



More than hope.
Progress.

2015 REPORT OF PROGRESS

LOUISE
LIVING WITH PROGRESSIVE MS SINCE 1997, DENMARK

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

CONNECT TO END PROGRESSIVE MS



ROBERTA, LIVING WITH PROGRESSIVE MS SINCE 1992, ITALY

BRIAN, LIVING WITH PROGRESSIVE MS SINCE 2005, CANADA

JENNIFER, LIVING WITH PROGRESSIVE MS SINCE 2000, US

GARY, LIVING WITH PROGRESSIVE MS SINCE 2000, AUSTRALIA

Multiple sclerosis (MS) is found in every country where studies have been conducted, and more than 2.3 million people worldwide currently live with the disease; **over 1 million people live with a progressive form of MS.**

Progressive multiple sclerosis, a chronic condition that disrupts the flow of information within the brain and body, is a form of MS that gets worse over time. Each day, progressive MS takes things away from people: vision, mobility, cognition, ability to work, and their very independence. Despite advances in treatments for other forms of MS, there are currently no treatments available for progressive MS.

AN UNPRECEDENTED GLOBAL EFFORT

For the first time, the international MS community has come together to tackle progressive MS. The International Progressive MS Alliance is a global initiative that aligns MS organizations from around the world including Australia, Belgium, Canada, Denmark, France, Germany, Ireland, Italy, Norway, the Netherlands, Spain, the United Kingdom, the United States and the MS International Federation.

MANAGING MEMBERS



MEMBERS



STRATEGIC PRIORITIES

The International Progressive MS Alliance is connecting resources and experts around the world to find answers and to expedite the development of effective therapies for people living with progressive forms of MS.

Worldwide collaboration among all stakeholders is at the heart of the Alliance's approach. MS organisations around the world are working together to further build research infrastructure, to share knowledge and to increase our worldwide funding capacity in support of progressive MS research. Academia and the pharmaceutical industry have come together to provide knowledge and contribute resources and research talent, which together with other stakeholders, will drive large-scale advances in progressive MS. In addition, the leading MS pharmaceutical companies have joined together as part of the Alliance Industry Forum, work that is instrumental in helping identify and address the scientific and regulatory challenges that are critical to accelerate progress.

This truly global collaboration includes the leading worldwide scientific MS experts as well as a shared commitment from 15 MS organizations (and counting) from around the world.

There are no longer geographic borders in the way of finding solutions needed by people with progressive MS everywhere.

In 2015, the work of the Alliance achieved key milestones toward new treatments in progressive MS, where we accelerate the work to deliver not just hope to people living with progressive MS, but true progress.



Cyndi Zagieboylo
Alliance Executive Committee Chair
National MS Society President & CEO, US

“I have lived with progressive MS for 18 years and I am very excited about the Alliance. Bringing together researchers from around the globe to understand the progression of MS, develop clinical trials and find treatments that have eluded us so far is vital to those of us who live with progressive MS.”

– Marie Vaillant, MSIF Board Vice Chair, MS Society Canada
Division Board Chair, and living with progressive MS

RESEARCH PRIORITIES

As Chair of the Alliance Scientific Steering Committee, I remain inspired and humbled by the strength of science and level of innovation demonstrated by my colleagues in this important work.

Last year, the Alliance awarded Challenge Grants for projects that focused on four research priority areas:

1. **Better understanding progression so we can identify and test treatments;**
2. **Designing shorter, faster trials that measure patient outcomes;**
3. **Conducting trials to test agents; and,**
4. **Developing and evaluating new therapies to manage symptoms.**

In 2015, these 22 projects focused on clinical trials and outcome measures, biomarkers of progression, gene studies, rehabilitation trials, new disease models, and research to better understand the pathology of progression.

In 2015, the Alliance also selected awardees for Planning Grants in support of Collaborative Network Awards. Following the work done by the Planning Grant recipients, a select group of Planning Grant awardees will subsequently be chosen in 2016 for large, multi-national and long-term Collaborative Network Awards. These awards will accelerate progress in:

- Drug discovery programs to either repurpose existing drugs or bring forth first-in-human drugs;
- Discovery, advancement and validation of new or existing biological or imaging biomarkers; and,
- Proof-of-concept trials and trial designs, including remyelination, neuroprotection and enhanced plasticity.

