

Survey discloses emotional impact of Multiple Sclerosis

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Merck-sponsored survey developed in collaboration with IACO and Eurocarers reveals lifelong effects of caring for a loved one with MS



Merck, a leading science and technology company, has announced the publication of results from a global Merck-sponsored multiple sclerosis (MS) carer survey, as well as the premiere of the #MSInsideOut documentary film, *Seeing MS from the Inside Out*, executive produced by Shift.ms, a social network for people with multiple sclerosis, at the 34th 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
- 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 organisations to help cope with the challenges of their role

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 premiered.

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 was 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.

"At Merck, 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.

"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."