END THE LEGACY

GENETIC ALS & FTD

END THE LEGACY'S GENETIC ALS & FTD COMMUNITY SUMMIT 2025

Philadelphia, PA | June 6-8, 2025

ALS Hope Foundation®

Hope is on the horizon

We are thrilled to be here with you in Philadelphia. When we formed a few years ago who could have imagined we would be coming together for two years in a row with dozens of people impacted being in communion like never has occurred before. Let's appreciate the time and expense it has taken for all of us to find ourselves here, and celebrate we all are choosing to build this movement for ourselves and our families.

We must be so thankful for the support and mentorship the ALS Hope Foundation and Dr Terry Heiman Patterson have provided to us. Their steadfast commitment has allowed us to achieve amazing things. We now have the first ever acknowledgment that being at risk for genetic ALS or FTD is a part of our personal medical picture. Imagine that! Our collective mark on the health of our families will be permanent as initiatives to integrate the prevention of our family curse grow ever more refined and widespread. If you have not yet read it, the paper detailing the first guidance is in your conference bag and Dr Heiman Paterson and our own Cassandra Haddad will be speaking on it Saturday.

We all know research is our biggest hope and we will be having lots to digest about it this weekend. Friday afternoon we will hear about studies where at risk people can be monitored for the earliest signs of disease. These are known as "natural history" studies. Saturday will feature both a high level state of disease overview and a more granular look at promising interventional therapies from both researchers and people who are benefiting from them.

Acknowledging the profound effect this risk has on our lives will be present in our living at risk panel Friday, and our two optional peer support morning sessions which we hope you might check out but given their emotional nature we do not require.

Finally on Sunday morning we will close with some important messages about the work in front of us.

Thank you to all our speakers, our sponsors, our planning committee and to all of you attending together we are taking our seat at the table of these diseases and we are not going back to a time where our community is hidden!

In Solidarity and Appreciation.

Jean Swidler
Executive Director
Genetic ALS & FTD: End the Legacy

ALS Hope Foundation
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We are so excited to welcome you to our hometown area, Philadelphia, for the 2nd annual Genetic ALS & FTD End the Legacy Community Summit. From our first discussions of partnership with the team at End the Legacy in 2023 we understood the unmet needs that existed for people living with genetic risk of ALS and FTD and wanted to help in building a coalition that could begin to address this important issue within the ALS and FTD community. However, while we understood the importance, we had no idea how rapidly this effort would grow within the community of those at genetic risk of ALS and FTD. We are so proud to be a part of this community and to support End the Legacy in their efforts.

To this end, we remain dedicated to making a difference through education, care and research. We are proud to have co-sponsored the first annual Genetic ALS & FTD Community Summit and CRLI in Chicago. We also sponsored the workshop on guidance for people at genetic risk of ALS and FTD which was co-chaired by Dr. Michael Benatar and Dr. Terry Heiman-Patterson, our President and Co-founder of the ALS Hope Foundation, which developed guidance recommendations for people at genetic risk and the report can be found with your conference materials. Our commitment does not stop there, we have developed in collaboration with End the Legacy the first ever End the Legacy Certified Center of Compassion at Temple Neurology dedicated to care of people at genetic risk and not just research. We also are proud to incorporate research as a site for the ambitious and expansive ALL ALS and Prevent ALS studies.

Please enjoy the coming weekend and know that the ALS Hope Foundation stands with all of you in the at risk community along side of End the Legacy until these diseases are cured.

Jamey Piggott, Executive Director
Terry Heiman-Patterson, MD Board President
ALS Hope Foundation

2nd Annual END THE LEGACY GENETIC ALS & FTD Community Summit

June 6-8 2025 • Philadelphia, PA

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END THE LEGACY GENETIC ALS & FTD

This event did not organize itself!

Please take a moment to show appreciation to our amazing planning committee who have spent many hours sorting through all the details to get us here this weekend:

Betsy Hall

Jary Larsen

Wanda Smith

Mindy Uhralub

Lauren

Kelsey Homyk

Stephen Fray

Anne Rohricht

Jamey Piggot

Jean Swidler

Cassandra Haddad

Kerri-Jean Winteler

Summit Information

The 2025 Genetic ALS & FTD Community Summit will be in session from Friday June 6th at 12pm until Sunday June 8th at 12pm.

