



multiple sclerosis
international federation

msif 2011

ANNUAL REVIEW



WHO WE ARE

The Multiple Sclerosis International Federation is the world's only global network of MS organisations. Together we lead the fight against MS and strive to improve the quality of life of people affected by MS. We bring together the work of 83 MS organisations to help people affected by MS around the world.

WHAT WE DO

INTERNATIONAL RESEARCH We stimulate global research into the cause and cure of MS and the development of better MS treatment and rehabilitation. No one knows why people get MS and there is no cure. Treatments are only partially effective and may be unavailable in some parts of the world. Only dedicated, internationally coordinated research will change this.

CAPACITY BUILDING National MS societies support people affected by MS and are essential to improve quality of life. We help existing MS organisations share ideas and expertise through programmes such as twinning and our e-communications. Where there is no MS organisation, we work with local people to support the development of strong MS organisations.

COMMUNICATION Sharing knowledge, experience and information about MS is at the heart of our work. We use our website, publications and e-communications to share information about MS and its impact. We particularly aim to reach people in countries where there is little support.

ADVOCACY We work with individuals and MS organisations worldwide to support campaigns to improve the quality of life of people affected by MS.

CHAIRMAN AND PRESIDENT
Sarah Phillips, UK (until November 2011)
Weyman T Johnson, USA (after November 2011)

| | |
|------------------------------------------------|-----------------------------------------------|
| VICE-CHAIRMAN Mario Battaglia, Italy | TREASURER Robert Hubbard, Australia |
|------------------------------------------------|-----------------------------------------------|

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Jon Temme, MSIF Coordinating Consultant for the International Pediatric MS Study Group

WELCOME TO OUR 2011 ANNUAL REVIEW

Every person affected by MS must be able to find support, wherever they live or whatever form of MS they have. Therefore, in 2011, MSIF and its members worked to increase international research on paediatric and progressive MS and stepped up work to support MS organisations in emerging countries.

Many thanks go to Sarah Phillips, whose term as Chairman ended at our Council meeting in November,

where Weyman Johnson took over the role. Sarah and Weyman worked to bring our members together in Delhi for this meeting, giving a clear signal on behalf of us all: MS is a global disease and we will grow our global movement on behalf of all. Read more about this, and our other highlights from 2011, in this annual review.

Peer Baneke, CEO



Ramkrishna Subbaraman, Bipasha Gupta, Meenakshi Bhujwala and Sheela Chitnis of the MS Society of India with MSIF CEO Peer Baneke, past MSIF Chairman Sarah Phillips and new Chairman Weyman Johnson, at the MSIF Council Meeting in New Delhi, India, in November 2011.

FROM OUR CHAIRMAN

*Dear friends,
I am honoured to serve the Multiple Sclerosis International Federation and humbled by the task of helping to lead the global effort to build a world free from MS. Now more than ever, the nature of our world and the nature of MS require that we band together to demand the best in research, in tireless advocacy, and in creative therapies and care for people affected by MS.*

I have known about MS almost all my life. But whether you've known this disease a long time or you are new to the movement, each of us has essentially

the same role to play. I ask of myself and of all others in this movement only one thing: that we think clearly and work hard for the interests of the person with MS, whether that person lives in Bangalore, Berlin, Buenos Aires or Boston. After all, people with MS, even if they live thousands of miles apart, are more alike than different. We are all in this together. Let's help one another and learn from one another.

*Thank you,
Weyman Johnson*

ELEVEN HIGHLIGHTS FROM 2011

We are proud of the hard work being achieved every day by the MS global movement. From our projects and programmes during 2011, we have selected 11 key highlights.

1 KEY MS INFORMATION SERIES PUBLISHED IN ARABIC



We were delighted to publish the full series of *MS in focus* in Arabic during 2011, filling an MS information gap in the Arabic-speaking region. A workgroup from the region guided and checked the translations. We now produce each new edition of the magazine in English, French, Spanish, German and Arabic.

“MS IN FOCUS IN ARABIC OPENED A KNOWLEDGE WINDOW FOR OUR MS PATIENTS”

SAMIRA AL-RASBI, CLINICAL NURSE SPECIALIST (MS),
SULTAN QABOOS UNIVERSITY HOSPITAL, OMAN

2 FIGHTING FOR ACCESS TO WORK FOR PEOPLE WITH MS

On 2 December, the eve of the International Day for Persons with Disabilities, Peer Baneke, MSIF's CEO, presented our petition calling on employers and decision makers to protect the rights of people with MS in finding and staying in work to Ms Navi Pillay, the High Commissioner for Human Rights (pictured below). The petition was signed by 23,987 people from 143 countries.



