



Multiple Sclerosis International Federation (MSIF) - Stimulating research into the understanding, treatment and cure of MS

MSIF aims 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. Through the International Medical and Scientific Board (IMSB), a unique group of medical professionals with over 70 experts in multiple sclerosis and its eight man executive committee, MSIF focuses on a number of research programmes and activities to achieve this aim.

International Progressive MS collaborative

On the 17-18 January 2012, volunteer and staff leaders from MSIF and the MS Societies of Canada, Italy, the Netherlands, United Kingdom and the United States, met in Washington to discuss the creation of an international collaboration that would leverage financial and intellectual resources to meet the unmet needs of people living with progressive forms of multiple sclerosis.

United by a mission to '*expedite the development of effective disease modifying and symptom management therapies for progressive forms of multiple sclerosis*', this group plans to engage the international MS research community to develop strategies and priorities in the following areas for research related to progressive forms of MS:

- Experimental models for improved preclinical evaluation of novel therapies,
- Targets/pathways identification and validation/repurposing of existing therapeutic agents,
- Proof-of-concept clinical trial strategies,
- Clinical outcome measures and trial designs,
- Symptom management therapies and rehabilitation strategies.

Working groups focused on each of these research priorities, chaired by a research leader and incorporating many members of the IMSB, will draw on expertise of additional experts from academia and industry to identify gaps in these areas and suggest funding strategies and collaborative models to most effectively address these needs. The groups will share their findings / recommendations at a meeting in London in late summer 2012. Members of the collaborative will then prioritize strategies and begin to formulate plans to fund research in the identified areas. The collaborative also intends to host an International Scientific Conference on Progressive MS in January 2013 chaired by Alan Thompson and Giancarlo Comi, along with the launch of the first call for research proposals by the group.

International Pediatric MS Study Group (IPMSSG) (www.ipmssg.org)

The IPMSSG are group of more than 100 paediatricians, neurologists and healthcare professionals from over 40 countries, united by the aim to optimize worldwide care, education and research in paediatric multiple sclerosis. MSIF plays a key, central role in coordinating and facilitating the work of this Study group.

On the 19-20 January 2012, the IPMSSG held a Summit Workshop in Washington on *Emerging Therapeutics in Paediatric MS*. The workshop was attended by 70 experts in MS including representatives from academia, the pharmaceutical industry and regulatory agencies. The primary goal of this Summit was to analyze the feasibility, methodology, and priorities for paediatric clinical trials for new medications in MS. Seven workgroups consisting of academic

experts met in advance to discuss and present the current state of knowledge and best practice in the areas of Clinical outcome measures, Clinical trial design, MRI outcome measures, Cognitive outcome measures, Paediatric pharmacology, Safety and biological mechanisms and Long-term outcome registries. Consensus was reached regarding the importance of clinical trials in pediatric MS, and a Clinical Trials Task Force was established to further develop consensus around trial design, outcome measures and feasibility to ensure advances in the treatment of MS in children are achieved in the shortest possible time with the highest degree of safety.

In December 2011, the Study group published in *Multiple Sclerosis Journal* a “Consensus statement: evaluation of new and existing therapeutics for pediatric multiple sclerosis” - a consensus paper on the current knowledge of treatments in pediatric MS and recommendations for future studies and clinical trials. This paper, intended to inform clinicians in the field, regulatory agencies and pharmaceutical companies, was a result of a meeting of the IPMSSG Steering Committee in September 2010, hosted by MSIF (with the National MS Society, USA and MS society of Canada).

The study group has also developed a grant proposal for their flagship research project on “Environmental risk factors in pediatric MS”. This multinational study, led by Prof Brenda Banwell, Director of the Pediatric Multiple Sclerosis Clinic at the Hospital for Sick Children in Toronto, will follow 800 children with a first demyelinating event to examine the relationship between environmental risk factors (e.g. vitamin D insufficiency, host responses to microbial infection, and pollutants) and the risk of developing MS. A pilot study for this research project – “Feasibility of Multinational Biological Studies in Children” - is expected to be completed by the end of 2012. This pilot study marks an important first step in the launch of one of the largest multinational collaborative research studies of its kind.

Research Awards and Fellowships

- **McDonald Fellowships** (www.msif.org/mcdonald).

Since the launch of the McDonald fellowships in 2007, to date we have awarded 15 fellowships to researchers from emerging countries including Argentina, Brazil, China, Hungary, India, Iran, Mexico, Romania, Spain and Thailand. The deadline for applications is 1 July 2012.

- **Du Pré Grants** (www.msif.org/dupre)

In 2011 MSIF awarded 15 Du Pré Grants to enable young researchers from Canada, Germany, India, Iran, Italy, Mexico, Poland, Sweden and the UK to travel to work on short term MS research projects in Canada, France, Italy, UK and USA. Since 2000 we have awarded 70 Du Pré grants enabling young researchers to be trained in established MS research centres and thereby promoting international collaborative research. The deadline for applications is 1 July 2012.

