Working towards a world without MS

2008 Annual Review
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 OBE, DL
Chairman and President

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
- 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.

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.
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 has 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.

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/msinfocus
- 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.
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.
- 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.
In 2008 we reviewed and updated our four-year strategy, which has:

- **Strengthen international research** for emerging MS organisations,
- **Inform relevant communication and advocacy initiatives**, we:
  - Facilitated and part-funded the first Research Symposium of the Consortium of Multiple Sclerosis Centers, Cairo in 2009.
  - Collaborated with member societies, the International Organization of MS Nurses to draft the sixth International Organization of MS Nurses to draft the guide, to present at the Developing MS Societies Committee meeting of the European MS Platform.
  - Attended MS events in Belgium, Germany, Romania, Hungary, Spain, and the UK to plan our first Arabic Development Seminar to take place in Qatar, Saudi Arabia and the UK.
- **Inform future funding decisions and the development of**
  - www.msif.org/msinfocus
  - www.ipmssg.org
  - www.msif.org/atlasofms
  - www.montreal08.net
- **Support and guidance to twinning**
  - Worked with volunteers from six countries: Croatia, Malta, Brazil, Hong Kong, Belgium, and the UK.
- **Support the work of MS nurses**
  - Awarded the 2008 Evelyn Nicholson Award for Nursing Excellence to Elisabeth Golding of the International Multiple Sclerosis Caregiver to Elisabeth Golding of the International Multiple Sclerosis Centre.
  - Co-hosted the Montreal 08 Living with MS Day Congress on Treatment and Research in MS in Montreal, Canada.
  - Planned the development of a new PDF publication, containing core information about MS, outside of the city.
  - Worked with volunteers from six countries: Croatia, Malta, Brazil, Hong Kong, Belgium, and the UK.
  - Worked with our member societies to develop a comprehensive programme of governance, containing core information about MS, outside of the city.
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- **Advocate for and support people affected by MS**
  - €148,634
  - €197,368
  - €866,774
  - €82,560
  - €38,848
- **Promote and support people affected by MS**
  - €372,396
  - €340,732
  - €340,732
  - €340,732
- **Stimulate research**
  - €361,579
  - €361,579
  - €361,579
  - €361,579
- **Develop national MS societies**
  - €30,850
  - €30,850
  - €30,850
  - €30,850

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**Financial information**

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

**Income**

- **£1,024,406**
  - Trusts and foundations: £340,732 (33%)
  - Member societies: £245,740 (24%)
  - Corporate donors: £372,396 (36%)
  - Individual donors: £26,690 (3%)
  - Interest: £38,848 (4%)

**Expenditure**

- **£866,774**
  - Stimulate research: £361,579 (42%)
  - Advocate for and support people affected by MS: £148,634 (17%)
  - Develop national MS societies: £50,850 (6%)
  - Communicate MS: £197,368 (23%)
  - Governance: £82,560 (9%)
  - Costs of generating voluntary income: £25,783 (3%)

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**MSIF members**

**Full Members (32)**

- 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
- Switzerland
- Turkey
- USA

**Associate Members (10)**

- Chile
- Cyprus
- Iran
- Israel
- Sweden
- Malta
- Mexico
- Romania
- South Korea
- Uruguay

**Corresponding (Individuals, Groups and Organisations (40))**

- Armenia
- Austria and Herzegovina
- Bulgaria
- Bosnia and Herzegovina
- Botswana
- Brazil
- Bolivia
- Brazil and Herzegovina
- Croatia
- Cuba
- Czech Republic
- Dominican Republic
- Ecuador
- Egypt
- Estonia
- Ghana
- Guatemala
- Haiti
- Indonesia
- Iraq
- Jordan
- Kosovo
- Lebanon
- Korea, South
- Latvia
- Lithuania
- Luxembourg
- Malaysia
- Malta
- Mexico
- Montenegro
- Morocco
- Mozambique
- Namibia
- Nicaragua
- Pakistan
- Palestine
- Paraguay
- Peru
- Qatar
- Russia
- Saudi Arabia
- South Africa
- Sri Lanka
- Syria
- Tunisia
- Turkey
- United Arab Emirates
- United Kingdom
- United States
- Uruguay
- Uzbekistan
- Vietnam
- Venezuela
- Zimbabwe
Thank you

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Juhan Ruutiainen (Finland)
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Profile of the Month translators

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Hana Al-Hussain (Saudi Arabia)
Anna Bogolyubova (Russia)
Claudio Conforti (Italy)
Nancy Daoust (Canada)
Jean-Marie Eral (France)
Sandra Fernández Villota (Spain)
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Nicole Murlasits (Australia)
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 Clare (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
**MS in focus Editorial Board**

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Christiane Tihon (Belgium)
Daniel Brunier (France)
Maryse Brunier (France)

**Russian:** (Survey on tremor and ataxia)
Anna Bogolyubova (Russia)
Irina Marfinina (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)

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Daniel Schwab (Switzerland)
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**Principles to Promote the Quality of Life of People with Multiple Sclerosis translator**

Pavel Zlobin (Russia)

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Ken Maynew (Canada)
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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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Polish MS Society  (Poland)
Rotarian Action Group for MS Awareness  (Australia)
Spanish Federation for the fight against MS  (Spain)
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