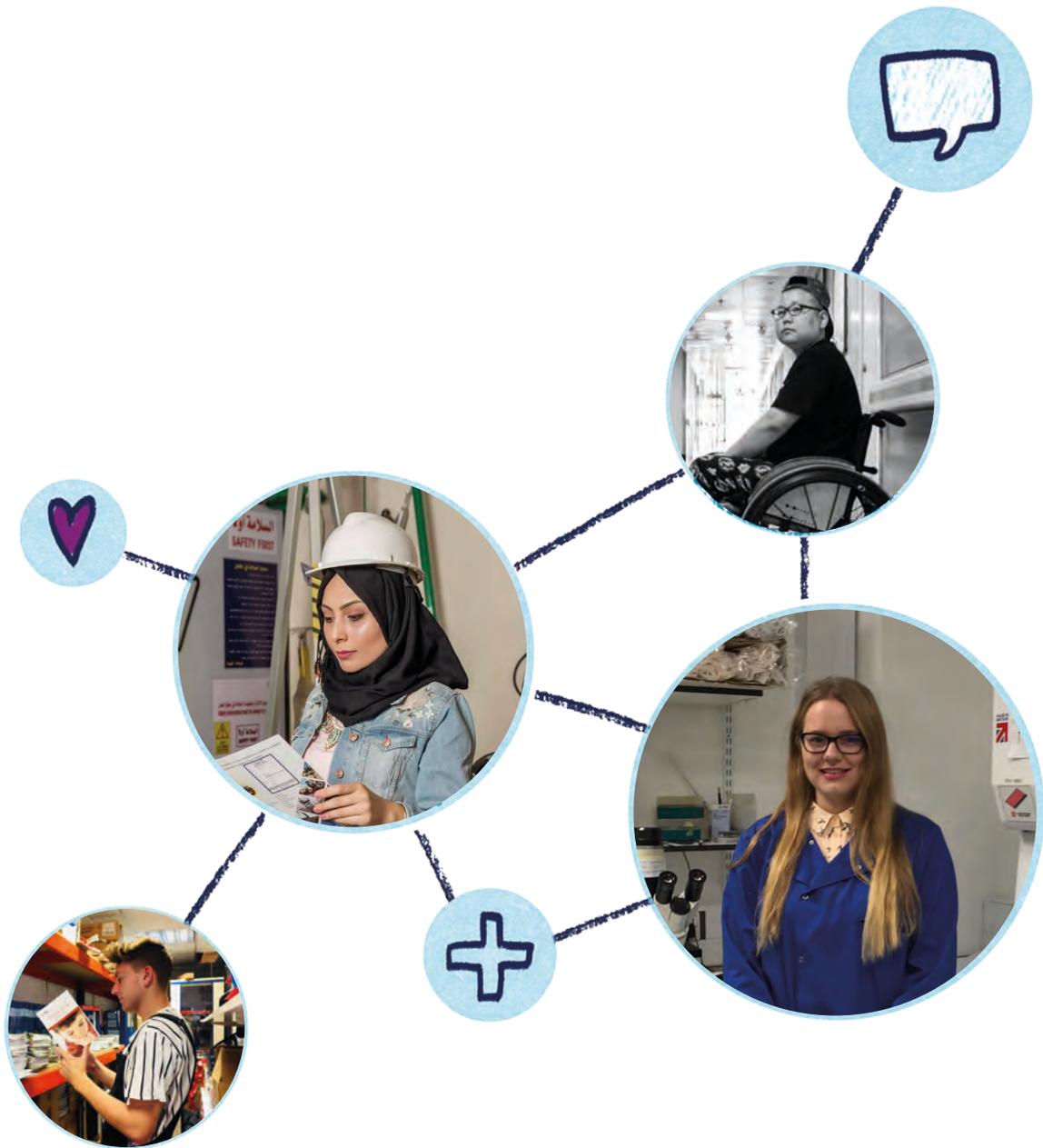


# Together we're stronger than MS

## Driving global change



# The global MSIF movement

The MS International Federation (MSIF) is the world's only global movement of people affected by MS and their national organisations. This movement of people and organisations shares ideas and experience across borders, develops international campaigns, improves care for people affected by MS where there is little or no support, and is a catalyst for ground-breaking research collaborations.