All sessions of the meeting will be held in the meeting rooms at Hotel West and Main.

On Saturday evening dinner will be held at Conshocken Brewing Company's King of Prussia location. To travel there we have arranged uber codes that will pay for your ride there and back. To steward our resources we are requesting all to carpool with 2 others. Our planning committee member Jary Larsen will be helping keep track of the carpools and codes, so please see him for your code!

All other meals will be served at the meeting area.

Ways to be involved in our movement after the summit

Stay in touch - make sure you are on our bi-monthly community meeting email list, or our quarterly newsletter list.

Get involved - when there are committees or events that need participants or legislators that need meeting with step up!

Keep the movement going - we are an organization with very little overhead. But we do have costs and if we are not supported by the community that we are speaking for, we cannot continue. Your financial support demonstrates our community has staying power.

MEETING AGENDA

FRI JUNE 6

12:00 pm	**Registration opens**
1:00 pm	**Welcome** ALS Hope & End the Legacy Jamey Piggot *(ALS Hope)*, Jean Swidler *(ETL)* and Kerri-Jean Winteler *(ETL)*
1:30 pm	**Ethical Considerations in Presymptomatic Neurodegenerative Diseases** Betsy Hall, *For Their Thoughts, ETL* Emily Largent, *University of Pennsylvania*
2:30 pm	**Mental Health Considerations for Those at Risk** Lauren, *ETL* Laynie Dratch, *University of Pennsylvania* Sarina Smith, *Huntington's Disease Youth Organization* Katherine Lietz, *University of Pennsylvania*
3:45 pm	*Break*
4:00 pm	**Natural History Studies for Those at Risk** Kelsey Homyk, *ETL* Terry Heiman Patterson, *Temple University* David Irwin, *University of Pennsylvania* Hristelina Ilieva, *Thomas Jefferson University*
6:15 pm	*Dinner*
7:00 pm	**Keynote / Book Reading** Mindy Uhrlaub in conversation with Cassandra Haddad

MEETING AGENDA

SAT JUNE 7

8:00 am	**Breakfast Buffet opens**
8:30 am	**Peer Support Breakfast Session for those impacted by Genetic ALS and FTD only** *(optional)* **"Big Feelings"** Mindy Uhrlaub Lauren
10:00 am	**Promising Research Overview** Yentli Soto-Albrecht, *ETL* Frank Shewmaker, *National Institute of Neurological Disorders and Stroke* Manish Raisinghani, *Target ALS* David Irwin, *University of Pennsylvania*
11:45 am	**Group Photo** *(optional)* Follow instructions informed by our photographer!
12:00 pm	*Lunch*
1:00 pm	**Guidance For Those at Risk** Cassandra Haddad, *ETL* Terry Heiman-Patterson, *Temple University*
2:00 pm	*Break*
2:30 pm	**Innovative Genetic Medicine Panel** Matthew Harms, *Columbia University* Stephen Fray, *ETL* Paul Little, *Vesper Bio* Jeff Vierstra
4:00 pm	**Optional Peer Sharing Discussion - IVF with PGT** **For those with experience or considering it** Facilitated by Shannon Therese Terek, *Temple University*
6:30 pm	*Dinner* *Conshohocken Brewing Company* King Of Prussia Location Carpool with Provided Uber Codes! See a Planning Committee Member and the logistics page in the program for details!

