IMSB Chair's Report

September 2020

Chair's introduction

The International Medical and Scientific Board (IMSB) of the MS International Federation (MSIF) is a global group of committed volunteers. We use our scientific and clinical expertise within global research and policy endeavours, aiming to improve the lives of people with MS across the world.

As ever, we are pleased to welcome new members into the Board from across the globe, bringing new insights and expertise. We offer our thanks for their work over the years to those departing.

I am very happy to take on the role as IMSB Chair, working closely with Professor Jorge Correale as Deputy Chair. It is a great honour to be able to shape the work of the IMSB, which has input on important research and access work on a global scale.

Three members' terms on the IMSB Executive Committee have now come to a close. On behalf of the IMSB and the entire MSIF movement I wish to wholeheartedly thank Professor Giancarlo Comi, Professor Catherine Lubetzki, and Professor Per Soelberg Sørensen for their many years of service. During your time in role, the IMSB has made important contributions to the global MS community.

With the approval of the MSIF Board of Trustees, the IMSB Executive Committee has been expanded. The new committee includes Presidents from the regional TRIMS networks to increase collaboration and global coverage, the RIMS President to broaden the professional experience to include rehabilitation, and more women leaders to improve gender balance.

I would like to welcome the new members: Dr Laura Musambayi, Professor Mohammad Ali Sahraian, Professor Frauke Zipp, Professor Olga Ciccarelli, Professor Daphne Kos (RIMS President), Professor Fernando Hamuy Diaz de Bedoya (LACTRIMS President,) Professor Bassem Yamout (MENACTRIMS President), and Professor Bernhard Hemmer (ECTRIMS President). A full list of all Executive Committee members can be found on the MSIF website.

2020 has so far been a challenging year for the MS community as we tackle the personal, professional and financial impact of the coronavirus pandemic. MSIF has brought us together to enable a global response: through the development of global COVID-19 advice for people with MS and through the creation of the COVID-19 and MS Global Data Sharing Initiative, developed in partnership with MS Data Alliance. Working together to rapidly collect, share and interpret data on COVID-19 in people with MS is crucial for people with MS and clinicians to make evidence-based decisions on how to manage their condition during the pandemic.
For the MSIF Awards, we have in 2020 expanded the eligibility criteria to allow Awardees to do a virtual project or to do a project in their country of origin, to accommodate for the global travel restrictions.

Global COVID-19 advice for people with MS

At the start of coronavirus pandemic, MSIF convened and I chaired a consensus group of international neurologists and researchers to discuss what advice we could provide to people with MS to minimise their risk from the virus. As there were very few documented cases in people with MS it was important to come together globally to learn from each other's experiences and to harmonise the advice being given nationally. The Global COVID-19 advice for people with MS was first published on 13 March and has been updated twice since then as our understanding of the virus in people with MS and the potential impact of MS treatments improved. The most recent statement was agreed on 17 June and can be found at: www.msif,org/covid19. This statement has been translated into multiple languages and widely shared, by MSIF and their member organisations and the TRIMS networks.

COVID-19 and the MS Global data sharing initiative

To meet the urgent demand for data on the impact of the coronavirus on people with MS, MSIF together with its members joined up with the MS Data Alliance and over 20 data collection partners to create a global data sharing initiative. The initiative's mission is to find rapid answers that can inform MS clinical management during the pandemic.

The initiative works by combining anonymous data from national registries and studies together in a global platform, providing the power to answer questions that matter to people affected by MS. In particular it seeks to understand whether different disease-modifying therapies can affect the severity of COVID-19 infection. The mission and approach has been published in the Multiple Sclerosis Journal.

The first results on the impact of disease modifying therapies on COVID-19 disease have been accepted for presentation at the MSVirtual2020 conference late-breaking session on September 26 and are being prepared for publication.