Together we're stronger than MS is the global movement's strategy, launched in 2017. The strategy's focus is to mobilise all of us – from MS organisations, people affected by MS, volunteers and staff – to reach our common mission: to bring the world together to improve the quality of life of everybody affected by MS. It is built on the belief that we can achieve this faster and better than if we each work on our own. This brochure sets out some of the highlights of progress made by the movement so far.

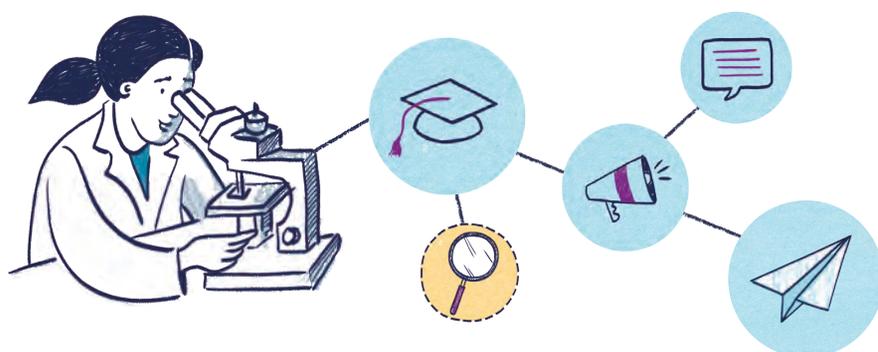
When MSIF was founded over 50 years ago in 1967, there were only a handful of MS organisations in the world. Now, the movement reaches more than 100 countries, with 48 members and links to many other MS organisations in all corners of the globe.

People affected by MS are at the heart of everything we do. As a movement, we are driven by the urgent needs of those affected by the disease to ensure that no one with MS is left behind, wherever they live in the world.

Our Atlas of MS shows that around 2.3 million people worldwide are living with MS. Many of these people have little access to support or treatment. For people with MS and their families, access to care and trustworthy information is vital. Just as important is the knowledge that scientists around the world are working every day to develop better MS treatments, and we are working to remove the barriers that prevent people getting them. We help to make this happen, both directly and through our member organisations.

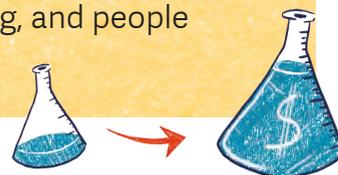
In recent years our international collaborations have grown in ambition. Through global initiatives such as the International Progressive MS Alliance, World MS Day, Kiss Goodbye to MS and Cykelnerven, the movement has committed to do whatever is needed to improve quality of life with MS.

As the global MSIF movement, together we tackle the big challenges for people affected by MS, in countries rich and poor. For people living with MS today we will improve quality of life, and ultimately we will end MS forever.



# Greater scientific understanding & more treatments

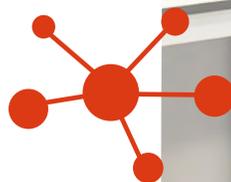
The MSIF movement believes that the widest pool of people, all committed to shared goals, will help break through the barriers that are holding us back, and speed up the day when we live in a world without MS. Our international research staff network is instrumental in analysing the gaps and barriers that need addressing, and people affected by MS have an important voice in our work.



By **funding talented young researchers** from developing countries we are growing the next generation of MS researchers. Since 2017 we have partnered with ARSEP in France, and Stichting MS Research and MoveS from the Netherlands, to increase the number of researchers who could make the breakthroughs we need. Our combined funding in 2018 will see up to seven young researchers receive potentially life-changing opportunities to work and develop their skills at world class centres of MS research.