MEETING AGENDA

SUN JUNE 8

8:00 am	**Breakfast Buffet opens**
8:30 am	**Peer Support Breakfast Session for those impacted by Genetic ALS and FTD only** *(optional)* **Talking with your Affected Family Group Share** Wanda Smith, *Cure GRN, ETL* Jary Larsen, *ETL*
10:00 am	**Clinical Care for Those at Risk** Cassandra Haddad, *ETL*
10:30 am	**Policy Strategy for the Genetic ALS and FTD Community** Tim Bergreen, *Hogan-Levells* Ambassador Karen Kornbluh, *Visiting Fellow at the Center for Democracy and Technology and Senior Advisor for Emerging Technology at the Milken Institute*
11:30 am	**End the Legacy State of The Organization** Jean Swidler *(ETL)* and Kerri-Jean Winteler *(ETL)*
12:00 pm	**Event Closes**

Our summit is a space for education, connection, and hope. To ensure a welcoming and respectful environment for all participants—including individuals living with ALS or FTD, genetic carriers, caregivers, clinicians, researchers, and advocates—we ask all attendees to agree to the following Code of Conduct.

1 Respect and Inclusion

- Treat every person with dignity, compassion, and respect.
- Embrace the diversity of our community, including different backgrounds, experiences, and perspectives.
- Avoid assumptions about others' medical status, abilities, or experiences.

2 Safe and Supportive Environment

- We are a trauma-informed space. Please be mindful that discussions may involve personal and emotional content.
- If someone chooses to share their story, receive it with respect and without judgment.
- Disagreements should be approached constructively. Harassment, intimidation,insults or bullying of any kind will not be tolerated.

3 Confidentiality and Consent

- Respect privacy. Do not share personal stories, photos, or identifiable information from sessions or informal conversations without permission.
- Ask before photographing or recording anyone.

4 Responsible Participation

- Attend sessions and activities with an open mind and a spirit of learning.
- Facilitators will recognize individuals before anyone speaks to the room.
- Be mindful of time during group discussions to allow space for others to speak.
- Follow all event guidelines, posted signage, and instructions from staff or volunteers.
- Speak from your own perspective and if relying on factual information please cite the source.
- Be mindful of behavior that results in added expenses for the organization and movement.

5 Reporting and Accountability

- If you witness or experience behavior that violates this Code of Conduct, please report it to an event planning committee member.
- We reserve the right to take appropriate action—including removal from the event—if someone engages in behavior that undermines the safety or integrity of the summit.

Thank you for helping us build a community rooted in mutual care, respect, and advocacy.

Yentli Soto Albrecht is an 8th-year MD-PhD student at the University of Pennsylvania's Perelman School of Medicine. She earned her PhD in 2024 from the Douglas Wallace lab, where she researched the impact of mitochondrial function on SARS-CoV-2 replication and pathogenesis. After losing her father to C9orf72 ALS less than a year ago, Yentli is now dedicated to using her training as a physician-scientist to advance research on familial ALS and FTD in his memory, with the goal of protecting her own family as well.

Tim Bergreen has in-depth knowledge of all facets of the U.S. government and an established reputation for working across party lines. Tim has more than 20 years of experience advising and legislating across a range of policy issues relating to national security, including foreign policy, trade, sanctions, defense, cybersecurity, cryptocurrencies, telecoms, satellite communications, and appropriations in the House, Senate, and Department of State.

Laynie Dratch, ScM CGC is a board-certified genetic counselor for the Penn Frontotemporal Degeneration (FTD) Center and Penn Amyotrophic Lateral Sclerosis (ALS) Center in the Department of Neurology at the University of Pennsylvania. She is the co-founder and chair of the ALS/FTD Working Group within the National Society of Genetic Counselor's Neurogenetics group, as well as the co-founder of the annual Penn Familial FTD/ALS Conference. Laynie completed her master's in genetic counseling at the Johns Hopkins University and National Institutes of Health, and completed her undergraduate studies at Colgate University.