The global dataset continues to grow and we invite all clinicians and people with MS to take part by reporting on cases of COVID-19 in people with MS. Find out more at: www.msif.org/covid19data

The Atlas of MS

Atlas of MS, 3rd Edition

The epidemiology report for the Atlas of MS 3rd edition was launched at the MSVirtual2020 conference. We estimate there are 2.8 million people living with MS worldwide, an increase from our estimate of 2.3 million in 2013. In fact, all world regions have seen an increase in prevalence over this period. Several factors are likely to have contributed to the increase, including: better counting methods nationally and globally as well as improved diagnosis, people with MS living longer and global population growth. The demographics of MS in terms of gender, age of onset, and MS type remain unchanged since 2013; however, more pediatric cases have been reported as awareness of childhood MS increases.

Globally, prevalence data quality has improved, with 84% of countries able to cite peer-reviewed publications, MS registries, or electronic health records as their source for prevalence, compared to 71% in 2013. Thanks to in kind support from the National MS Society (US), we worked with McKing Consultancy to improve our methodology for assessing data quality and filling in missing data for the global prevalence calculation. This makes the new global prevalence estimate of 2.8 million people our most accurate to date.

The report shows global surveillance of MS is improving but important gaps persist. We put forward recommendations for policy makers, healthcare professionals and MS patient organisations to take action to close the gaps. The report can be viewed on the MSIF website, with an updated and much improved set of online data visualisation tools. We encourage you to use the new data and work with MSIF to update and improve the country statistics.

View the 3rd Edition of the Atlas of MS here.

For more information about the Atlas of MS, contact Rachel King at atlas@msif.org.

MSIF's Awards

We have taken several steps to amend the MSIF Awards to adapt to the impact of the COVID-19 pandemic. We extended the deadline for the 2020 Research Awards round from June 30 to August 31 for both Du Pré Awards and McDonald Fellowships. We have also amended the eligibility criteria around the awards, considering alternative ways to carry out research projects. We are allowing flexibility around how the awards are spent, as well as when and where the project would be carried out. They may be carried out virtually, in their home country, or as in previous years in a different host country.

In total we have **30** applications, which is 10 more than last year. We continued to have applications from the established countries of Iran and India, and to some extent Brazil and Argentina, but new for this year we have had applications from 5 additional countries: **Algeria, Nigeria, South Africa, Turkey, Zambia.**

We are very pleased to see this success because it means that despite the global pandemic we managed to reach people by a more extensive promotion campaign and by having more flexible terms and conditions. The application review process is ongoing and winners will be announced in November.

2019 McDonald Fellowship recipients

Dr Zahra Nasr from Iran has been awarded the McDonald Fellowship for a project titled 'Gene-environment interactions: Pesticide Exposure and Risk of Developing Pediatric Onset Multiple Sclerosis'. This project 'seeks to explore the effect of pesticide exposure in the context of genetic variants located in biological pathways leading to immune changes or neurological injury from pesticide exposures that may contribute to increase MS

Dr Reza Rahmanzadeh from Iran was awarded the McDonald Fellowship for a project called 'Myelin/Axonal brain damage and genetic susceptibility in multiple sclerosis: A GWAS-advanced MRI Coupled study'. Dr Rahmanzadeh aims to explore the relationship between genetic risk factors for MS patients and the extent of myelin and axonal damage as measured by advanced MRI techniques. This project risk.' It will take place in Dr Emmanuelle Waubant's lab at the University of California, San Francisco. This fellowship has been made available through the financial support of Fondation d'Aide pour la Recherche sur la Sclerose en Plaques (ARSEP). We are very grateful for this support.

will take place in Professor Cristina Granziera's lab at the University of Basel, Switzerland. This fellowship was possible thanks to the financial support of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS).

MSIF Young Investigator Award

We continue to present the Young Investigator Award for best presentation of a translational project at ECTRIMS by an early career researcher. The 2020 winner will be announced on September 28th due to the Encore Session on September 26th by ACTRIMS/ECTRIMS.

