INTERNATIONAL
PROGRESSIVE MS ALLIANCE

More than hope. Progress.

More than hope.
Progress.

PROGRESS REPORT

MARCH 2025

Najia living with MS since 2014, Morocco

MORE THAN HOPE. PROGRESS.

The International Progressive MS Alliance is an unprecedented global collaboration of MS organizations, researchers, clinicians, pharmaceutical companies, and people with progressive MS, working together to address the unmet needs of people affected by progressive MS. **Our promise is more than hope, it is progress.**

Today, 19 MS organizations financially contribute to the Alliance. The funding provided by MS organizations equips us to invest in the world's best and most promising research focused on ending progressive MS. These organizations, as well as all member organizations of the MS International Federation ensure that people affected by MS worldwide are informed and inspired by the work of the Alliance. We are also proud to have seven pharmaceutical and biotech companies participating as members of our Industry Forum, as well as 27 donor, trust and foundation members.

2024 ALLIANCE MEMBERS

MANAGING MEMBERS

MS AUSTRALIA

MS Canada

SCLEROSI MULTIPLA ONLUS associazione italiana
un mondo libero dalla SM

ms international federation

MS Society

MS National Multiple Sclerosis Society

MEMBERS

abem Associação Brasileira de Esclerose Múltipla

dmsg Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.

M Esclerosis Múltiple España

FRANCE SCLÉROSE EN PLAQUES S'unir pour guérir

NEUROLIITTO

SCLEROSE FORENINGEN

SPEM Sociedade Portuguesa de Esclerose Múltipla

MS FÉLAG ÍSLANDS

MS MS Ireland

ms-forbundet

Nationale Belgische Multiple Sclerose Liga vzw
Ligue Nationale Belge de la Sclérose en Plaques asbl