The quality, breadth and innovation of the science being conducted are extremely promising. Looking toward 2016 and beyond, some of the most important and potentially transformative work in the area of progressive MS is just on the horizon.



A handwritten signature in black ink that reads "Alan J. Thompson". The signature is written in a cursive, flowing style.

Professor Alan J. Thompson, MD
Alliance Scientific Steering Committee Chair
University College, London, Faculty of Brain Sciences, UK



2015 PROGRESS IN MS RESEARCH

CHALLENGE AWARDS:

The Alliance awarded 22 awards of €75,000, designed to improve understanding of genetic and biological processes, repurpose existing drugs and speed clinical trials. These 1–2 year research projects began in 2015, and are focused on:

Clinical trials and outcome measures: Hasselt University (Belgium), Imperial College London (United Kingdom), Johns Hopkins University (United States), Mount Sinai School of Medicine (United States), Umeå University (Sweden)

Biomarkers of progression: VU University Medical Center Amsterdam (The Netherlands), Vall d’Hebron Research Institute (Spain)

Gene studies: Karolinska Institute (Sweden), University of California-San Francisco (United States), The International Multiple Sclerosis Genetics Consortium (IMSGC) (United Kingdom)

Rehabilitation trials: Kessler Foundation Research Center (United States), Plymouth University (United Kingdom)

Underlying pathology of progression: Brigham and Women’s Hospital (United States), VU University Medical Center Amsterdam (The Netherlands), McGill University (Canada), Monash University (Australia), University of Edinburgh (United Kingdom), University of Verona (Italy), Yale University (United States)

Developing new disease models: Renovo Neural, Inc. (United States), Stanford University (United States)

CHALLENGE GRANT PROGRESS HIGHLIGHTS:

- Participants enrolled in a trial of memory and learning interventions designed to maintain or improve cognition in progressive patients
- A mobile app is being developed for the remote capture of movement data that can accurately measure step acceleration and walking speed over a wide range of disability.
- Studies looking at the pathophysiology of progressive MS, including changes in mitochondrial functioning and the development of new imaging tools and biomarkers.
- Markers identified from blood and cerebrospinal fluid samples that might be indicative of progression and the development of disability. The aim of the project was to correlate radiological (imaging) changes with biomarker changes and understand how these markers might aid in predicting and understanding disease progression. The group has been successful and is conducting further analysis on a number of candidate markers pulled from their screens.
- Twenty people with progressive MS participated in a trial testing intrathecal (IT) delivery of rituximab (RTX). Published results indicate that even minute quantities of RTX delivered IT would deplete peripheral B lymphocytes almost immediately. This work has provided valuable information regarding the pharmacokinetics (delivery and breakdown of the drug) of IT injections and has clinical implications.
- Challenge grant recipients were published in scientific journals such as *Neurodegenerative Disease Management*; *Cell*; *Seminars in Immunopathology*; *Annals of Neurology* and *Nature Neuroscience*. They also presented abstracts at meetings such as European Committee for Treatment and research in MS (ECTRIMS); MS Frontiers; Meeting of the Society of Italian Neurology (SIN); Conference on Rehabilitation in Multiple Sclerosis (RIMS); Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC); and, International Society for Neurochemistry-Asia Pacific Society for Neurochemistry (ISN-ASPN) Biennial Meeting with Australian Neuroscience Society (ANS).

Additional progress from these studies will be reported throughout 2016.

PLANNING GRANTS IN SUPPORT OF THE COLLABORATIVE NETWORK AWARDS:

2015:

The second global Request for Applications for Collaborative Network Planning Grants generated

52 APPLICATIONS

representing more than

500 RESEARCHERS

from around the world

Following an extensive **PEER AND TECHNICAL REVIEW** involving key academic and industry experts,

11 PROJECTS

received a 12-month,

€50,000 PLANNING GRANT

Planning award networks involve

139 INVESTIGATORS

FROM

17 COUNTRIES

including: Austria, Canada, the Czech Republic, Denmark, Finland, France, Germany, Ireland, Israel, Italy, the Netherlands, Spain, Sweden, Switzerland, the UK and the US

Recipients of planning grant awards focus on one of the three priority areas and include the following:

- 1** Projects that will drive development of one or more pre-clinical drug candidates within the 4-year funding period of the full network award include:
 - a. Development of a drug discovery pipeline for secondary progressive MS**
Francisco Quintana – Lead Researcher (US)
 - b. Stem cell-derived oligodendrocyte progenitor-based therapy of progressive MS**
Steven Goldman – Lead Researcher (US)
 - c. Bioinformatics and cell reprogramming to develop an in vitro platform to discover new drugs for progressive multiple sclerosis (BRAVEinMS)**
Gianvito Martino – Lead Researcher (Italy)
 - d. Mitochondria and progressive MS**
Don Mahad – Lead Researcher (UK)
 - e. An international network to decipher function and impact of CNS-relevant risk variants for MS and Gene discovery and lead compound identification for progressive MS**
Philip DeJager – Lead Researcher (US)

2 Projects that will drive development of a meaningful outcome measure that could be integrated into early clinical development within the 4-year funding period include:

- a. An MRI biomarker for disability progression for use in clinical trials**
Douglas Arnold – Lead Researcher (Canada)
- b. SPINE: Spinal cord imaging to Identify Novel biomarkers of disease Evolution and treatment monitoring in progressive MS**
Massimo Filippi – Lead Researcher (Italy)
- c. Prospectively Defining Secondary Progressive MS**
Fred Lublin – Lead Researcher (US)

- d. Novel molecular imaging probes to predict disability progression and evaluate therapies in MS: The PROBIMS network**
Bruno Stankoff (France)
and Targeting microglia in progressive MS
Richard Nicholas (UK) – Lead Researchers
- e. Development and validation of an innovative, comprehensive measuring system for disease progression in MS**
Peter Fuhr (Switzerland)
and The International MS Visual System Consortium (IMSVISUAL)
Peter Calabresi (US) – Lead Researchers

3 Project that will drive initiation of clinical trials of new interventions for progressive MS within the 4-year funding period is:

- a. Cognitive rehabilitation and exercise for people with progressive MS: a multicenter, multidisciplinary study**
Anthony Feinstein (Canada)
and Targeting nervous plasticity in progressive MS — a translational approach
Letizia Leocani (Italy) – Lead Researchers

- Awardees work closely with members of the Alliance Scientific Steering Committee and consult with the Alliance Industry Forum during the planning stage to ensure the strongest research designs and translational science for the Collaborative Network Awards as possible.

- In May 2016, planning grant awardees will have the opportunity to apply for a 4-year, €4.2 million Collaborative Network award.

ALLIANCE INDUSTRY FORUM:

- Industry's collaborative partnership with the Alliance is managed through the Industry Forum — the framework where Alliance and industry stakeholders discuss and actively support and inform the critical work of the Alliance.
- A Scope of Work for the Industry Forum was developed, which provided a framework for engagement with the pharmaceutical and biotech industry.
- A meeting was conducted in December bringing Industry Forum members, SSC and the Network Collaborative investigators together to facilitate discussion in order to strengthen proposals and maximize impact.
- Industry Forum collaborators include Biogen; EMD Serono; Genentech, a member of Roche; Sanofi Genzyme; Novartis AG; and Teva.
- Industry is critical in helping the Alliance fulfill its goals through their ability to contribute extensive knowledge, resources and financial investment to accelerate progress and drug development

EXPANDING ALLIANCE MEMBERSHIP:

- New Alliance members in 2015: Fondation ARSEP (France), Ligue française contre la sclérose en plaques (France), Multipel Sklerose Forbundet i Norge (Norway) and The MS Society of Ireland (Ireland)