3 UNDERSTANDING THE NEEDS OF PEOPLE WITH MS IN CHINA



Our **China Feasibility Study** provided us with increased knowledge of MS in China and helped us to understand the roles MSIF can play supporting Chinese people with MS, as well as the medical and research communities. The study outlined the need for increased MS awareness in China, investment in capacity-building and the need to link up the professional MS community with the community of people with MS.

4 GLOBAL MEETINGS HELD IN INDIA

“ I LOOK FORWARD TO THE NEXT STEPS WITH THIS GROUP AND I AM PLEASED TO BE PART OF SUCH A TERRIFIC ORGANISATION ”

MSIF BOARD MEMBER

Representatives of the global MS movement met in New Delhi, India, for our biennial Council meeting, during which MSIF's plans for the next five years were agreed. It was the first time the meetings have been held in India, with delegates from 18 countries attending. The location supported MSIF's strategy to increase our global reach, and gave delegates a chance to learn about the challenges facing people living with MS in India. The meetings ended with a day of knowledge, that included sessions led by international and Indian MS experts.

5 ADVOCACY TRAINING WORKSHOP FOR ARABIC-SPEAKING REGION

MSIF held a capacity-building workshop to address the advocacy needs of MS organisations. It was the first workshop of its kind, focusing specifically on the Arabic-speaking region, and covered topics such as identifying advocacy issues and using advocacy strategies for empowerment. Representatives from nine MS organisations took part, and delegates returned home with a full tool kit – including the publication *Making change happen* published in English and Arabic – for raising awareness of MS and running campaigns in their own countries.



7 WORLD'S FIRST INTERNATIONAL COLLABORATIVE ON PROGRESSIVE MS

Currently there are no effective disease modifying treatments for progressive MS and many people with this type of MS feel “forgotten”. To address this gap in MS research, MSIF helped to form an international collaborative that will support research into primary and secondary progressive MS and its treatment.

6 OUR BEST WORLD MS DAY YET

The third World MS Day took place on the 25 May and was a great success, with activities happening in a record 73 countries around the world. Wide use of social media channels encouraged people to view our new videos and other resources.

Selected activities from around the world are described below (and shown right).

- A People living with and affected by MS walked to raise awareness in Malaysia on World MS Day.
- B In Australia, for World MS Day the MS society ran a “Kiss Goodbye to MS” campaign.
- C People marched to raise awareness of MS in South Korea on World MS Day.
- D Volunteers in the United Arab Emirates held a promotional iFly event to raise awareness.
- E World MS Day was celebrated in India with a human chain to help raise awareness.
- F Hundreds of people ran for MS in Spain on World MS Day.
- G In Uruguay, advocates from the Esclerosis Múltiple Uruguay met with key policy makers to talk about living with MS in their country.

10-15% of people with MS are diagnosed with the primary progressive type

50% of people with relapsing remitting MS are diagnosed with secondary progressive MS within a decade