Stephen Fray, in his words: In 2014 my mom Alvera Fray at the age of 81, was diagnosed with ALS and after her 5-year battle, mom passed in 2019. Fast forward to 2022, 3 years after Mom's ordeal ended, the baton was passed to me. How ironic that at the "11th hour of the 11th day of the 11th month" on November 11, 2022, Veterans Day, the same doctor that treated my mother told me at my 11 AM appointment, I had ALS. Genetic testing confirmed that the mutated SOD1 gene that is passed on genetically and causes ALS, was in me. With the two ALS diagnoses, our family is now officially part of the 10 percent of cases that are considered FALS, familial ALS. As soon as results of the geneOc test were received confirming the SOD1 mutation, I was put into the trial for Qalsody/Tofersen and was the first patient to receive the FDA approved medication in August of 2023. Upon learning of the genetic connection to ALS and realizing that the disease is part of my family, I began looking for support my four children who had a front row seat to their grandmother's bad movie and are now they are watching the sequel with dad in the starring role and the nagging thought that they may have ALS too! My search brought me to Genetic ALS & FTD: End The Legacy, a group that was thinking just like me. For 90% of ALS patients, the book comes to an end, the remaining 10% turn the page and start a new chapter. Having been a caregiver and now an ALS patient my goal is to raise my voice to support and encourage the patients and family members of our community; to be a spotlight to make sure the researchers, industry and government are addressing the unique geneOc needs. I have been fortunate to be a part of the 3% Tofersen Club and I know it is working. With over 3 years of treatment, when you compare mom's 3rd year to mine, I'm doing cartwheels and backflips! From day 1 of being told I have the disease, my attitude and plan for living with ALS is, no matter how much I scream and cry nothing is going to change, besides I did that already for mom.

So, I take it one day at a time and Today, I'm doing what I can do today, and I'll keep doing it until I can't do it no more. And when tomorrow becomes today, I'll do what I do for today.

Cassandra Haddad is a Family Nurse Practitioner dedicated to health and wellness. In addition to her clinical work, Cassandra serves as the Vice-Chair of End the Legacy, a nonprofit organization dedicated to the needs of the genetic ALS & FTD community. As a SOD1 gene carrier, she is committed to changing the care paradigm for at risk people. Her advocacy has resulted in global participation as a speaker and contributor to numerous boards, projects, and initiatives within the ALS community. She serves in her capacity as a Nurse Practitioner in the first End the Legacy certified center of compassion for those at risk of genetic ALS and FTD at Temple Neurology.

Betsy Hall - Founding Exec Director For Their Thoughts® Foundation Engineer, leader and young dementia/caregiver advocate: Betsy Hall is the Founding Director of For Their Thoughts® Foundation (FTTF) focused on delivering direction and relief to family caregivers while championing local and national initiatives to alter how dementia is perceived and addressed.Hall's involvement in dementia care advocacy began with a personal journey as a caregiver to her mother and grandmother with FTD. Inspired to make an impact, Hall initiated unique opportunities for community action through weekly volcano summits and mountain races prior to establishing FTTF. Ultra-marathons continue to be a passion and personal reprieve for her. Prior to FTTF, Hall's 16-year career as a Department of Defense strategic consultant focused on sustainable engineering and leadership. Both domestically and in Europe, Africa and the Middle East, Hall led diverse teams to implement energy security for the DoD through feasibility analysis, strategic planning, project/program implementation and community outreach education. Hall is committed to leveraging these skills in partnership with the dementia industry experts and advocates to initiate compounding change in how dementia is understood, treated and supported.

Matthew Harms, MD is an Associate Professor of Neurology and Associate Director of the Eleanor and Lou Gehrig ALS Center at Columbia University. An alum of Harvard (undergraduate, biology), UC San Francisco (medical school and neurology residency), and Washington University in St. Louis (neurophysiology and neuromuscular fellowships), Dr. Harms' research has focused on the neurogenetic underpinnings of ALS for 15 years. His lab discovered the genes underlying a form of spinal muscular atrophy and LGMD 1D before turning attention on ALS. He has contributed to early understanding of *C9ORF72* and helped lead the first large-scale exome sequencing project in ALS, identifying *TBK1* and *NEK1*. As the principal investigator of the "GTAC" study, North America's largest prospective study linking genomics to environmental exposures and outcomes in ALS, he further contributed to implicating ATXN2, DNAJC7, KIF5A, and HTT. He is co-PI of the ALS Families Project at Columbia, co-PI of the PREVENT ALS study of ALL ALS, and an investigator in SILENCE ALS. Dr. Harms is Chair of the ClinGen expert panels for ALS and Related Motor Neuron Disease.