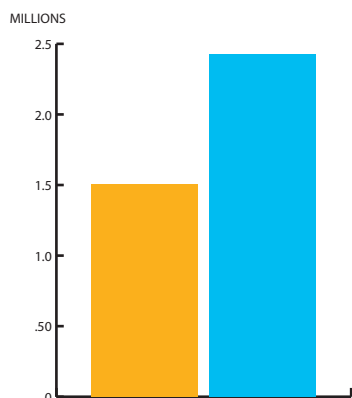
IMPORTANT ALLIANCE ENGAGEMENT ACTIVITIES DURING 2015

- Alliance Scientific Meeting – March: Thought leaders from around the world convened in Boston, Massachusetts to focus on specific, critically-important areas related to progressive MS. The Multiple Sclerosis Journal published an article “Progressive MS: from pathophysiology to drug discovery”, which summarized the outcomes of this meeting. (Marco Salvetti, Douglas Landsman, Peter Schwarz-Lam, Giancarlo Comi, Alan J Thompson and Robert J Fox; *Multiple Sclerosis Journal*, October 2015; vol. 21, 11: pp. 1376-1384., first published on September 11, 2015)
- European Committee for Treatment and Research in MS (ECTRIMS) – October: During ECTRIMS, the largest MS conference in the world, scientific leaders in MS research met in Barcelona, Spain to address the main topics signaling the path to future MS management. The Alliance hosted executive leadership meetings and a reception for scientists, Alliance members, and prospective donors. Alan Thompson delivered the ECTRIMS lecture: “Progressive MS — how do we meet the therapeutic challenge?”
- Established and conducted two Industry Forum meetings, engaging industry stakeholders in moving solutions forward
- Donors worldwide participated in Alliance fundraising activities

FY2015 FINANCIAL HIGHLIGHTS

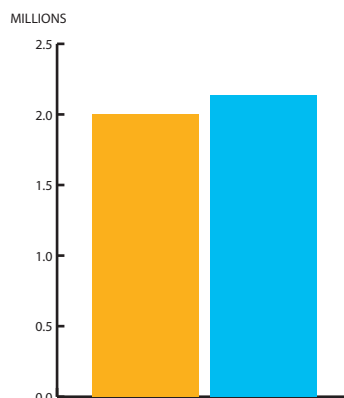
The Alliance exceeded FY15 budgeted revenue as a result of growing membership and financial commitments. FY15 expenses exceeded budget due to support of emerging and promising research and other collaborative activities worldwide that will accelerate progress toward treatments.

REVENUE



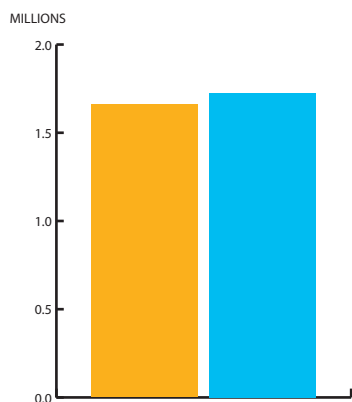
- Budgeted revenue: €1,502,596
- Actual revenue: €2,426,351

EXPENSES



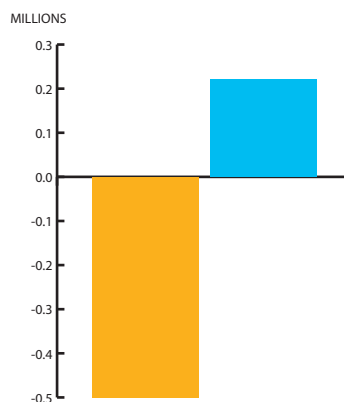
- Budgeted expenses: €2,002,980
- Actual expenses: €2,136,622

RESEARCH INVESTMENTS



- Budgeted research: €1,660,945
- Actual research investments: €1,725,789

TOTAL NET INCOME IN FY15



- Budgeted: (€500,384 deficit)
- Actual net income: €222,967

MANAGING MEMBERS

Cyndi Zagieboylo (Chair)

President and CEO, National Multiple Sclerosis Society, US

Peer Baneke

CEO, Multiple Sclerosis International Federation

Matthew Miles

CEO, MS Research Australia

Michelle Mitchell

CEO, MS Society, UK

Mario Battaglia

CEO, Associazione Italiana Sclerosi Multipla, Italy

Yves Savoie

CEO, Multiple Sclerosis Society of Canada

SCIENTIFIC STEERING COMMITTEE

Alan Thompson (Chair)

University College London Faculty of Brain Sciences, UK

Giancarlo Comi (Vice-Chair)

Director of the Department of Neurology, Scientific Institute San Raffaele, Italy

Bruce Bebo

Executive Vice President, Research National Multiple Sclerosis Society, US

Sorrel Bickley

Head of Biomedical Research, MS Society, UK

Ceri Angood Napier

Director of Programmes, Multiple Sclerosis International Federation, UK

Bill Carroll

Neurologist, MS Research Australia Board Director, MS Society of Western Australia, First Vice President of World Federation of Neurologists

Dhia Chandraratna

Head of International Medical and Scientific Research, Multiple Sclerosis International Federation, UK

Tim Coetzee

Chief Advocacy, Services and Research Officer, National Multiple Sclerosis Society, US

Gabriele Dati

Biomedical Research and Grant Office Coordinator, Associazione Italiana Sclerosi Multipla, Italy

