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INTIMATE DOCUMENTARY “MATTER OF MIND: MY ALS” SHARES ILLUMINATING ACCOUNTS OF THOSE LIVING WITH THE NEUROMUSCULAR DISEASE ALS, PREMIERING MAY 1, 2023, ON PBS’S INDEPENDENT LENS

February 27, 2023

Filmmakers Follow Three Individuals Living with ALS, Also Known as Lou Gehrig’s Disease, and Spotlight the Complex Decisions They Face in Their Everyday Lives Following Their Diagnoses

(San Francisco, CA) February 27, 2022 — From award-winning co-directors Anna Moot-Levin and Laura Green (“The Providers”) comes the profound documentary “Matter of Mind: My ALS,” which follows three people in the U.S. living with amyotrophic lateral sclerosis (ALS), a neuromuscular disease that leaves those impacted with—on average—two to five years to live. A profound and intimate story, the film examines the complex, yet everyday choices that people with ALS and their families face, as they live alongside this progressively debilitating disease and seek answers on how best to move forward with dignity.

“Matter of Mind: My ALS” will make its broadcast debut on PBS’s INDEPENDENT LENS on May 1, 2023, at 10 p.m. ET (check local listings). The film will also be available to stream on the PBS App.

Commonly known in the U.S. as Lou Gehrig’s disease, ALS is a neuromuscular illness that breaks down motor neuron cells. As it advances, ALS impacts the brain’s ability to control muscles, resulting in the inability to move, speak, eat, and—ultimately—breathe. Filmmakers Moot-Levin and Green explore the impact of ALS at different stages of the disease’s progression: from the early onset of symptoms with one patient to the last six months of the disease with another. Through poignant interviews with the diagnosed individuals

and their families, and documentation of the rhythms from interrupted and altered daily routines, “Matter of Mind: My ALS” takes viewers through the demanding realities of the illness through those whose life plans are forever changed.

In Durham, North Carolina, renowned African-American architect Phil Freelon receives his diagnosis of ALS on the eve of completing his life’s work: The Smithsonian National Museum of African American History and Culture in Washington, D.C. As he inches toward paralysis and loss of speech, he and his family grapple with the illness’ erosion of control, reflect on what it means to live and die with dignity, and lean on one another for support and strength.

In the rural California town of Arvin, former mechanic Charlie Wren lives on a life support ventilator, completely paralyzed except for his eyes. Cared for by his wife Angelina Flores Wren, who left her job as a medical assistant to become his 24/7 caregiver, Wren’s story highlights the herculean effort the two must make to live with this illness without a financial safety net.

In Nutley, New Jersey, Michele Stellato is diagnosed with ALS at the age of 32 and becomes the second person in the world to receive a new, experimental treatment at Columbia University. Motivated by this treatment opportunity, and with a background as a communications director, Stellato leans into her calling to raise awareness and advocate for the ALS community. She’s seen speaking on panels alongside others diagnosed with ALS, fighting for a future in which people can live with—rather than die from—the disease.

“It’s been over a century since the first diagnosis of ALS, and yet we still have more questions than answers in the current understanding of this disease,” Moot-Levin said. “The opportunity to broadcast our film on INDEPENDENT LENS means welcoming audiences to the experiences of those living with this disease, and hopefully, to feel empowered to fight for answers and a cure.”

“We learned so much about what it means to live a joyful and meaningful life, from the people who we had the tremendous privilege of making this film with, and we think our INDEPENDENT LENS audience will too,” adds Green.

“Matter of Mind: My ALS” provides snapshots of each person’s life, a culmination of unimaginable decisions the diagnosed and their families must grapple with. The film is the first of a series of three documentaries from Moot-Levin and Green, each focusing on a different neurodegenerative disease.

The documentary received funding via ITVS's Series and Special Projects initiative.

Visit the ["Matter of Mind: My ALS"](#) page on INDEPENDENT LENS to learn more about the film.

ABOUT THE FILMMAKERS:

ANNA MOOT-LEVIN

Anna Moot-Levin is an award-winning documentary filmmaker, producer, and editor with a passion for stories about health and healthcare. Her debut documentary, "The Providers," aired on PBS's INDEPENDENT LENS in 2019. She is also an associate producer of the Academy Award-winning documentary "Inside Job" (2010). She is based in Brooklyn.

LAURA GREEN

Laura Green is an award-winning documentary director and editor based in San Francisco. Her debut documentary, "The Providers," aired on INDEPENDENT LENS in 2019. She edited "When I Write It," which premiered at Tribeca in 2020, and the IDA award-nominated web-series "The F-Word." She is an assistant professor at San Francisco State University.

DAVID ALVARADO

David Alvarado is a documentary director and producer focusing on science, technology, and human rights. His new project is about a legendary Chicano playwright and filmmaker, Luis Valdez.

JASON SUSSBERG

Jason Sussberg is a Bay Area-based documentary filmmaker. He has produced and directed several theatrical documentaries that have broadcast on PBS and streamed on Netflix and Amazon. His work includes "The Immortalists" (2014), "Bill Nye: Science Guy" (2017), and "We Are As Gods" (2021).

CREDITS:

Directors

Anna Moot-Levin

Laura Green

Producers

David Alvarado

Laura Green

Executive Producers

Anna Moot-Levin
Jason Sussberg
Sally Jo Fifer
Tamara Gould
Lois Vossen

Visit the INDEPENDENT LENS [website](#) for more information.

ABOUT INDEPENDENT LENS

INDEPENDENT LENS is an Emmy® Award-winning weekly series, airing on PBS Monday nights at 10:00 p.m. ET. The acclaimed series, with Lois Vossen as executive producer, features documentaries united by the creative freedom, artistic achievement, and unflinching visions of independent filmmakers. Presented by ITVS, the series is funded by the Corporation for Public Broadcasting, a private corporation funded by the American people, with additional funding from PBS, Action Family Giving, the John D. and Catherine T. MacArthur Foundation, Wyncote Foundation, and the National Endowment for the Arts. For more visit pbs.org/independentlens. Join the conversation on Twitter, Facebook, and Instagram at @independentlens.

ABOUT ITVS

ITVS is a San Francisco-based nonprofit organization that has, for over 25 years, funded and partnered with a diverse range of documentary filmmakers to produce and distribute untold stories. ITVS incubates and co-produces these award-winning films, and then airs [them](#) for free on PBS via our weekly series, INDEPENDENT LENS, as well as on other PBS series, and through our digital platform, OVEE. ITVS is funded by the Corporation for Public Broadcasting, The National Endowment for the Humanities: American Rescue Plan, Acton Family Giving, the John D. and Catherine T. MacArthur Foundation, the Ford Foundation, and Wyncote Foundation. For more information, visit itvs.org.

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