Progressive MS Alliance

At the start of the year the Alliance launched the *Challenges in Progressive MS Awards*. These are small pilot grants worth up to €75,000 over 12 months that aim to challenge current thinking and shift our understanding of the mechanisms that lead to progression in Progressive MS. 119 applications were received from 20 different countries and 85 have been invited to submit full applications. Due to research disruption from the coronavirus pandemic the deadline for full applications was extended. In early 2021 the Alliance expects to make up to 15 awards.
In February, a two-day meeting was held in Milan, Italy to review implementation plans for three of the Alliance's priority areas: experimental medicine, fluid biomarkers of progression and enhanced well-being. Clare Walton (Interim Head of Research and Access) and Peer Baneke represented MSIF on the Scientific Steering Committee and the Executive Committee, respectively. The Fluid Biomarkers team is focusing on the development of serum neurofilament light chain (NfL)l as a biomarker for clinical trials and for predicting future disability. They have published a position paper in Neurology this summer and are currently organising a consensus meeting and developing a targeted research funding call. They are also submitting applications to the FDA and EMA to consider NfL as a biomarker for progressive MS. The Experimental Medicine team also has a position paper under review and aims to develop a clinical trial framework for testing promising drug candidates, particularly any emerging from the Collaborative Networks. The Enhanced Wellbeing team is currently preparing a position paper and next steps will be further developed after it is published.

The Progressive Alliance is currently recruiting a new Chair for the Scientific Steering Committee to succeed Professor Alan Thompson. The Scientific Congress planned for June 2020 was postponed to next year and will take place instead as a series of virtual events. A working group consisting of members from across the Alliance's leadership and operational teams has been formed to review and refresh the strategic plan through the second half of this year.

PROMS initiative - a new global multi-stakeholder initiative on Patient Reported Outcomes for MS

This is a joint initiative from the Charcot Foundation and MSIF, with the Italian MS Society as lead agency, that aims to develop a unified global view on the role of Patient Reported Outcomes (PROs) in MS. Membership of the Executive Committee (EC), Scientific Steering Committee (SSC) and four key working groups have now been established and work is underway to map out the scope of work that will run until 2022. Full membership of the EC and SSC can be viewed here.

The four working groups are addressing the following priority areas:

1. Research, Development and Validation of PROs to capture the outcomes that are most important to people living with MS. This working group is chaired by Maria Pia Amato (Italy), Giampaolo Brichetto (Italy) and Bernard Uitdehaag (Netherlands)
2. PROs in clinical trials and clinical practice. This working group is chaired by Gilles Edan (France), Jeremy Hobart (UK), Robert McBurney (USA), Gary Cutter (USA) and Iris-Katharina Penner (Germany)
3. Digital tools for PRO measurement, including the passive collection of data. This working group is chaired by Robert Hyde (Switzerland) and Letizia Leocani (Italy)
4. Incorporation of PROs into healthcare systems. This working group is chaired by Gavin Giovannoni (UK) and Fabio Pammolli (Italy).

Each working group consists of research experts, MS clinicians and individuals from industry and MS patient organisations. The full engagement of people affected by MS across the initiative is paramount. The Executive Committee has approved the establishment of an Engagement Coordination Team (ECT) to develop this patient engagement strategy. The ECT will be co-chaired by Emma Gray (UK MS Society) and a person with MS. Recruitment is currently underway to identify the co-chair and members of the ECT who have personal experience of MS and will join the working groups. A consortium meeting is planned for December to bring together the four working groups, the EC, SCC and ECT to agree a final agenda and scope of work for the initiative.

Improved access to treatment and healthcare

Revised membership of the International Working Group on Access (IWGA)

The membership of IWGA now comprises of at least two members from all World Health Organisation (WHO) regions, has a good gender balance , includes people with MS, clinicians and both larger and smaller MS organisations. We have aimed for a balance from different income levels (10 high income, 5 upper middle income, 5 low middle income countries). IWGA’s role is to develop a strategic approach to improve access to treatment and healthcare. It will work collectively to implement the projects and activities resulting from this strategy.