- **International Research Meeting Grants**

In 2009, we launched the International Research Meeting Grants to support the organisation of meetings focused on MS research. In 2011 we funded an international meeting on ‘*Exercise for People with Multiple Sclerosis*’ held in Glasgow on 15-16 February 2012, the primary aim of which was to reach a consensus on a core set of outcomes measures for exercise studies. We also funded a MAGNIMS meeting on ‘*Magnetic resonance in optic neuritis: Structural-functional interactions*’ which was held in Copenhagen in January 2012. This year, we have also agreed to support a meeting on ‘*Reassessment of MS phenotype descriptions*’ by the International Advisory Committee on Clinical Trials in MS, to be held later this fall.

- **MSIF Young Researchers Award**

The annual MSIF Young Researchers Award was launched at ECTRIMS 2009 in Düsseldorf. The £1000 award for the best presentation of a translational project at the ECTRIMS Young Researchers' session was set up under the MSIF Research Alumni programme, to support young researchers and encourage them to remain in the MS field. In 2011 the third award was given to Maarten Witte, a pre-doctoral student at the VU University Medical Centre, Amsterdam, the Netherlands, for his presentation '*PGC-1alpha –driven downregulation of mitochondrial protection and energy production in MS cortex*'. Former Du Pré Grant recipient Dr. Olga Ciccarelli presented the award on behalf of MSIF.

MSIF Research Alumni Programme

The MSIF Research Alumni Programme was launched in April 2008 to foster a lifelong relationship between alumni and MSIF with the aim of promoting scientific communication and the formation of a global MS research network. We have over 80 alumni to date. The fourth event of the MSIF Research Alumni programme was held in Amsterdam during ECTRIMS 2011 and featured short research presentations by alumni, followed by a drinks reception attended by IMSB members, senior MS researchers, clinicians and member society research staff providing an important networking opportunity for the young researchers. Further details can be found on www.msif.org/en/research/msif_research_alumni/index.html

Member society research funding database

In 2008, we developed a database to hold details of annual research funding by our member MS societies. The database continues to be updated yearly and annual monitoring and analysis of the data can help us and our member societies to determine global funding trends and patterns, which may inform future research funding decision making, raise awareness of the global commitment to MS research and the development of international collaborative initiatives.

Atlas of MS update (<http://www.atlasofms.org/>)

The Atlas of MS online Database was launched by MSIF in June 2006 with a limited data set, and subsequently the WHO and MSIF published the comprehensive Atlas of MS publication in September 2008, providing for the first time, information and data on the epidemiology of MS and the availability and accessibility of resources for people with MS at country, regional, and global levels. The Atlas of MS marked the culmination of a groundbreaking three-year global project that involved the collection, presentation and illustration of data from 112 countries, and has become an important resource for researchers and MS advocates around the world.

It is now 6 years since the data presented in the Atlas of MS was collated, and since then the number of published epidemiological studies of MS has increased considerably. Consequently, we decided to update the Atlas of MS database, which will also provide us with an opportunity to address some of the limitations of the original survey. This project is expected to be completed in late 2013.

International Mesenchymal Stem Cell Transplantation Study Group (IMSCTSG)

At the MSIF international research coordination meeting held in July 2009, stem cell therapy was identified as a priority area in which we should play a role in coordinating international collaboration. We have officially endorsed the collaboration of the IMSCTSG who are planning the MEsenchymal StEm cells for Multiple Sclerosis (MESEMS) trial, a phase 1 / 2 multi-center clinical trial to run in several countries. We are reviewing plans to financially support the

collaborative infrastructure, while individual studies will be funded by national MS societies and other national funding bodies.

Research publications

- **Making Connections and MS Research News**

MS Research News continues to be the most widely subscribed section of MSIF's free, weekly e-newsletter *Making Connections*. It contains a synopsis of research articles on the latest developments in MS research, selected by a specialist team at the Institute of Neurology who scan scientific and medical literature every week to identify relevant peer-reviewed articles which are communicated to the global MS community.

- **MS in focus**

MSIF's flagship publication, *MS in focus*, is available in a range of languages and over 700,000 copies are downloaded annually. In 2011 two editions focused on research into MS. Issue 17, in January 2011, was entitled "Research in MS" and examined how scientifically valid research is performed, while issue 18 in August 2011, titled "Pharmacological treatments in MS" discussed a range of therapies used in the treatment and management of MS. In 2012 we will issue revised and updated versions of earlier editions of *MS in focus*, starting with the January 2012 edition of *Fatigue*. New titles will also be added to the series.. See <http://www.msif.org/msinfocus>

World MS Day (www.worldmsday.org)

Finally, we have been instrumental in setting up and coordinating global activities of World MS Day which is now in its fourth year. Our theme for World MS day 2011 was employment. MSIF surveyed employers worldwide about work-based policies that could enable people with MS to stay in work. The results of the survey (3,506 responses from 107 countries) were published on 25 May 2011 in a report entitled: *Multiple sclerosis at work: an employer's perspective*. World MS Day 2012 falls on Wednesday 30 May and the theme is 'Living with MS'. The working title for the 2013 theme is 'Young people and MS' and for 2014 'Access to Treatment, Care and Services'.