NEURO FÖRBUNDET

stichting MS research

TRUST AND FOUNDATION MEMBERS

HOPE FOR A CURE MS

The Al Otaiba Family

Anonymous Donor

The Avidan Family Charitable Trust

John and Kris Bradley

In memory of Georg Bruun
on behalf of the Bruun Family and CP ApS

The Alan Buegeleisen Fund

The Chesney Miles Charitable Fund

Crush MS

Foundation for a Better World

Gil Greenman Fund

Elizabeth Dawley Hanson

Margaret and Frank Hofland

Johnson Family

Dick and Robin Kelly Foundation

L P Brown Foundation, Special Fund

Kathleen C. Moore Foundation

Nadine M. Mosely Foundation

Cathy and Bill Onufrychuk

Rabbits Unlimited Wisconsin

Geoffrey H. Radbill and Jan Allison Kohn
in memory of Linda Anne Radbill

The Emanuel Rouvelas Family

The Rubschlager Family

M&H Schwartz Family Foundations

Dean Smith on behalf of FUMS

Jim Tidwell MS Memorial Research Fund

Yellow Rose Gala Foundation

INDUSTRY FORUM

Biogen

Bristol Myers Squibb

EMD Serono

Genentech Roche

GSK

Novartis AG

Sanofi

ASSOCIATE INDUSTRY FORUM MEMBERS

BrainStorm Cell Therapeutics

Immunic Therapeutics

ACCELERATING BREAKTHROUGH TREATMENTS

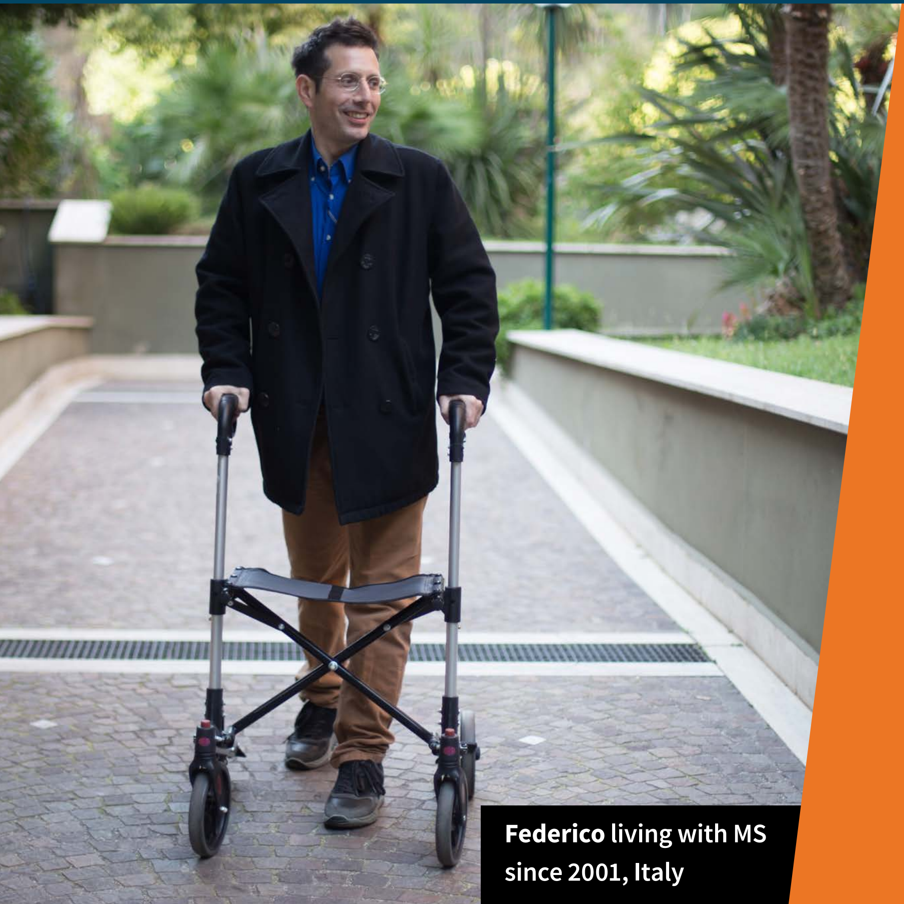
THE ALLIANCE'S VISION IS CLEAR AND BOLD: END MS PROGRESSION.

Over one million people around the world live with a progressive form of MS. They face uncertainty, losing ground each day as they experience worsening symptoms.

We must find solutions for everyone affected by MS. And we must ensure that people with progressive MS can live fulfilling lives—enhancing well-being through symptom management and rehabilitation.

To date, the Alliance has awarded more than €30 million to research networks and discovery projects, all with the aim to accelerate the development of new treatments, better and faster clinical trials and wellbeing strategies for people living with progressive MS. Hundreds of investigators from more than 20 countries are connected to more than 60 Alliance projects, and those numbers continue to grow.

The commitment and contributions of so many knowledgeable leaders, organizations and people living with MS underscores the importance of what the Alliance is striving to accomplish. Our momentum is gaining due to the engagement and generous support from organizations and people all around the world.



Federico living with MS since 2001, Italy

> “The work and the purpose of the Alliance is very ambitious, and as a member of the People Affected by MS Engagement Coordination team, I am very enthusiastic about the impact we are making. **The power of the Alliance is to dream big dreams and translate them into more precise, effective and tailored treatments** that improve quality of life for people living with progressive MS.”
>
> **– Federico Bozzoli, Italy**
> International Progressive MS Alliance
> People Affected by MS Engagement
> Coordination Team

To date, the Alliance has awarded more than €30 million to research networks and discovery projects.

Hundreds of investigators from more than 20 countries are connected to more than 60 Alliance projects…

…all with the aim to accelerate the development of new treatments, better and faster clinical trials and wellbeing strategies for people living with progressive MS.

“Since its inception in 2013, the International Progressive MS Alliance has made remarkable strides, offering hope through groundbreaking advancements. Yet, the journey is far from over. From pioneering drug-discovery initiatives to tackling the complex, day-to-day challenges of living with progressive MS, the Alliance is steadfast in its mission to stop disease progression and empower people to live fulfilling lives.

Driven by purpose and unwavering determination, we are acutely aware that over one million people with progressive MS face daily uncertainty and loss. This reality fuels our commitment to accelerate progress.

The road ahead is demanding, but together, we can make a difference. Join us in this global effort to meet the urgent, unmet needs of those living with progressive MS.”

Tim Coetzee

Tim Coetzee, PhD
Alliance Executive Committee Chair
National MS Society
President and CEO, U.S.

“We take immense pride in uniting the world to address the challenges of progressive MS. In our pursuit of solutions, we explore every promising path, embracing innovation and taking calculated risks — knowing that even setbacks could yield valuable insights.