Terry Heiman-Patterson is a professor of neurology and Vice Chairman of Research at Temple University Lewis Katz School of Medicine, where she is director of the MDA ALS Center of Hope. She has served on the Executive Board of Northeast ALS Consortium and is a member of the ALSRG, an international study group. She serves on the vision setting committee for ALS for the CDRP and is co-chair of the ALS Quality of Life Committee for the National Institute of Health. She has published over 120 papers, abstracts, and chapters on ALS and related motor neuron diseases along with more than 60 additional papers on other areas of muscle and nerve disease. As an extension of her commitment to ALS she founded the ALS Hope Foundation, a non-profit organization dedicated to making a difference to people living with ALS.

Kelsey Homyk comes from a C9orf72 family and is a carrier herself. She holds a Biochemistry degree with research experience. Kelsey advocates passionately for gene carrier recognition and for targeted efforts that go towards finding a cure for ALS and FTD. Kelsey's wonderful mother is battling the advanced stages of PPA FTD.

Dr. Ilieva specializes in adult neuromuscular disorders including amyotrophic lateral sclerosis (ALS), peripheral neuropathies, neuromuscular junction disorders, and muscle diseases. She has achieved a broad and comprehensive training in neurology and neuroscience with emphasis on neurodegenerative diseases. In the last 5 years she has been affiliated with the Jefferson ALS Weinberg Center in Philadelphia where she is clinical director and a principal investigator for several trials including the Healey platform trial. Dr. Ilieva has an interest in translating basic science knowledge and advances into therapies which could one day delay the progression of currently difficult to treat conditions like ALS. Some of the stepping stones to achieve this goal will be to develop sound knowledge about possible disease biomarkers and to better understand factors that cause variability in disease presentation and progression.

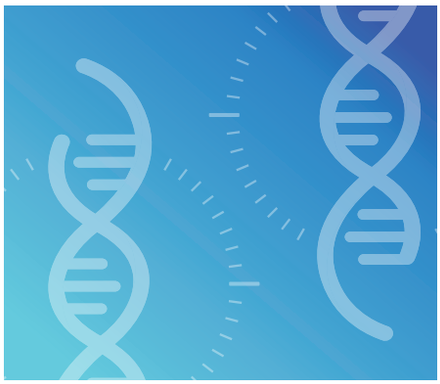
Dr. David Irwin is the clinical director of the Penn Frontotemporal Degeneration Center and PI of the Penn Digital Neuropathology Lab at the University of Pennsylvania Perelman School of medicine. He has dual training in cognitive neurology and neuropathology and his lab focuses on integrating human brain histopathology and molecular techniques with antemortem clinical data, with the overall goal of identifying therapeutic targets and markers of disease progression that can serve as endpoints in treatment trials for FTD, LBD, AD and related neurodegenerative Disorders.

Ambassador Karen Kornbluh is a Visiting Fellow at the Center for Democracy and Technology and Senior Advisor for Emerging Technology at the Milken Institute. She served until January as Principal Deputy White House Chief Technology Officer and Director of the National Artificial Intelligence Office. Previously, she served as Ambassador to the Organization for Economic Cooperation and Development. Previously she served as a senior official at the

Treasury Department and Federal Communications Commission. She started her career in the private sector as an Economist and served as Executive Vice President at global data firm Nielsen. Kornbluh She was the subject of a *New York Times* profile titled "Fighting for Economic Equality." Her articles have appeared in outlets including Foreign Affairs, *The New York Times, Washington Post, Atlantic Monthly*, and *Harvard Journal of Law and Technology*. She is a member of the Council on Foreign Relations and serves on the Maryland Economic Commission.

Jary Larsen is a licensed neuropsychologist, who currently is affiliated with the Neuropsychology Service at the University of California, San Francisco/ Zuckerberg San Francisco General Hospital (UCSF/ZSFG), as well as the Cognitive Neuropsychology and Electrophysiology (CNE) Laboratory at VA Northern California, where he has also served as the Chair of the Institutional Review Board (human research ethics board) since 2012. Jary's family has been impacted by GRN-FTD going back many generations. In addition to his father and uncle who died from GRN-FTD, Jary's brother died in 2013 and his sister died in 2024. Recently, he also connected with family in Denmark, who have been impacted by the same Progranulin pathogenic variant. Jary continues to be very active in the fight to treat GRN-FTD on many different levels, and very much appreciates the work being done by End The Legacy and all of the families also impacted by genetic ALS and FTD.