0 disease modifying treatments for people with progressive MS



8 MSIF AWARDS RECORD NUMBER OF RESEARCH GRANTS

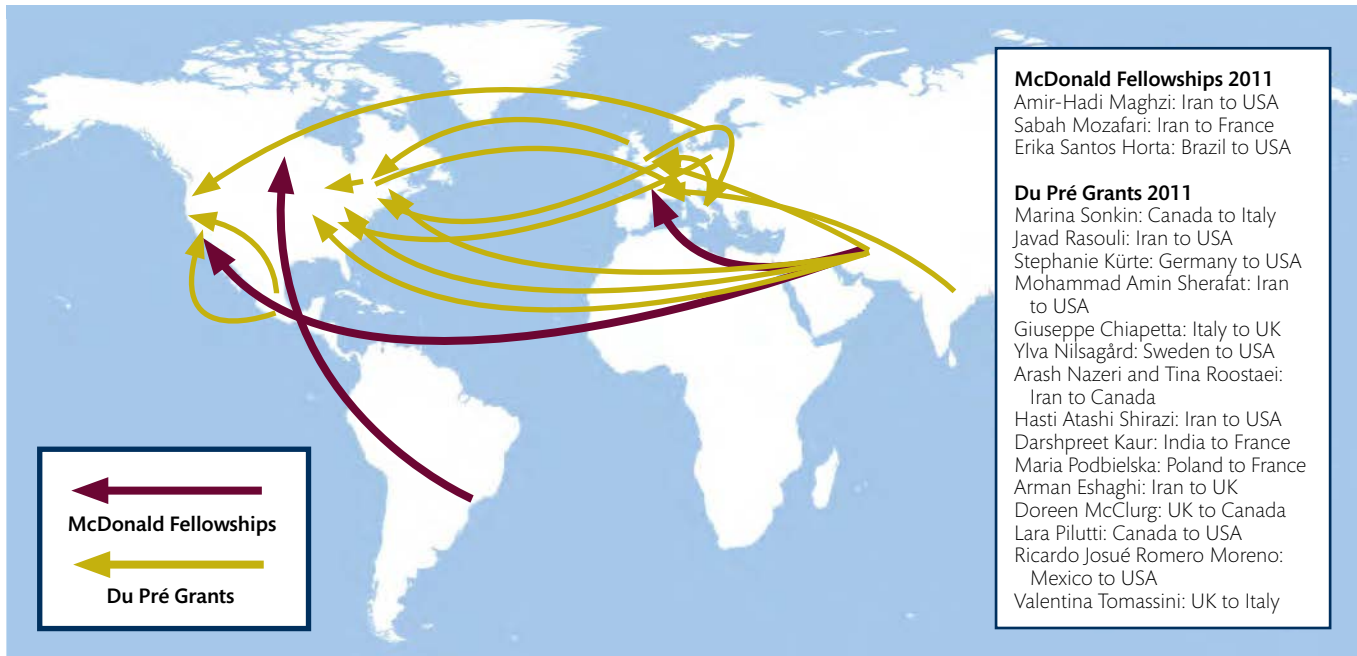
It was an outstanding year for supporting research for MSIF. We awarded 18 research grants to young researchers around the world through our prestigious programmes: the McDonald Fellowships and the Du Pré Grants.

A unique aspect of the awards is that they are aimed at people from emerging countries. The awards fund recipients to travel to another country to further their research, thereby fostering international research collaboration. The awards also encourage recipients to take home their new skills to increase support for people with MS in their home countries, many of which have limited resources. The map below is a representation of the journeys made by award recipients.



McDonald Fellowship 2011 recipient

Sabah Mozafari, a postgraduate researcher at the Department of Physiology of Tarbiat Modares University in Tehran, Iran, went to INSERM, Centre de recherche de l'institute du cerveau et de la moelle épinière, Pitié-Salpêtrière Hospital, Paris, France, under the supervision of Professor Anne Baron-Van Evercooren. Her project involves characterisation of Neural Precursors derived from Human iPS Cells: in vitro and in vivo after transplantation into the demyelinated CNS. Following her McDonald fellowship, Sabah plans to return to Iran to apply the techniques learned to undertake research in the Royan Institute in Tehran and to join the Iranian MS Association.



9 ESTONIAN MS SOCIETY JOINS THE GLOBAL MOVEMENT

The Union of Estonian MS Associations joined MSIF in November as our 43rd member. The Union works nationally for more than 480 people (QiGong training run by the Union pictured below). CEO Pille-Katrin Levin says, "Being part of MSIF has broadened our horizons and given strength to our actions. I hope we can help bring young-at-heart energy to the global MS movement!".



11 INTERNATIONAL PAEDIATRIC MS STUDY GROUP STARTS PILOT

This pilot project involves 10 countries spanning the globe. It aims to establish the feasibility of biological sample procurement from children in diverse locations. Challenges of international research, such as differing legal requirements and the stability of biological samples during shipping, will be addressed. The pilot is a platform for a larger project comparing healthy children and children with acute demyelination. The key question is whether children destined for a diagnosis of MS have the same risk exposures irrespective of their country.