As a founding member of the **International Progressive MS Alliance** we are not just giving hope to people affected by progressive MS, but making real scientific progress. Since 2017 we have helped grow the Alliance to fund three ground-breaking scientific collaborations across nine countries and 19 world-leading institutions, such as Harvard, VU (Netherlands) and University College London. These projects focus on removing research barriers and speeding up the development of new treatments. In 2018 we were delighted to announce a new strategy to address the remaining unsolved barriers in progressive MS, including a programme to improve rehabilitation, helping people live better lives despite MS.

There is now a strong consensus that how we measure the effectiveness of treatments must reflect the real life experience of the people using them. This is called **patient reported outcomes**. Enabling people to report how treatments change their quality of life can support better research and smarter treatments, as well as improving clinical management and self-management. Led by the Italian MS Society, and in partnership with our members in Germany, Australia, the UK, the USA, and a range of international research experts, we are building a programme that is setting global standards in this field. In 2018 we will begin developing the world's first harmonised MS patient reported outcome measures that will help improve clinical trials and enable better treatment decisions.



# Access to effective treatments & healthcare

New treatments will not make any difference to people with MS if they don't have access to them. Yet in every part of the world there are barriers to effective MS treatment, particularly in low to middle income countries.

The challenge is complex and tackling it needs an international response with different strategies for global or regional problems. As the only global MS body with international networks and special status with the World Health Organization (WHO), MSIF is perfectly placed to take on this challenge.



MSIF is pursuing two projects. One is addressing regulation of 'biosimilars', starting in Latin America; and a global project starting with the WHO Essential Medicines List.

Around the world there are companies producing 'generic' and **'biosimilar' versions of existing treatments**. In simple terms, a generic is a copy of a treatment that has the same chemical substance as the original drug. A biosimilar is a copy of a 'biological' treatment; for example an antibody which your immune system uses to fight disease.

Many national and regional medicine regulators have strict rules for producing biosimilars because of the complexity of making them safe and effective. Unfortunately, this is not the case everywhere. MSIF is commissioning independent research into the regulations in Latin America and to explore how we can influence access to safe and effective biosimilars in the region.

Before we can address other global barriers we need to ensure that governments in low and middle income countries prioritise MS and MS treatments. One powerful way to do this is by driving MS treatment into the global discussion. The **WHO Essential Medicines List** is an important start to setting a global priority for treatments and diseases that governments should prioritise.

The Essential Medicines List contains the medications that the WHO considers to be the most critical in treating the disease and that meet the most urgent needs, taking into account safety and effectiveness. The list is frequently used by countries to help develop their own national lists. In 2018 MSIF has assembled many of the world's leading MS neurologists and other experienced groups, making significant efforts towards getting the first ever MS treatments onto the Essential Medicines List.



# Confident & informed decision making

When people affected by MS understand their condition, their options and the impact of their decisions, their choices and quality of life can improve dramatically.

MS affects almost every part of life for people who are diagnosed with the disease, and for the people who care for them. MSIF can't change that but we can try to provide **free, reliable and easily accessible information and resources so people affected by MS can take ownership of their health and lives**. MSIF will only publish scientifically rigorous information, independent of any exterior editorial control or influence. Our only considerations are, 'what do people want to know' and 'what is right', so you know that anything you get from MSIF is factual, fair and balanced.



We know that a great wealth of information materials already exists across the MSIF movement. To use this and to avoid duplication of effort, we take the best materials produced by national MS organisations, **repurposing and translating** them so they can be used by people affected by MS in different countries around the world. In 2018 the first resource we have adapted is an animation – originally produced by the Italian MS Society – that explores some of the intimate and sexual problems that people with MS can experience. Each year we will recycle different information materials that address a pressing gap and need in the MS community.

