



# 2014 REPORT OF PROGRESS

INTERNATIONAL  
PROGRESSIVE MS ALLIANCE

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**CONNECT** TO END PROGRESSIVE MS



More than 2.3 million people worldwide live with multiple sclerosis. More than half, over 1 million people, live with a progressive form.

Progressive MS gets worse over time, taking things away from people each and every day; things like vision, mobility, cognition, and the ability to work and be independent. Despite advances in other forms of MS, there are currently no treatments for progressive MS.

The International Progressive MS Alliance (Alliance) is a growing global initiative, working together to connect resources and experts around the world to find answers and develop solutions to end progressive MS.

The Alliance sets research priorities, facilitates global collaboration to share knowledge and build research infrastructure, and increases worldwide funding capacity to drive large-scale global research initiatives.

Our Mission: To expedite the development of effective therapies to manage progressive forms of MS.



## STRATEGIC PRIORITIES

The International Progressive MS Alliance is determined to address the urgency to find solutions for everyone living with progressive MS, irrespective of location. We must work together to uncover the answers and bring forth solutions. To achieve this goal, the Alliance will focus on three important strategic priorities:

- **Global Leadership** – ensuring that research is focused on eliminating barriers to treatment development, is integrated across the MS community worldwide, and systematically measured and refined.
- **Innovation** – leveraging research already underway and stimulating new research and breakthroughs through a significant grants program.
- **Funding Research** – driving worldwide resources to fund the best research, wherever it may be, and unleash the research community to accelerate results with the greatest impact and potential.



**Cyndi Zagieboylo**  
Chair of the Alliance  
Executive Committee

*Cyndi Zagieboylo*

People with progressive MS cannot wait any longer – it is up to us. Together, we can become stronger and more powerful than progressive MS. We can give back the things progressive MS takes from the people we love and care about.

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## MANAGING MEMBERS



## RESEARCH PRIORITIES

The Alliance Scientific Steering Committee has responsibility for stimulating and encouraging the most promising research worldwide to overcome existing barriers to the development of new treatments for progressive MS. Four priorities anchor our work:

- Better exploring and understanding progression so we can identify and test new treatments
- Designing shorter, faster trials that measure patient outcomes more effectively
- Conducting trials to test new agents – with better trial design, more life changing treatment choices will be available to people faster
- Developing, evaluating and advancing effective rehabilitation and symptomatic treatments that will improve daily quality of life

To drive this progressive agenda, the Alliance funds three types of Awards to address the most pressing issues:



**Professor Alan J. Thompson, MD, (Chair)**

University College, London, Faculty of Brain Sciences, UK

A handwritten signature in black ink that reads "Alan J. Thompson".

- Challenge Awards – encouraging scientific innovation
- Infrastructure Awards – promoting data sharing and knowledge management
- Collaborative Network Awards – stimulating answers to big questions facing MS researchers

We are bringing the MS research world together so that we can solve progressive MS.

## SCIENTIFIC STEERING COMMITTEE MEMBERS

**Prof. Alan Thompson, MD (Chair)**  
University College London Faculty of Brain  
Sciences, UK

**Prof. Giancarlo Comi, MD (Vice Chair)**  
Vita-Salute San Raffaele University, ITALY

**Ceri Angood**  
Director of Programs, Multiple Sclerosis  
International Federation, UK

**Bruce Bebo, PhD**  
Executive Vice President, Research,  
National Multiple Sclerosis Society, USA

**William Carroll, MD**  
Neurologist, MS Research Australia, First Vice  
President of World Federation of Neurologists, AUS

**Dhia Chandraratna, PhD**  
Head of International Medical and Scientific  
Research, Multiple Sclerosis International  
Federation, UK

**Timothy Coetzee, PhD**  
Chief Advocacy, Services and Research Officer,  
National Multiple Sclerosis Society, USA

**Anthony Feinstein, MD**  
Professor of Psychiatry, University of Toronto,  
Neuropsychiatrist, Sunnybrook Hospital, CANADA

**Robert Fox, MD**  
Medical Director, Mellen Center for MS,  
Cleveland Clinic, USA

**Jeroen Geurts, PhD**  
Professor, VU Medisch Centrum,  
THE NETHERLANDS

**Emma Gray, PhD**  
Acting Head of Biomedical Research,  
MS Society UK

**Reinhard Hohlfeld, MD**  
Professor, Ludwig-Maximilian-University Munich,  
GERMANY

**Raj Kapoor, MD**  
Consultant Neurologist, National Hospital for  
Neurology and Neurosurgery, UK

**Susan Kohlhaas, PhD**  
Head of Biomedical Research, MS Society, UK

**Douglas Landsman, PhD**  
Senior Director, International Programs, National  
Multiple Sclerosis Society, USA

**Karen Lee, PhD**  
VP of Research, MS Society of Canada, CANADA

**Xavier Montalban, MD, PhD**  
Vall d'Hebron, University Hospital and Research  
Institute, SPAIN

**Lisa Melton, PhD**  
Research Development Manager, MS Research  
Australia, AUSTRALIA

**Marco Salvetti, MD**  
Director, Center of Neurology and Experimental  
Therapies, La Sapienza University, ITALY

**Kathryn Smith, PhD**  
Managing Director, Fast Forward LLC, USA

**Per Soelberg Sørensen, MD**  
Professor of Neurology, Danish Multiple Sclerosis  
Center, DENMARK

**Paola Zaratina, PhD**  
Director of Scientific Research Department,  
Associazione Italiana Sclerosi Multipla, ITALY



## 2014 PROGRESS

- The first global Request for Applications for the Challenge Awards generated 195 responses; 22 were awarded.

