

Amyotrophic Lateral Sclerosis (ALS) Consensus Study Lived Experience Consultants

The National Academies' Committee on Amyotrophic Lateral Sclerosis: Accelerating Treatments and Improving Quality of Life would like to acknowledge the following volunteer consultants who have been appointed to meet with the committee and provide feedback on portions of the draft consensus study report:

Michael Cosgray is a presymptomatic genetic carrier of the C9orf72 mutation that can cause ALS. Michael lost multiple family members to ALS and saw the impact of the disease on his mother, who was a fast progressor and died on April 11, 2004. Michael made the decision early in life not to have children to avoid the risk of passing down this devastating mutation to future generations.

Desiree (Desi) Galvez Kessler was diagnosed with ALS at age 28 shortly after giving birth to her daughter. Desi is a volunteer member of a support organization, Her ALS Story. The group seeks to raise awareness of the impact ALS has on young women diagnosed before age 35 and provide a community for them to connect, learn from each other, and find support so they can live their best lives.

Bernadine A. Okeke was diagnosed with ALS in 2019 at age 63. She is a volunteer member of the Many Shades of ALS Community Team at I AM ALS, a nonprofit advocacy organization. The Community Team brings attention to and provides resources for the mental, physical, and social health of people of color living with and impacted by ALS.

Ann Oliff is a caregiver for her spouse, Layne Oliff, who was diagnosed with Primary Lateral Sclerosis (PLS) in 2017 and then ALS in 2020 after lower motor neuron symptoms emerged. Ann retired from her career as a nurse and massage therapist to provide full-time care for Layne. She previously served on a pharmaceutical company patient advisory board related to her experience as an ALS caregiver.

Kristin Rankin was diagnosed with ALS at age 38. She is a supportive mom to three daughters—ages 15, 12, and 10—who provide inspiration to live life to the fullest and remain hopeful. Since 2022, she has served as a volunteer with the Community Outreach Team of I AM ALS. Kristin continues to work part time for the University of Illinois at Chicago School of Public Health, where she previously taught epidemiology methods and currently studies maternal and child health issues.

Julian (Jules) Rodriguez is a 38-year-old husband and father who was diagnosed with ALS in 2020. Jules receives full-time care from his wife and partner, Maria Aleandra. Along with their son, Skyler, the Rodriguez family lives by the mantra and motto, "Right Here, Right Now," as they weather the multitude of challenges (emotional, physical, mental, and spiritual) that ALS brings.

To learn more about the consensus study, please visit www.nationalacademies.org/ALS.