Our mission drives us to identify and fund groundbreaking research wherever it may emerge, prioritizing transformative, life-changing breakthroughs. With discipline, agility, and focus, we approach every endeavor with rigor, inspiring and catalyzing others to join us in this vital work.

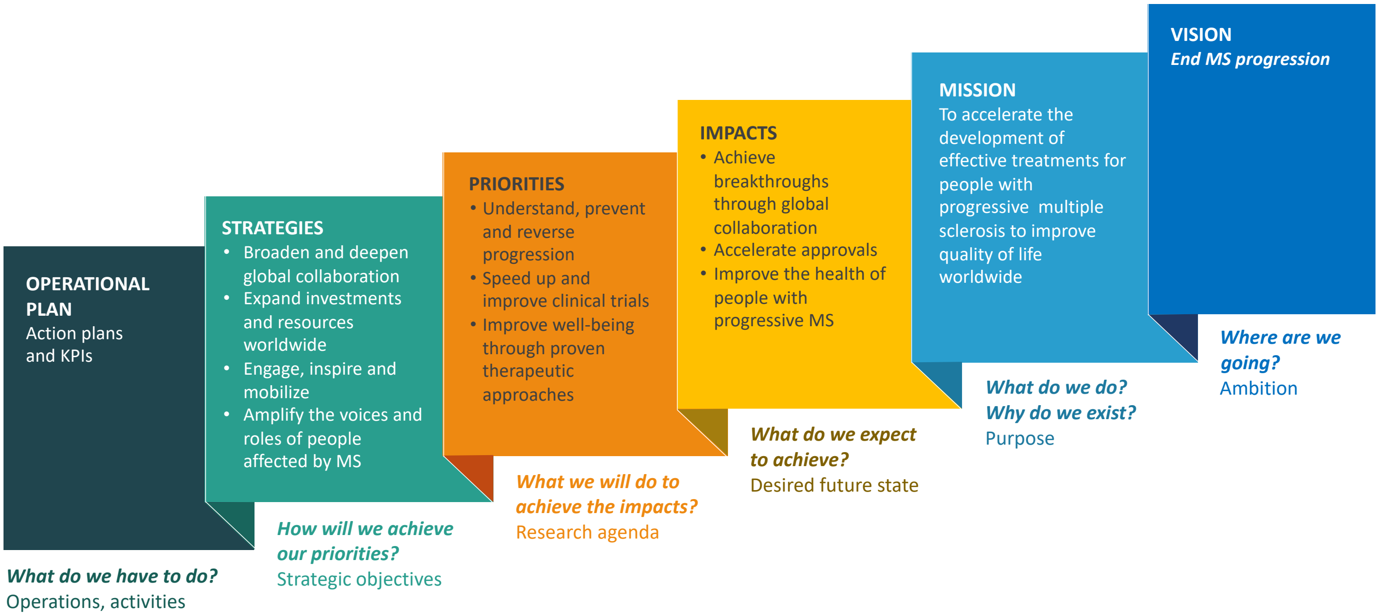
As we reflect on the accomplishments of the past year and set our sights on the future, our resolve remains constant. Together, we must stay passionately committed to finding solutions that will redefine the journey for those living with progressive MS.”

Robert J Fox

Robert Fox, MD
Alliance Scientific Steering Committee Chair
Mellen Center for MS
Vice Chair for Research, Neurological Institute
Cleveland Clinic, U.S.

ALLIANCE STRATEGIC PLAN:

The Alliance ensures focus and discipline in accelerating the development of effective treatments for people with progressive MS through our Strategic Plan.



OPERATIONAL PLAN
Action plans and KPIs

What do we have to do?
Operations, activities

STRATEGIES
- Broaden and deepen global collaboration
- Expand investments and resources worldwide
- Engage, inspire and mobilize
- Amplify the voices and roles of people affected by MS

How will we achieve our priorities?
Strategic objectives

PRIORITIES
- Understand, prevent and reverse progression
- Speed up and improve clinical trials
- Improve well-being through proven therapeutic approaches

What we will do to achieve the impacts?
Research agenda

IMPACTS
- Achieve breakthroughs through global collaboration
- Accelerate approvals
- Improve the health of people with progressive MS

What do we expect to achieve?
Desired future state

MISSION
To accelerate the development of effective treatments for people with progressive multiple sclerosis to improve quality of life worldwide