10 ENHANCING SUPPORT FOR PEOPLE WITH MS IN EGYPT

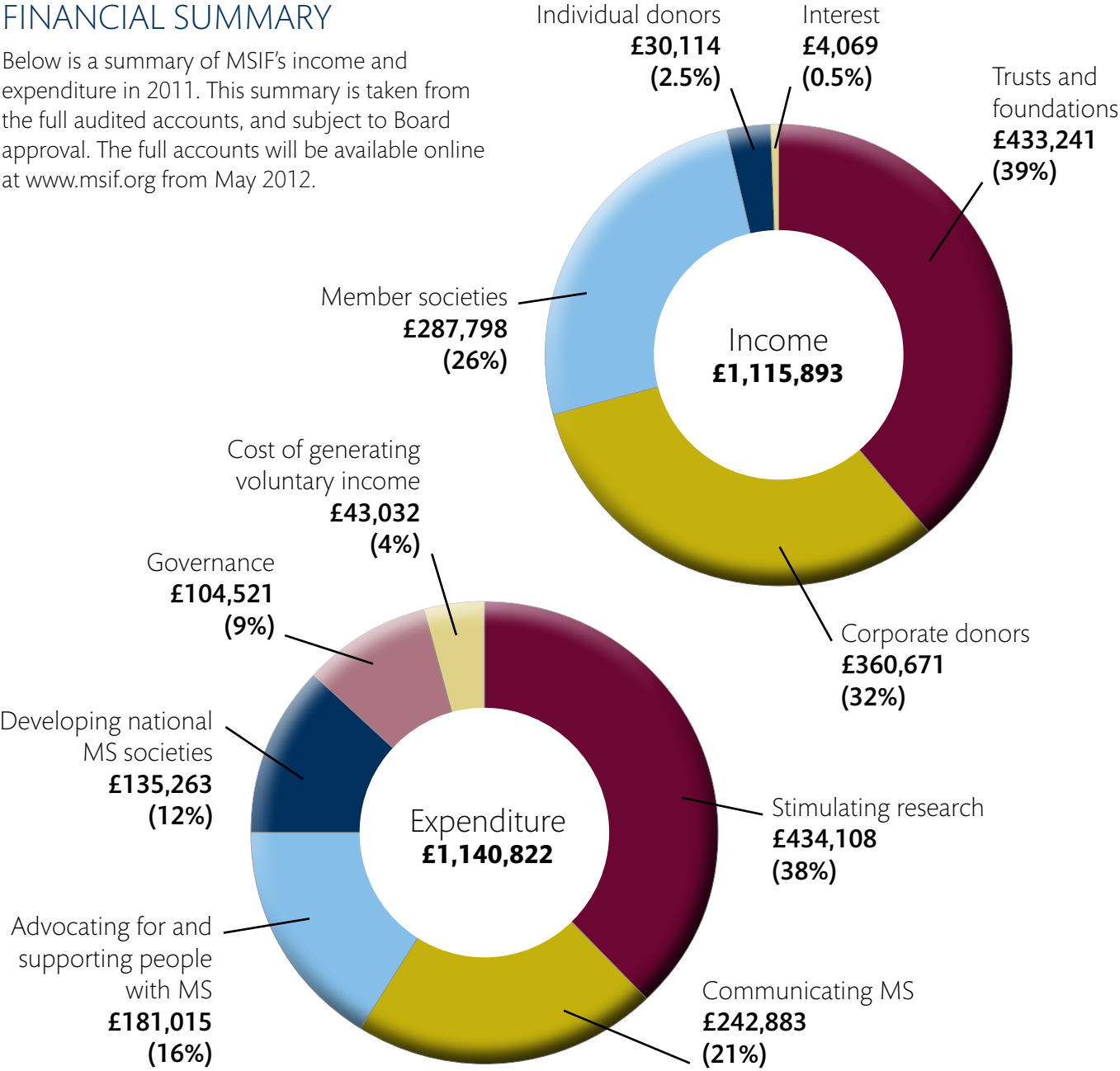
The Arabic-speaking region continued to be a focus for MSIF. We worked closely with the recently established Egyptian MS Care Society (members meeting, pictured above) to build its capacity and reach, and we were delighted that one of the Society's key activists is now a member of MSIF Board of Trustees.



Dr Terrence Thomas, from Singapore, is working with children as part of the pilot IPMSSG study.

FINANCIAL SUMMARY

Below is a summary of MSIF's income and expenditure in 2011. This summary is taken from the full audited accounts, and subject to Board approval. The full accounts will be available online at www.msif.org from May 2012.