Funded Challenge Award grants are short-term innovative pilot studies to begin filling knowledge and infrastructure gaps such as identifying and testing potential treatments; understanding nerve degeneration; and building databanks and biobanks – repositories of biological samples for use in research – to better understand long-term imaging, genetics, and outcomes associated with progressive MS.

- The second global Request for Applications for the Collaborative Network Awards was released November 2014.
- The Collaborative Network Awards are long-term, multi-national projects that will stimulate answers to big questions facing MS scientists.
- A global progressive MS research portfolio was developed to understand where and in what area current research is underway.



**MARY**  
LIVING WITH MS SINCE 2006, UK



**ROBERTA**  
LIVING WITH MS SINCE 1992, ITALY

## 2014 PROGRESS

- Expanded Alliance membership:
  - > New Managing members: MS Research Australia, MS Society of Canada
  - > New members: Ligue Nationale Belge de la Sclerose en Plaques (Belgium), Stichting MS Research (The Netherlands), Deutsche Multiple Sklerose Gesellschaft (Germany)
  - > Alliance Member financial commitments now total € 18.7 million
  - > Established and conducted two Industry Forum meetings, engaging industry stakeholders in moving solutions forward as Alliance members
  - > Secured worldwide media during a global press launch at ECTRIMS in September
  - > Donors worldwide participated in Alliance fundraising activities, receptions, and made online gifts



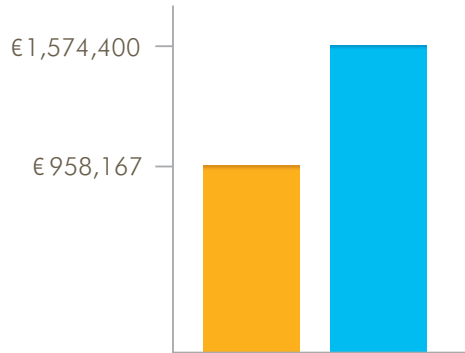
**SUSAN**  
LIVING WITH MS SINCE 1998, USA



**GARY**  
LIVING WITH MS SINCE 2000, AUSTRALIA

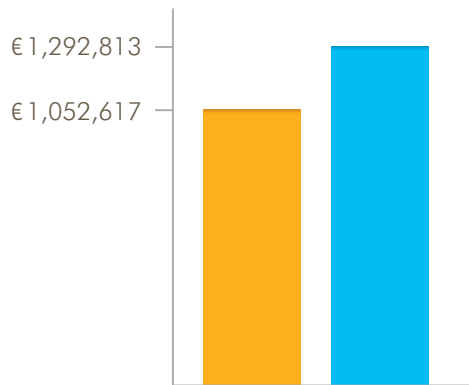


# FY2014 FINANCIAL HIGHLIGHTS



## REVENUE

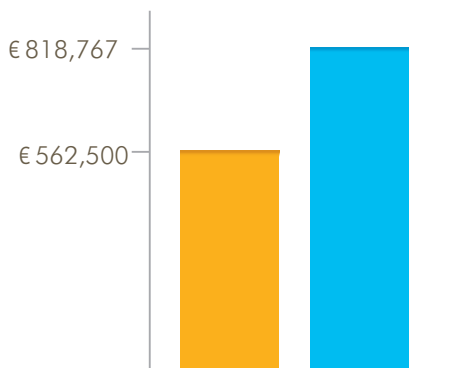
- Budgeted Revenue: € 958,167
- Actual Revenue: € 1,574,400



## TOTAL EXPENSE

- Budgeted Expense: € 1,052,617
- Actual Expense: € 1,292,813

\*Total expenses exceeded the approved FY14 budget due to allocation of additional funds to support an increased number of research projects (as listed below in "Research Investments"). These increased allocations were approved by the Executive Committee, following the advice of the Scientific Steering Committee.



## RESEARCH INVESTMENTS

- Budgeted Research: € 562,500
- Actual Research Investments: € 860,992
  - 18 Challenge Grants: € 669,967
  - 4 Infrastructure Grants: € 148,808
  - Rehabilitation Pilot: € 42,356



## IT IS UP TO US

Be a part of the most ambitious global initiative in the history of MS research.

Together, we can achieve unprecedented progress that will provide much needed hope and solutions for more than 1 million people worldwide living with progressive MS.

JOIN US TODAY

[www.ProgressiveMSAlliance.org](http://www.ProgressiveMSAlliance.org)

