

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

More than hope. Progress.

UPDATE

October 2023

Welcome

News and highlights keeping you informed as we work together to accelerate life-changing treatments for people with progressive MS worldwide

Mark Your Calendars for Our Next Global Webcast



**COGNITIVE CHALLENGES
IN PROGRESSIVE MS**

Advances in Treatment and Research

**GLOBAL WEBCAST
THURSDAY, 9 NOVEMBER**

INTERNATIONAL
PROGRESSIVE MS ALLIANCE
More than hope. Progress.

Sponsor:
Sanofi

Register Now: www.msif.org/progressiveMSwebcast/

Thursday, 9 November 2023 at 11:00 am EST, 4:00 pm GMT, 5:00 pm CET

Cognitive impairment is common in MS, and people with the disease frequently report difficulties such as following along in complex conversations, recalling information and forgetfulness. These cognitive challenges can impact the successful completion of everyday tasks. Fortunately, there are proven strategies that can help manage these challenges and research is providing insights into new solutions for people with progressive MS.

Learn about the latest advances in treatment and research in cognition and MS during this 30-minute global webcast. From simple ways to manage or reduce cognitive challenges to research seeking the cause and developing new treatments, this webcast will provide information to help individuals improve quality of life and keep you informed. The webcast will be streamed by the MS International Federation and from multiple MS organization Facebook pages.

Panelists include:

- **Nancy D. Chiaravalloti, PhD**, Director of Neuropsychology, Neuroscience and Traumatic Brain Injury Research at Kessler Foundation and Research Professor of Physical Medicine and Rehabilitation at Rutgers University, New Jersey Medical School
- **Dawn Langdon, PhD**, Professor of Neuropsychology at Royal Holloway University of London
- **Kathy Zackowski, PhD**, Associate Vice President for Research at the National MS Society
- **Angela White**, Volunteer Leader and MS Ambassador at the National MS Society, diagnosed with MS in 2002

Amplifying the Voices and Roles of People Affected by MS

Meet Najia Chafai, Member of the People Affected by MS Engagement Coordination Team



Resides: Tetouan, Morocco

MS diagnosis: Najia was diagnosed with MS in 2014 after she noticed she was losing her balance. She also had severe fatigue, some numbness in legs, and she found herself less able to concentrate on work as an event planner. Her husband, a doctor, chalked it up to stress. It was summer at that point, and it was very hot. “One day I was at the beach, and I spent an hour in the sun, and after that, I couldn’t get up from my place,” Najia says. “I couldn’t move,” adding, “when it’s hot it’s not easy for people with MS to move.” A doctor in a clinic advised her to see a neurologist. In the clinical exam, they said “maybe it’s MS,” so they sent her for an MRI. The initial diagnosis was relapsing-remitting MS. But after multiple

relapses, occurring every two to three months, that diagnosis changed to secondary progressive MS.

How it’s impacted her life: “When I heard MS, my first thought was that I was really afraid because I knew this disease,” says Najia, who had a friend in France who passed away shortly after being diagnosed. “I said, ‘my life is over,’” And yet, eight years later, she is still very much alive. She doesn’t work—she had actually stopped working after the birth of her daughter—but she lives in the same place and is still married to the same man, whom she describes as “very kind,” and, because he knows about the disease, takes good care of her. Her daughter also checks in on her and helps out, and she has someone who comes and cooks. Najia, who loves languages and speaks Spanish, Arabic, French and English, now uses a wheelchair and can’t move her left hand. She’s wistful about her losses: “I was a dynamic, active woman. I had everybody over at my home,” she says. But at the same time, she adds, “I have my phone and my computer and my friends.”

What the Alliance means to her: “It means a lot to me, believe me,” says Najia, who joined the local MS Society in Morocco and is now its president. She subsequently joined the MS International Federation, and once she heard that the Alliance was engaging people with MS in its research, she joined the Alliance in 2019. “The first time I heard about the Alliance—the first organization whose mission is to accelerate the development of treatments for people with progressive MS, I knew I needed to help, I needed to join this mission,” says Najia, adding, “I’m very dynamic and have too much adrenaline!”

How she’s contributing to the Alliance: Since joining the Alliance, Najia’s contribution has been in numerous areas including providing testimony as a person with progressive MS, and giving her perspective on proposed MS studies the Alliance is considering and their potential impact on improving the quality of life for people with progressive MS.