean-Pierre Rihoux	(Belgium)
	Jacques Steffen	(Luxembourg)
	Christiane Tihon	(Belgium)
	Daniel Brunier	(France)
	Maryse Brunier	(France)
Russian:	(Survey on tremor and ataxia)	
	Anna Bogolyubova	(Russia)
	Irina Marinina	(Russia)
	Oleg Ipatov	(Russia)

MS: The Guide to Treatment and Management authors

Allen C Bowling	(USA)
T Jock Murray	(Canada)
John H Noseworthy	(USA)
Chris H Polman	(Netherlands)
Alan J Thompson	(UK)

World of MS mini site translators

Magdalena Chorylok	(Poland)
Izabela Czarnecka	(Poland)
Aleksandra Mróz	(Poland)

World MS Day Work Group

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Adam Michel	(Germany)
Antonella Moretti	(Italy)
Graham McReynolds	(USA)
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Matthew Trainer	(UK)

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Arja Hill	(Sweden)
Dolly Khanna	(India)
Fabiana Pérez Montañés	(Uruguay)
Allen O'Connor	(Ireland)
Daniel Schwab	(Switzerland)
Jim Wolfgang	(Canada)

Principles to Promote the Quality of Life of People with Multiple Sclerosis translator

Pavel Zlobin	(Russia)
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Global Economic Impact of MS Oversight Group

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Torben Damsgaard	(Denmark)
Ian Douglas	(MSIF)
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Tarun Dua	(WHO)
Bernadette Porter	(UK)
Shekhar Saxena	(WHO)
Alan J Thompson	(UK)

Volunteer legal advice

Volkmar Bruckner	(Germany)
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Dorothea Pitschnau-Michel	(Germany)
Matthew Trainer	(UK)

Strategic Plan Communications Reference Group

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Antonella Moretti	(Italy)
Pam Seto	(Canada)
Charles van der Straten	(Belgium)

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Nusin Misirli	(Turkey)
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Jon Temme	(Canada)
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Participant in Run to the Beat 2008

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Fred Eckert
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