Aida Alic, 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!”
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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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.
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

- 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.
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 Klintsy Torres-Hernandez from Mexico. Klintsy 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.

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

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.

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.

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

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.

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

- Member Societies: £257,213
- Trusts and Foundations: £417,731
- Interest: £8,321
- Corporate Donors: £288,292
- Individual Donors: £47,362

Expenditure: £1,147,706

- Stimulate research: £317,506
- Develop national MS societies: £93,765
- Communicate MS: £229,709
- Advocate for and support people affected by MS: £311,794
- Costs of generating voluntary income: £63,594
- Governance: £131,338

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.
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.

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- Hertie Foundation
- Hilton Foundation
- Points of Light Foundation
- Vanneau Trust
- Wolfensohn Family Foundation

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- Bayer Schering
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- Dr Alexander Burnfield
- Heather Drane
- Joseph Kusters
- Francois Moes
- Roland Pels
- Donald Rutherford
- 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*
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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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)
René de Boer (Netherlands)
Ali Ahmad Hijjawi (Palestinian Authority)
Mandi Kingsbury (New Zealand)
Adriana 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.

Paulette Freichel (Luxembourg)
Guenter Lampert (Austria)
Yao Liu (China)
Nicole Mulasits (Austria)
Sabinne Paz Vergara (Spain)
Celina Prieto Pérez (Spain)
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Margot Sepke (Austria)
Jacques Steffen (Luxembourg)
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Dr Pablo Villoslada (Spain)
Marcell Weiler (Luxembourg)
Pavel Zlobin (Russia)

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René de Boer (Netherlands)
Alina Braden (Colombia)
Taragh Donohoe (Ireland)
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Becca Kornfeld (US)
Adam Michel (Germany)
Geeta Mirchandani (India)
Yves Savoie (Canada)
Sandra Fernández Villota (Spain)

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

Please return this form to:
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Thank you!
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!”

Please support MSIF
$16/£11 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 could help us support new MS societies in countries where there is little assistance or treatment for people with MS.
$208/£125 could help us to connect the world’s top researchers in childhood MS.

Please complete the form overleaf
Please support MSIF

- $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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I would like more information about:
- ☐ publications and resources
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- ☐ $16/€11/£10
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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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☐ We would like to keep you up to date with our work. Please tick if you would prefer not to be contacted.