To improve the quality and availability of information for people affected by MS around the world, we know that we have to work **together** and share best practice across the movement. This is why we are building a **network of communications staff and volunteers**. Through digital forums and online meetings, the network has started to share resources, ideas and expertise in communications.



The MSIF website ([www.msif.org](http://www.msif.org)) – which has an average of 21,000 users every month – is a dynamic hub of information for people with MS, their families and caregivers, and MS organisations. Alongside this, our regular newsletters and social media channels are a great way to find out what is happening around the world in the MSIF movement.



# Positive changes to attitudes, policies & practices

To speak up for yourself, or on behalf of others, you need passion and to be armed with the best information. It also helps to be part of a global movement, so that your voice echoes around the world. MSIF is developing the knowledge base with products like the **Atlas of MS** and **Seven Principles of Quality of Life**, and building the global community through **World MS Day**.

The **Seven Principles of Quality of Life** were published in 2017 and are already being used to help guide the strategies of patient organisations, companies and other organisations. People affected by MS have also found it very helpful in prioritising the areas of their life they need to improve. It is at the heart of our strategy, and feeds into every MSIF programme and decision.

One of the barriers to better research, improved access to treatment and better understanding of life with MS is the availability of data on the disease. To really understand MS, information on the quality of life for people with MS in different countries and regions is also essential. Some national MS databases exist, and pharmaceutical companies collect data to make commercial decisions, but this is not easily accessible. MSIF is the only organisation that collects national level data on MS globally and produces a free database that can be used by researchers, governments and individuals. Whether it is to conduct research, plan services or advocate for better care in your country, the **Atlas of MS 2020** will be an essential tool.

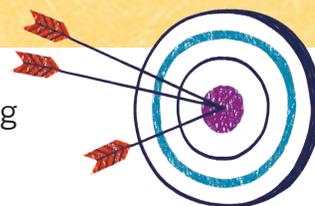
**World MS Day** is the flag-bearer for the global MS movement. Since MSIF established the first World MS Day in 2009, it has united individuals, groups and organisations in a global day of action, campaigning for change and raising awareness of the condition. In 2018, the theme focused on research. We used #bringingucloser on social media to help people affected by MS and people involved in research engage and better understand each other. This year World MS Day reached further and wider than ever, with more than 900 online and in-person activities, spanning over 100 countries.



# A stronger, broader MSIF movement

Strong patient organisations play a vital role in the lives of people with MS. They provide services, campaign for change and raise awareness of the disease; not to mention offering a community so that people don't feel like they are going through this alone.

MSIF works with MS organisations, big and small, to make them stronger and more sustainable. In the **Middle East**, **Latin America** and **Asia** we are also investing in emerging MS organisations so that, no matter where they live, people with MS can get the care and support they need.



Through our regional programme in the **Middle East**, we are working with 22 organisations in 15 countries. In 2018 we are collaborating with these organisations on an exciting project to develop the first region-wide MS awareness-raising campaign.

We also give tailored support to individual organisations that have the potential to make bigger changes. In our last round of country-focussed support the MS societies of Egypt and Lebanon saw huge developments in leadership, membership and impact. In 2017 we launched our work with MS organisations in Morocco and Saudi Arabia.

MS organisations in **Latin America** are seen as a second family for many people affected by MS, and share many of the same challenges of those in the Middle East. MSIF started working in this region in 2017. We support the planning and implementation of the region's annual meetings. This is playing an important role in building a stronger voice for patient organisations, sharing expertise and coordinating a regional collaboration. We currently work with patient organisations in more than 32 countries from the region.

At a country-level, in 2018 MSIF is launching tailored programmes with patient organisations in Brazil and Uruguay.

In **Asia**, we recently developed a training and mentoring programme with the MS Society of India, to enhance its influence and effectiveness at a national level.

Globally, we strive to build a sense of shared identity, ambition and direction to the movement. One of the ways we do this is by running events like **Cykelnerven** and campaigns like **Kiss Goodbye to MS**, which is the world's biggest international community of people fundraising for MS.



