

News Release

Your Contact  
Erin-Marie Beals

+1 781-681-2850

October 11, 2018

## **Global Survey and Documentary Film Expose Emotional Impact of Multiple Sclerosis**

- **Merck KGaA, Darmstadt, Germany-sponsored survey developed in collaboration with IACO and Eurocarers reveals lifelong effects of caring for a loved one with MS**
- **#MSInsideOut documentary film, executively produced by Shift.ms, provides artistic take on the experiences of those impacted by MS**

Darmstadt, Germany, October 11, 2018 – Merck KGaA, Darmstadt, Germany today announced the publication of results from a global Company-sponsored multiple sclerosis (MS) carer survey, as well as the première of the #MSInsideOut documentary, *Seeing MS from the Inside Out*, executive produced by Shift.ms, a social network for people with multiple sclerosis, at the 34<sup>th</sup> Congress of the European Committee for Treatment and Research In Multiple Sclerosis (ECTRIMS), in Berlin, Germany.

The '*Living with Multiple Sclerosis: The Carer's Perspective*' report was developed in collaboration with The International Alliance of Carer Organizations (IACO) and Eurocarers to examine the experiences of 1,050 multiple sclerosis (MS) carers across seven countries (US, Canada, UK, France, Germany, Italy and Spain). The survey found that almost half (48%) of those surveyed became MS carers when they were below the age of 35, and nearly one in three had been caring for somebody for 11 years or more.

Additional key findings from the carer survey included:

- 43% and 28% of carers surveyed reported an impact on their emotional/mental health and physical health respectively



## News Release

- 34% said being an MS carer impacted their financial situation, more than a third (36%) stated they had to take time off work, and as a result, 84% of those carers reported their work and career being impacted
- Only 15% of carers surveyed connected with other carers or patient organizations to help cope with the challenges of their role

"MS can be a devastating disease for both patients and carers, with the responsibilities assumed by carers over an extended length of time and intensifying as the disease progresses. Carers can experience a profound impact on their physical and emotional health, finances, and employment," said Nadine Henningsen, Board Chair, IACO. "Not surprisingly, the survey results reinforced the large number of young people who are becoming carers – often in a formative time of their life."

As part of the *#MSInsideOut* campaign, an initiative aimed at providing a deeper understanding of MS, the MS Inside Out documentary film, *'Seeing MS from the Inside Out'*, will be premièred. Developed with Shift.ms as executive producers, it is the first global documentary film to pair artists and people from across the MS community, with a view to interpreting the experiences and perspectives of those impacted by MS through art.

"In line with our broader mission at Shift.ms, the aim of this documentary is to highlight the individual stories in a unique and innovative way across the MS community, digging deeper into the elements of MS that remain under-represented with a view of interpreting the unmet needs of those impacted by MS through art," said George Pepper, Co-founder and CEO, Shift.ms. "By bringing these stories out into the open we will be able to address those challenges that remain, opening lines of communication and ultimately raising awareness of MS."

The documentary follows three stories: Maria Florencia, a person living with MS from Argentina, Jon Strum, a caregiver from the US, and Dr. Luigi Lavorgna, a healthcare professional from Italy. Each were paired with a local visual artist to bring their stories to life through an emotional interpretation not bound by words but through art, reflecting the often difficult-to-explain nature of MS.

## News Release

The premiere will take place at 12:00 – 1:30 pm EST today on October 11, duringECTRIMS 2018 and can be accessed through a livestream link here: <http://www.touch-stream.com/MSinsideout>.

“We are extremely proud to highlight the unmet needs in the community through our work with Shift.ms, IACO and Eurocarers which expose the experiences of different members of the MS community, including the perspective of MS carers, whose voices have traditionally not been heard as strongly,” said Andrew Paterson, Senior Vice President, Global Head of Neurology and Immunology, at the biopharma business of Merck KGaA, Darmstadt, Germany. “Forming part of our ongoing company-wide commitment to carers, and connecting with the broader Embracing Carers initiative, the outcomes from both the survey and documentary film highlight the need for additional support and awareness. We therefore encourage and call upon the MS community to take these findings and identify ways in which they can better assist both MS carers and patients.”