Kate Lietz *i*s a licensed clinical social worker who joined the Penn FTD Center in August 2022, after completing her field training with the Penn Memory Center in the 2021-2022 academic year. At the FTD Center, Kate provides support and education to individuals and loved ones impacted by a diagnosis of FTD or related dementia. She also runs support groups for caregivers loving someone with early-onset dementia. She graduated from Boston College with a degree in Sociology and received her Master's in Social Work from the University of Pennsylvania, where she specialized in geriatric practice. Kate also sees patients in the cognitive neurology and neuromuscular clinics at Penn Medicine.



Paul Little has been working in the biotech field for more than 20 years and as an investor for almost a decade. In biotech Paul has taken multiple rare orphan disease products from the bench to clinic with one of those achieving market authorization so far. Paul has a passion for developing science that will bring benefit to people and their families especially where there has been little to no treatment options available. Paul is based in Denmark and works for Lundbeckfonden BioCapital and is CEO of Vesper Bio and has previously worked in 7TM Pharma, Orphazyme, NMD Pharma and CytoKi Pharma.

Jamey Piggott became involved in ALS when helping his best friend who was diagnosed with the disease. While doing so, he saw how devastating the disease is and became passionate about helping those fighting ALS, their families and caregivers. A graduate of Eastern University, Jamey developed and managed his own entertainment agency for twenty years before dedicating his career focus to fight ALS in 2014. Jamey joined the ALS Hope Foundation in 2018 and his

goals in this role at the ALS Hope Foundation are to raise awareness about ALS; to raise funds for care and finding a cure; and serve as an advocate for the ALS community.

Manish Raisinghani, M.B.B.S., Ph.D. As Chief Executive Officer of Target ALS, Manish drives forward the organization's mission of breaking down barriers to ALS research to find effective treatments. Manish has led the organization since its founding in 2013, growing Target ALS into the largest private funder of ALS research globally. With Manish's vision and leadership, Target ALS established the organization's landmark Innovation Ecosystem model. By eliminating barriers that traditionally limit scientific progress, the Innovation Ecosystem catapults the best ideas on ALS research across the drug discovery pipeline at an unprecedented pace. Prior to Target ALS, Manish served in senior scientific and executive roles at Columbia University, Sigma-Aldrich, and Taconic Biosciences, including over 10 years focused in neuroscience. He is a member of the Society for Neuroscience and has published dozens of research articles. Manish earned his Ph.D. from Southern Illinois University and his Bachelor of Medicine,Bachelor of Surgery degree from the Seth G.S. Medical College and KEM Hospital in Mumbai, India.

Dr. Frank Shewmaker joined the National Institute of Neurological Disorders and Stroke (NINDS) in 2023 and serves as the Frontotemporal Dementia Program Director. Prior to joining NINDS, he was a Program Director of Protein Biophysics at the National Institute of General Medical Sciences (NIGMS). Dr. Shewmaker earned a Ph.D. in biochemistry from Tulane University and performed his postdoctoral research at the NIH, where he studied the structural properties that enable proteins to form self-propagating amyloid conformations. Before becoming a Program Director at NIGMS, Dr. Shewmaker was an Associate Professor of Biochemistry in the medical school of Uniformed Services University at Walter Reed National Military Medical Center in Bethesda, MD. His research focused on protein aggregation and its consequences to cellular functions.

Sarina Smith is a Huntington's disease (HD) family member and Ph.D student studying ALS at the University of Pennsylvania who is passionate about rare disease research and advocacy. She is an Ambassador for the Huntington's Disease Youth Organization (HDYO) and a Young Adult Rare Representative (YARR) through the EveryLife Foundation. She is also a member of a small group of patient/community advocates called HD-PACE, who strive to accelerate the pace of HD research by identifying and breaking down barriers impeding progress. In her free time, she loves running, spending time outdoors, and watching *Survivor*.