Communications

Following our application to add MS treatments to the WHO Essential Medicine List (EML), we have published our process and rationale in *Multiple Sclerosis Journal* to raise awareness in the scientific community of the EML and ensure a strong basis for a revised application. The application was also featured in the December Editorial of *Lancet Neurology*, which we followed by a correspondence article highlighting the need for treatment guidelines that take into account different resource levels.

Looking to the future in access

Since MSIF's access meeting in July 2019, IWGA has been working on how to take forward the 11 actions identified during the meeting. Five large, multi-year, projects have been prioritised: an approach to guide off-label use of disease-modifying therapies (DMTs), a revised application to the WHO EML, global summit on affordability of DMTs and resource-stratified treatment, and diagnostic guidelines. These projects need to run sequentially and will be a collaborative effort by MSIF members and clinicians from the MS community.

IWGA has decided to aim for a revised WHO EML application in 2022, which will also consider commonly used off-label DMTs (azathioprine and rituximab) as requested by the WHO Expert Committee. To review the commonly used DMTs we have formed a MSIF off-label task force (MOLT). The task force will define a review process for off-label DMTs and will review azathioprine and rituximab. The process will consider both if and when these off-label treatments would be appropriate. The off-label task force is co-chaired by Bassem Yamout (MENACTRIMS President) and Bernhard Hemmer (ECTRIMS President).

The off-label review and EML application will remain independent pieces of work and we will form a new task force for the EML application.

Next steps

- Project planning and establishing task forces to tackle an independent review of the data available for commonly used off-label DMTs and a revised EML application.
- Ensuring MSIF's ambitious plans are built on IWGAs insight and strategic approach to access to treatment and MSIF's expertise and capacity building experience

Improved access in Latin America

After completion of the scoping study on the regulation of follow-on DMTs in Latin America we conducted a survey of MS organisations across Latin America to identify priority areas for working together. The consensus from 16 organisations was the need for training/guidance for national organisations to do their own advocacy work. The highest priority areas to address are improving the transparency of regional drug approval processes and improving the pharmacovigilance and traceability of MS treatments.

A translated teleconference with the Red Latinoamericana de Asociaciones de Esclerosis Múltiple (Latin American MS Associations Network, LATEM) Access Group leads, Sumaya Afif from ABEM, Brazil and Freddy Girón from ASOGEM, Guatemala, further identified a lack of robust data on people with MS and their access to healthcare as a significant barrier to progressing effective advocacy work on drug access.

During 2020 we are supporting the delivery of a series of advocacy training workshops for MS Patient organisations in Latin American to build organisational capability for national advocacy work. We are currently scoping out options for activity in 2021 that can build on this advocacy training to help organisations develop plans for advocacy work on drug access issues.

Joanna Laurson-Doube, MSIF's International Consultant on Access, will keep the Executive Committee updated at regular intervals, but if you have any questions please contact Joanna on joanna@msif.org.

Communications, Campaigns and Fundraising

World MS Day

In total 1,377 World MS Day activities were recorded across 109 countries (up from 107 in 2019). 378 organisations took part, including MSIF's 48 member organisations. 5 MS organisations participated for the first time, demonstrating the growing reach of World MS Day. There were 2 countries where World MS Day activity took place for the first time, or the first time in a number of years: Mauritius and the Maldives.

Social distancing did not stop the MS community getting active for World MS Day! Virtual walks in Croatia and yoga classes in Japan got people moving for MS. Live cooking workshops in Lebanon brought MS connections to the kitchen. Iconic landmarks were illuminated and decision makers were lobbied in Parliament. Not to mention the creative wave inspired by India's World MS Day mandalas! Around 90% of survey respondents posted about World MS Day on social media. More than half of respondents shared stories, MS Hearts and promoted the 'Tune in for MS' event. It has been fantastic to see such strong online engagement across the globe.