Alexis Donnelly

Living with primary progressive MS, Ireland

Anthony Feinstein

Professor of Psychiatry, University of Toronto Neuropsychiatrist, Sunnybrook Hospital, Canada

Robert Fox

Medical Director, Mellen Center for MS, Cleveland Clinic, US

Jeroen Geurts

Professor and Chair, Department of Anatomy and Neurosciences, VU University Medical Center, Netherlands

Reinhard Hohlfeld

Professor, Institute of Clinical Neuroimmunology, Ludwig-Maximilian-University Munich, Germany

Nick Rijke

Executive Director of Policy and Research, MS Society, UK

Per Soelberg Sørensen

Professor of Neurology, Danish Multiple Sclerosis Center, Denmark

Raj Kapoor

Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UK

Doug Landsman

Associate Vice President, Biomedical Research, National Multiple Sclerosis Society, US

Karen Lee

VP of Research, MS Society of Canada

Catherine Lubetzki

Professor of Neurology, Pierre and Marie Curie University and Head of the Neurology Department, Salpêtrière Hospital, Paris, France

Lisa Melton

Head of Research, MS Research Australia

Xavier Montalban

Chair of Neurology-Neuroimmunology, Hospital Universitari Vall d'Hebron, Spain

Marco Salvetti

Director, Center of Neurology and Experimental Therapies, La Sapienza University, Italy

Caroline Sincock

Living with secondary progressive MS, UK

Kathy Smith

Managing Director, Fast Forward LLC, US

Jonathan Strum

Caring for wife living with secondary progressive MS, US

Paola Zaratin

Director of Scientific Research Department, Associazione Italiana Sclerosi Multipla, Italy

“Progressive MS is slowing down my life. I hope Alliance research will soon run faster than my MS, to finally overtake and stop it.”

– Romilda, living with progressive MS in Italy

INDUSTRY FORUM

Giancarlo Comi
(Co-Chair)

Director, Department of Neurology,
Scientific Institute San Raffaele, Italy

Mike Panzara
(Industry Forum Co-Chair)

Group VP, Therapeutic Area Head
Multiple Sclerosis and Neurology,
Sanofi Genzyme

Kim Ramsey
(Industry Forum Project Manager)

Sr. Director, Corporate Pharmaceutical
Relations, National MS Society, US

Kathy Smith

Managing Director, Fast Forward LLC,
US

Paola Zaratin

Director of Scientific Research
Department, Associazione Italiana
Sclerosi Multipla, Italy

WORK TEAM LEADS

Shawna Golden

Senior Director, Operations,
International Progressive MS Alliance

Sherri Giger

(Communications Work Team Lead)
Executive Vice President, Marketing,
Corporate Counsel, National Multiple
Sclerosis Society, US

Graham McReynolds

(Fundraising Work Team Lead)
Chief Marketing and Development
Officer, National Multiple Sclerosis
Society, US

COLLABORATING MEMBERS OF THE INDUSTRY FORUM:

- Biogen
- EMD Serono
- Genentech, a Member of the Roche Group
- Sanofi Genzyme
- Novartis AG
- Teva



“Our purpose is clear —
to speed up the development
of treatments for people with
progressive MS.”

– Professor Giancarlo Comi
Director, Department of Neurology
Scientific Institute San Raffaele, Italy

PEOPLE WITH PROGRESSIVE MS CANNOT WAIT ANY LONGER.

The Alliance relies on the support of generous donors from around the world.

With the participation of each person, organization and partner, we become stronger and more powerful than progressive MS.

Join us and change the world for people with progressive MS.

TOGETHER WE WILL END THIS DISEASE.



JESSE
LIVING WITH PROGRESSIVE MS, AUSTRALIA



LAURENCE
LIVING WITH PROGRESSIVE MS SINCE 1981, UK

“Being a young person, I want to get married, progress my career, buy a house, but those wants seem unattainable to me and the future that I thought I had feels out of reach. That’s why the work of the Progressive MS Alliance is so important to me, because it could help me to have a future that isn’t dictated by severe and progressive disability.”

– Jesse

“I know much of the work of the International Progressive MS Alliance focuses on ending MS, but they’re also working on better understanding the condition. Hopefully, this will mean quicker development of new treatments for us who are faced with the complexities of living with progressive MS now, every single day.”

– Laurence

CONTACT US TODAY

www.ProgressiveMSAlliance.org | info@progressivemsalliance.org