Wanda Smith's advocacy began 40 years ago with the challenges of caring for a parent, a toddler, and an infant, all in diapers. In 1986, Life magazine published the first nationally recognized article on Alzheimer's Disease, featuring Wanda and her mother. Sixteen years later, researchers identified that it wasn't Alzheimer's at all, but FTD progranulin (GRN). Today, research is on a hopeful pathway to a treatment for FTD GRN.

Jean Swidler is committed to transforming how those at risk of genetic ALS and FTD, and ultimately all adult-onset neurological conditions, are treated. Following a career as a labor union organizer and negotiator, and her mother, aunt and uncle dying from C9orf72 ALS, Jean confirmed she carried the C9orf72 repeat expansion presymptomatically. With others she co-founded Genetic ALS & FTD: End the Legacy and was appointed its first Executive Director. Jean lives with her husband and daughter in California.

Jeff Vierstra, PhD is an investigator at the Altius Institute for Biomedical Sciences. His research focuses on deciphering the structure-function relationship of chromatin. Some of my main areas of interest are: Mapping chromatin structure & function using nucleases, Understanding gene regulation through the lens of human genetics, Cis-regulatory encoding of cell identity and fate potential. Prior to Altius, Jeff did both doctoral and postdoctoral training at the University of Washington. He obtained His BSc in Genetics and Computer Science at the University of Wisconsin.

Kerri-Jean Winteler has worked in adult developmental services in Canada for over 30 years and was a caregiver to her parents for over 10 years. Her caregiving journey began when her boys were young for her father with Parkinson's and then for her mother with FTD. Kerri-Jean has been connected to End the Legacy since 2022 and is a longitudinal study participant.

Mindy Uhrlaub participates in more than twenty ongoing longitudinal studies for C9orf72 ALS. For work on her forthcoming ALS memoir, Last Nerve, A Memoir of Illness and the Endurance of Family, Uhrlaub was awarded residencies at Millay Arts, The Hambidge Center, Joyce Maynard's Write by The Lake, Litcamp, and Ragdale for the Arts. Since learning she carries the C9orf72 mutation for ALS/FTD, she has testified before the FDA and the NIH about pre-symptomatic carriers of ALS's need for medical treatment. In February 2023, Mindy was nominated onto a committee at the National Academy of Science, Engineering, and Medicine to make ALS a livable disease. The report, Living with ALS, was published in June of 2024. For co-founding End the Legacy with Jean Swidler, Uhrlaub won the 2025 Harvey and Bonny Gaffen Advancements in ALS Award from the Les Turner ALS Foundation.

Lauren has been a member of End the Legacy since 2023. She is a co facilitator of the Peer Support Hour and actively working on genetic discrimination policies in her home state of Maryland. Professionally she is a Nonprofit Director and Geriatric Social Worker.

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About the Event Partners

Genetic ALS & FTD: End the Legacy Genetic ALS & FTD

End the Legacy debuted as a formal non-profit organization in January 2023. The first patient-led group dedicated solely to the needs and interests of the genetic ALS & FTD community, it encompasses individuals from nearly all major ALS & FTD related genes. Through weekly and monthly meetings, they provide peer support. Through regular webinars and in-depth resources on their website, they provide education. Through original analysis and linking peers to studies, they support research. And most importantly, through taking seats at any table debating these diseases, they ensure the genetic community is always represented.

ALS Hope Foundation

Founded in 1999 by Terry Heiman-Patterson, MD, and Jeffrey Deitch, PhD, the ALS Hope Foundation provides funding for the MDA/ALS Center of Hope at Temple University Lewis Katz School of Medicine, one of the first multidisciplinary ALS clinics in the country, and the Dr. Robert Sinnott Research Lab at Temple University College of Medicine. The Foundation also provides educational events to inform people living with ALS and the public about ALS research. The ALS Hope Foundation funds local and international efforts to find the cause and cure of ALS. This much needed support is generated through fundraisers and private donations. We are honored to have spent more than 25 years serving the ALS community and are committed to continuing our work until there is a cure.