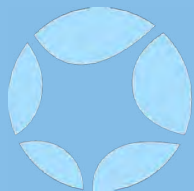


THANK YOU

Our programmes would not be possible without the support of many volunteers from around the world. Each has given their expertise, time and energy to the global MS movement, and we would like to thank the following:

ARABIC-LANGUAGE MS IN FOCUS WORK GROUP Amal Abdulrahman (Saudi Arabia) Samira Al-Rasbi (Oman) Hesham Azmi (Qatar) Abdulla Bucheery (Bahrain) Salpy Degirmendjian (Lebanon) Shereen Fathi (Egypt) Ali Hijjawi (Palestine) Nicolas Kerbage (Lebanon) Joseph Maloof (Lebanon) Mai Sharawy (Egypt) **DU PRE AWARDS WORKGROUP** Prof Reinhard Hohlfeld (Chairman, Germany) Prof Hans Lassmann (Austria) Prof Catherine Lubetzki (France) Prof Hartmut Wekerle (Germany) Dr Amit Bar-Or (Canada) Prof Howard Weiner (USA) **FUNDRAISING COMMITTEE** Antonella Moretti (Chair, Italy) Graham McReynolds (USA) Dorinda Roos (Netherlands) Frits Deiters (Netherlands) Adam Michel (Germany) Helle Ousted (Denmark, until May 2011) **INTERNATIONAL MEDICAL AND SCIENTIFIC BOARD EXECUTIVE COMMITTEE** Prof Alan J. Thompson (Chairman, UK) Prof Chris Polman (Deputy Chairman, Netherlands) Prof Alastair Compston (UK) Prof Reinhard Hohlfeld (Germany) Prof Fred Lublin (USA) Dr Xavier Montalban (Spain) Dr Carlo Pozzilli (Italy) Dr Ernest Willoughby (New Zealand) **MS IN FOCUS MAGAZINE EDITORIAL BOARD** Michele Messmer Uccelli (Editor, Italy) 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) **PERSONS WITH MS INTERNATIONAL COMMITTEE** Trevor Farrell (Australia) Guy De Vos (Belgium) Maria De Lourdes Faber (Brazil) André Lespérance (Canada) Mary Makridou (Cyprus) Svatoplukcablík (Czech Republic) Irene Jensen (Denmark) Daniel Brunier (France) Dr Pia Marks (Germany) Constantine Michalakis (Greece) Sándor Sipocz (Hungary) Berglind Gudmundsdóttir (Iceland) Daníel Ármannsson (Iceland) Jyoti Ravindra Ronghe (India) Tara Rao (India) Allen O'Connor (Ireland) Emma Rogan (Ireland) Claudio Conforti (Italy) Roberta Amadeo (Italy) Naomi Banno (Japan) Liga Mazure (Latvia) Fernand Haas (Luxemburg) Kenneth Muscat (Malta) Héctor García Caballero (Mexico) Reni de Boer (Netherlands) Noel Wierzbicki (New Zealand) Siri Malde (Norway) Eli Engebretsen (Norway) Izabela Czarnecka (Poland) Ana Nina (Portugal) Dragos Zaharia (Romania) Alojzij Ješelnik (Slovenia) Madeleine Cutting (Spain) Kent Andersson (Sweden) Daniel Schwab (Switzerland) Kürsat Korkut (Turkey) Martin Stevens (UK) Ellen Boyd (USA) **WORLD MS DAY WORK GROUP** Adam Michel (Germany) Amal Abdulrahman (Saudi Arabia) Chris Yankee (USA) Pille-Katrin Levin (Estonia) Geeta Mirchandani (India) Jeremy Wright (Australia) Maria José Wuille-Bille (Argentina) Sandra Fernandez Villota (Spain) Taragh Donohoe (Ireland) **VOLUNTARY INTERNS** Kirsty Mitchell (UK) Ayman Uweida (UK) Zoe Walker (UK).

We rely on the generosity of individuals and organisations to fund our programmes. Their support has helped us to make a difference to the lives of people living with MS around the world. We would like to thank the following for their generous donations in 2011: Bayer Healthcare, Biogen idec, Genzyme Corporation, Merck Sereno, MSIF Foundation, Novartis Pharma AG, Sanofi Aventis, Vanneau Trust, Wolfensohn Family Foundation.



multiple sclerosis international federation

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