### **About Multiple Sclerosis**

Multiple sclerosis (MS) is a chronic, inflammatory condition of the central nervous system and is the most common, non-traumatic, disabling neurological disease in young adults. It is estimated that approximately 2.3 million people have MS worldwide. While symptoms can vary, the most common symptoms of MS include blurred vision, numbness or tingling in the limbs and problems with strength and coordination. The relapsing forms of MS are the most common.

### **Merck KGaA, Darmstadt, Germany and Multiple Sclerosis**

For more than 20 years, Merck KGaA, Darmstadt, Germany has been relentlessly focused on understanding the journey people living with MS face in order to create a meaningful, positive experience for them and the broader MS community. However, there is still much that is unknown about this complex and unpredictable disease. Merck KGaA, Darmstadt, Germany is digging deeper to advance the science and reconstruct a new understanding of MS, inside and out. We are committed to delivering solutions that improve the lives of all those affected by MS.

### **About Merck KGaA, Darmstadt, Germany**

Merck KGaA, Darmstadt, Germany, is a leading science and technology company in healthcare, life science and performance materials. More than 53,000 employees work to further develop technologies that improve and enhance life – from biopharmaceutical therapies to treat cancer or multiple sclerosis, cutting-edge systems for scientific research and production, to liquid crystals for smartphones and LCD televisions. In 2017, Merck KGaA, Darmstadt, Germany, generated sales of € 15.3 billion in 66 countries.

Founded in 1668, Merck KGaA, Darmstadt, Germany, is the world's oldest pharmaceutical and chemical company. The founding family remains the majority owner of the publicly listed corporate group. Merck KGaA, Darmstadt, Germany, holds the global rights to the „Merck“ name and brand. The only exceptions are the United States and Canada, where the company operates as EMD Serono, MilliporeSigma and EMD Performance Materials.

### **About Embracing Carers**

Embracing Carers is a global initiative led by Merck KgaA, Darmstadt, Germany in collaboration with leading caregiver organizations around the world designed to increase awareness, discussion, and action about the often-overlooked needs of caregivers. Given that caregivers need support and often do not know where to turn for help, Embracing Carers was created to help fill that void.

### **About IACO**

## News Release

The International Alliance of Carer Organizations (IACO) is a global coalition of 15 member nations committed to building a global understanding and respect for the vital role of family carers. Recognized as an official NGO by the United Nations, IACO works to improve the quality of life and support the needs of carers, through international partnerships and advocacy that strengthens and honors the voice of carers. To learn more, visit [www.internationalcarers.org](http://www.internationalcarers.org).

### **About Eurocarers**

Eurocarers is the European umbrella organisation representing informal carers and their organizations, irrespective of the particular age or health need of the person they are caring for. Eurocarers works to raise awareness of the significant contribution made by carers to care systems while ensuring that all relevant policies across Europe take account of their needs and preferences. To learn more, visit [www.eurocarers.org](http://www.eurocarers.org).

### **About Shift.ms**

Shift.ms - [www.Shift.ms](http://www.Shift.ms) - is the social network for people with multiple sclerosis. Founded by MSers, for MSers, the charity supports many thousands of recently diagnosed people across the world as they make sense of MS. It's independent and it's free.

### **About #MSInsideOut**

*#MSInsideOut* is a campaign supported by Merck KGaA, Darmstadt, Germany which focuses on understanding the journeys people living with MS face and telling the inside story of the disease. For more than 20 years, Merck KGaA, Darmstadt, Germany has been relentlessly focused on understanding the journey people living with MS face to create a meaningful, positive experience for them and the broader MS Community. With the *#MSInsideOut* campaign Merck KGaA, Darmstadt, Germany aims to better understand MS and, importantly, enable others to do the same.