Funding our research and access programmes

We wouldn't be able to carry out our work in access, or fund all our research initiatives, without dedicated fundraising from a variety of sources. This includes substantial support from MSIF member organisations, especially towards the Progressive MS Alliance. We are also particularly grateful to all those members of the public who fundraise for MSIF.

This year we piloted The May 50K, this is a global fitness challenge to run/walk 50km in May. The campaign launched on 23rd March and we raised over £700,000 for MSIF's research and access to treatment work.

Cykelnerven was launched in 2018, and in 2019 we had 7 cyclists tackling the toughest climbs from the Tour De France in order to raise US$22,000 for MSIF. The Cykelnerven for 2020 is cancelled due to COVID-19.

In 2019 we launched our fundraising platform 'Against MS' – allowing people to fundraise in whatever they want for us – sporting events, challenges, bake sales, anything they can think of! We had participants, running, cycling, swimming, baking and much more! In its first year we raised nearly €30,000.

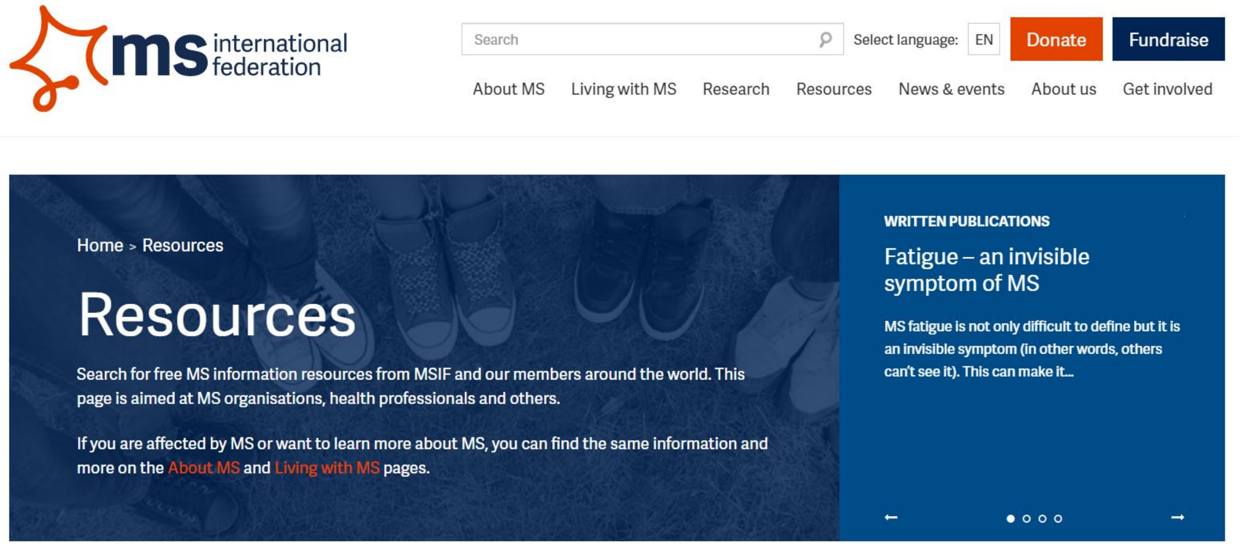
Resources

MSIF provides resources to support people with MS around the globe, covering important topics such as fatigue and MS, sex life and MS, COVID-19 and MS, aging with MS, and much more.

Thank you to those IMSB members who commented on aspects of the our resources as well as other resources.

Don’t forget to sign up to our newsletters if you are interested in hearing more about MSIF’s activities: www.msif.org/get-involved/our-newsletters/

Link to the resource Hub is found here.



Resources

Search for free MS information resources from MSIF and our members around the world. This page is aimed at MS organisations, health professionals and others.