What do we do? Why do we exist?
Purpose

VISION
End MS progression

Where are we going?
Ambition

WE FOCUS ON THREE SCIENTIFIC PRIORITIES:

1. Understand, prevent and reverse progression
2. Speed up and improve clinical trials
3. Improve well-being through proven therapeutic approaches

WE ACHIEVE THESE PRIORITIES BY:

✓ Broadening and deepening global collaboration

✓ Expending investments and resources worldwide

✓ Engaging, inspiring and mobilizing

✓ Amplifying the voices and roles of people affected by MS

Gary living with MS since 2000, Australia

INTERNATIONAL PROGRESSIVE MS ALLIANCE: 2024 YEAR IN REVIEW

During 2024, the Alliance invested €6 million in 15 new research projects, including **six Challenges in Progressive MS awards, and nine Innovations in Wellbeing Awards**.

CHALLENGES IN PROGRESSIVE MS AWARDS

Understanding and generating new knowledge about the biological mechanisms of what leads to progressive MS is key to developing new treatments that will ultimately slow or stop disability progression. The innovative research being funded has the potential to fundamentally advance the understanding of the mechanisms underlying progressive MS, with a priority on those projects that have the potential to result in a paradigm shift in progressive MS.

EXAMPLES OF THESE RESEARCH INITIATIVES INCLUDE:

- A clinical trial study using the drug istradefylline to reduce inflammation in progressive MS
- Advancing the understanding of the biological pathways that contribute to progression of MS in order to help predict disease progression at diagnosis
- Understanding why nerve and other cells in the brain and spinal cord die prematurely in progressive MS, and identifying protective treatments that can be tested in clinical trials

Kirsten, living with MS since 2001, Denmark

INNOVATIONS IN WELLBEING AWARDS

For many of the most common symptoms of progressive MS, such as fatigue, mobility, pain and cognitive impairment, there are insufficient treatment approaches that can improve quality of life.

In 2023, the Alliance launched a research pipeline to identify, test and implement solutions to some of the most challenging symptoms that people with progressive MS experience. Nine projects were funded in early 2024 at €100,000 each. Projects are underway and we expect updates from researchers in spring 2025. Successful projects will be considered for more significant funding to test the efficacy of the interventions and ultimately implement solutions into healthcare systems.

EXAMPLES OF WELLBEING RESEARCH PROJECTS INCLUDE:

1. Creating a new way to more specifically and accurately monitor the progression of disability and changes in function in people with MS with the use of socks with sensors in the fabric.
2. Customizing and testing an existing intervention known as “circadian synchronization therapy with light” (CST-L) to treat fatigue in people with progressive MS.
3. Developing a tablet-based tool that will reliably and efficiently screen for several key factors that can contribute to cognitive difficulties in people with MS.
4. Adapting evidence-based psychological interventions for pain in progressive MS.

More than hope.
Progress.

COLLABORATIVE RESEARCH NETWORKS

The first-of-their-kind International Collaborative Research Networks remain central to the Alliance's research portfolio. These three networks represent ambitious, innovative international teams of experts driving transformative research. With an initial investment of €12 million in 2016, these networks have all concluded the first phase of their projects and are now working with the Alliance on the best means to advance their groundbreaking work.

The network led by Professor **Francisco Quintana** from Harvard University in the United States focuses on the innate immune system. While the innate immune system normally functions to protect the body from infections, Dr. Quintana and others have found that aberrant signaling between innate immune cells in the nervous system promotes disease activity in MS. The network is focusing on finding a safe and optimal compound to protect the brain against damage from MS.

This drug discovery network, led by Professor **Gianvito Martino**, at San Raffaele Hospital in Milan, Italy, involves a network of 13 investigators from Europe, Canada and the U.S. The collective knowledge and capabilities of this group do not exist anywhere else in academia or industry. Professor Martino's team developed an innovative drug discovery platform that leverages the best scientific knowledge and uses cutting-edge technology to identify molecules that may protect nerve cells and/or promote myelin repair.

Led by Professor **Doug Arnold** at McGill University in Montréal, Canada, this network is developing computer algorithms that will predict future MS progression and, ultimately, individual treatment responses to therapies. The research is predicated on the idea that MS progression can be detected with deep learning models prior to identification by physicians in a clinic visit. Using cutting-edge advances in artificial intelligence and machine learning, the tools could be used to predict if potential treatments will slow or reverse damage in the brain — thus addressing a major barrier in current treatment development.

AMPLIFYING THE VOICES AND ROLES OF PEOPLE WITH PROGRESSIVE MS

PEOPLE AFFECTED BY MS ENGAGEMENT COORDINATION TEAM

People affected by MS are actively involved and provide leadership in every aspect of the Alliance. The People Affected by MS Engagement Coordination Team includes seven individuals from six different countries who provide their expertise and lived experience to inform and prioritize Alliance work. Their collective efforts help ensure the Alliance maintains focus on where the greatest impact can be achieved in improving the health of people with progressive MS worldwide.

In 2024, the team finalized and, in partnership with all Alliance members, implemented the **Principles of Patient Engagement in MS Research**. These principles define the beliefs regarding patient engagement in research that ensure the best possible outcomes and are hoped to be a model for others conducting MS research throughout the world.

Front Row: Federico, Italy; Najia, Morocco; Bernhard, Denmark; Cory, Canada
Back Row: Vanessa, Australia; Mike, United States; Marie, Canada; Martyn, United Kingdom

ADDITIONAL HIGHLIGHTS OF THE ENGAGEMENT COORDINATION TEAM'S 2024 INITIATIVES INCLUDE

- Reviewed applications and made recommendations on research funding for investment in the Experimental Medicine Trial Awards
- Working in partnership with MULTI-ACT, an initiative of the European Union led by the Italian MS Society to increase impact in brain research, members of the ECT co-wrote and submitted a paper for publication in a scientific journal regarding the value that people with MS can bring to research, including serving as co-authors of scientific papers.

  This work is in response to a recent finding that many scientific journals would not consider publishing papers where a patient/person with lived disease experience served as a co-author and is based on the results of a global survey of people affected by MS. It is an example of the barriers that exist to engaging people with MS in the research process.
- Began the process of implementing communications activities and assets that highlight care partners for people living with progressive MS. This is an often-overlooked aspect of the overall experience for people living with progressive MS, and the team wishes to capture video, sound bites and other content that brings to life the care partner experience.

LOOKING AHEAD

The Alliance is increasing its momentum in developing life-changing treatments to improve the lives of people with MS worldwide. By 2030, we will have committed €60 million toward multiple research initiatives focused on achieving our three strategic priorities.

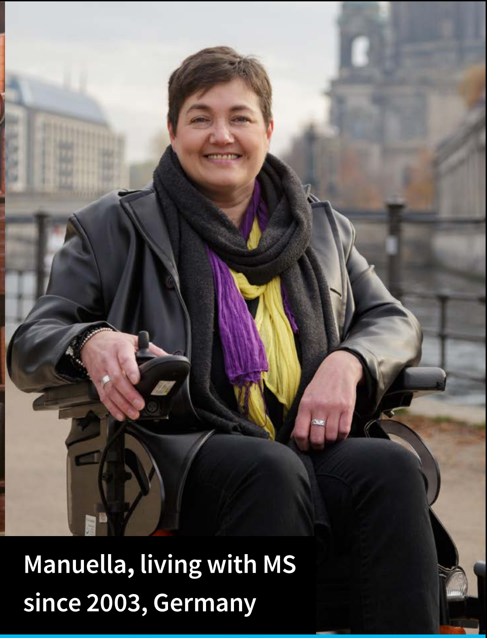
WE MUST AND WILL CONTINUE TO ACT WITH URGENCY AND DETERMINATION.

People with progressive MS lose ground each day to this unpredictable disease and need solutions now to improve their quality of life. Ending MS progression is a bold and ambitious endeavor. Solving a challenge of this magnitude requires the energy and investment of the entire MS movement. Your support and initiative have equipped the Society to lead the Alliance as the largest contributor – through insight, funding and strategy.

Together, we create an unstoppable force in finding solutions for people affected by progressive MS. **Together, we are stronger than progressive MS.**


Cinzia, living with MS since 2011, Italy


Bruce, living with MS since 2008, England


Manuella, living with MS since 2003, Germany


Brian, living with MS since 2005, Canada

Together, we are stronger than progressive MS

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

More than hope. Progress.

ProgressiveMSAlliance.org


Karen, living with MS since 2012, U.S.


Kirsten, living with MS since 2001, Denmark


Mirta, living with MS since 1997, Argentina