If you are affected by MS or want to learn more about MS, you can find the same information and more on the About MS and Living with MS pages.

Fatigue – an invisible symptom of MS

MS fatigue is not only difficult to define but it is an invisible symptom (in other words, others can't see it). This can make it...

IMSB – Contributions

We would like to acknowledge the all the members of the IMSB who gave their time and expertise this year to various MSIF-related projects. Our apologies if we have inadvertently left your name off this list. This does not include the many other members of the MS scientific and clinical community or members of staff from MSIF member organisations who have made significant contributions to MSIF projects – our thanks to them as well.

Progressive MS Alliance

Members of the IMSB who are also members of the Alliance Scientific Steering Committee
Professor Giancarlo Comi
Professor William Carroll
Professor Reinhard Hohlfeld
Professor Catherine Lubetzki
Dr Julia Morahan
Professor Marco Salvetti
Professor Xavier Montalban
Professor Per Soelberg Sorenson
Dr Paola Zaratin

PROMS Initiative

Executive Committee:
Professor Giancarlo Comi
Professor Xavier Montalban

Scientific Steering Committee
Dr Paola Zaratin
Professor Bernard Uitdehaag

As members of the following Working Groups

Research, validation, and development:
Professor Bernard Uitdehaag
Professor Alexey Boyko
Professor Krzysztof Selmaj
Professor Bassem Yamout
Clinical Management:
Professor Aksel Siva
e-Health:
Professor Ludwig Kappos
Professor Daphne Kos
Health Care System:
Professor Per Soelberg Sørensen

Dr Julia Morahan
Dr Alexander Stahmann

Executive Committee of the IMSB
Reviewing and selecting the winners of the McDonald Fellowships
Professor Brenda Banwell (Chair)
Professor Jorge Correale (Deputy Chair)
Professor Olga Ciccarelli
Dr Laura Musambayi
Professor Mohammad Sahraian
Professor Frauke Zipp
Professor Jeffrey Cohen (ACTRIMS President)
Professor Kazuo Fujihara (PACTRIMS President)
Professor Fernando Hamuy Diaz de Bedoya (LACTRIMS President)
Professor Bernhard Hemmer (ECTRIMS President)
Professor Daphne Kos (RIMS President)
Professor Bassem Yamout (MENACTRIMS President)

Du Pré Grants Panel
Reviewing and selecting the winners of the Du Pré Grants
Professor Jorge Correale (Chair)
Professor Daphne Kos
Professor Mohammad Ali Sahraian
Dr Laura Musambayi
Professor Hans Lassmann

Young Investigator Award Panel 2020
Reviewing and selecting the winner of the Young Investigator Award
Dr Julia Morahan
Prof Kjell-Morten Myhr
Dr Emmanuelle Plassart
Dr Jan Meilof

Access to Treatment and Healthcare
Professor Brenda Banwell
Professor Jorge Correale
Professor Lekha Pandit
Professor Mohammed Sahraian
Prof Bernhard Hemmer (ECTRIMS)
Professor Jeff Cohen (ACTRIMS)
Professor William Carroll (WFN)
Professor Kazuo Fujihara (PACTRIMS)
Professor Bassem Yamout (MENACTRIMS)
Professor Fernando Hamuy Diaz de Bedoya (LACTRIMS)
Professor Alexey Boyko (RUCTRIMS)
Dr Laura Musambayi
Professor Kameshwar Prasad

The Atlas of MS
Advising on the scope of the survey, the structure of the questionnaire, and helping to source contacts in specific countries.
Professor Riadh Gouider (Tunisa) – Working Group
Dr Lasse Skovgaard (Denmark) – Working Group
Professor Bernard Uitdehaag (Netherlands) - Expert advisor
Professor Kazuo Fujihara (Japan) – Expert advisor

MSIF's resources
Advising on treatments for fatigue in MS
Professor Bénédicte Dubois
Professor Jeannette Lechner-Scott
Dr Ana Martins da Silva