



Sean M. Healey & AMG Center for ALS

Summer 2024 Newsletter

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Greetings from the Sean M. Healey & AMG Center for ALS,

Thanks to your steadfast partnership, the Healey & AMG Center for ALS is achieving our goal of creating a global community of researchers, individuals with ALS and advocates, who work together to help stop, repair, reverse, and ultimately prevent ALS.

While our researchers continue to advance our understanding of the biology of the disease and identify drug targets, we are committed to engaging more individuals with ALS in research. We are so proud to partner with ALS One, Never Surrender and the Les Turner Foundation to launch an Acceleration Center of Enrollment Initiative at the Healey & AMG Center for ALS at Mass General, the Les Turner ALS Center at Northwestern Medicine and the University of Minnesota, to ensure enrollment is efficient and available.

Our goal is to have opportunities for every individual with ALS to be part of clinical trials. We know that gathering a critical mass of information will reveal the answers we need.

Together, we are taking monumental steps forward in determination to move us closer to a future without ALS.

Sincerely,

Merit Cudkowicz, M.D., MS.c.

New & Noteworthy

At the Healey & AMG Center for ALS, our patients are our priority. Our work is shaping the landscape of ALS treatment and understanding, and we are excited to share the latest news from our center with you.





First Participant Enrolled in NIH-Funded Access for All in ALS Consortium

The Access for All in ALS Consortium (ALL ALS) announced the enrollment of the first participant in the NIH-funded multi-institutional effort to advance ALS research.

[Read More](#)



Acceleration Centers of Enrollment Initiative Launch

We are thrilled to announce the launch of the Acceleration Centers of Enrollment (ACE) initiative. The initiative aims to accelerate enrollment and operational improvements in ALS clinical research.

[Read More](#)

Healey & AMG Center, Never Surrender, Inc. Establish Acceleration Center of Enrollment at University of Minnesota

As part of the new ACE initiative, Never Surrender, Inc has established an Acceleration Center of Enrollment at the University of Minnesota under David Walk, M.D., F.A.A.N.

[Read More](#)

Healey & AMG Center for ALS Announces 2024 ALS Scholars in Therapeutics & MGH ALS Young Investigators. Attracting the best and brightest to ALS research!

The Healey & AMG Center for ALS has recognized nine scientists in total this year as recipients of the 2024 global ALS Scholars in Therapeutics and 2024 MGH ALS Young Investigators. Both recognize and support the work of new, early career researchers and innovators in the field of ALS research.

[Read about the 2024 ALS Scholars in Therapeutics](#)

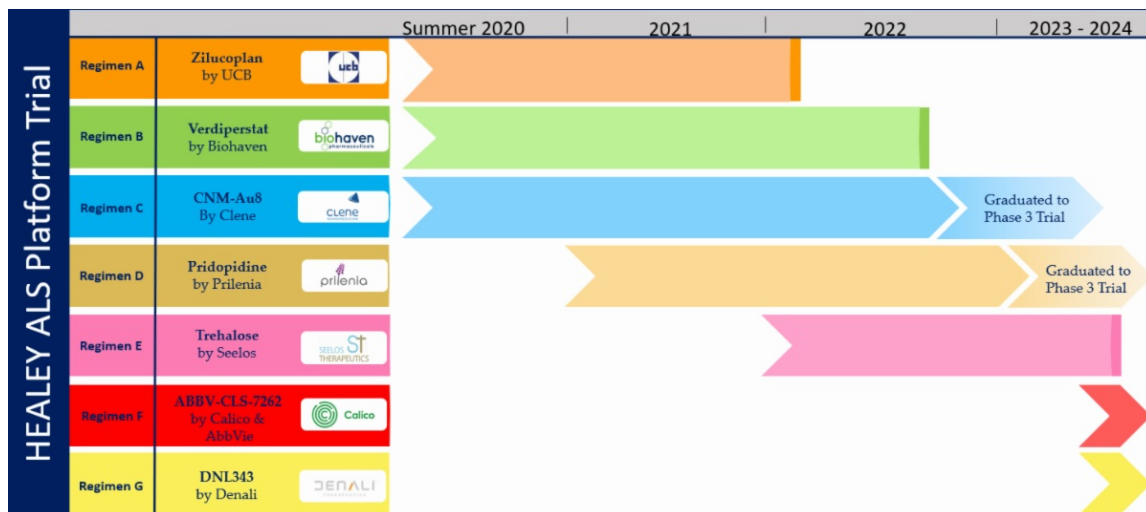
[Read about the ALS MGH Young Investigators](#)

HEALEY ALS Platform Trial

The HEALEY ALS Platform Trial is a multicenter, double-blind, placebo-controlled, perpetual, adaptive platform trial testing multiple investigational products in parallel.

Results of first five investigational products have been announced. Two of the first five have positive results on secondary outcome measures and are proceeding to next steps for drug

development (CNM-AU8, Clene Nanomedicine and pridopidine, Prilenia). For both of these investigational products, the National Institute of Health recently funded expanded access programs (see below).



We are also excited to share that we have contracted with PharmAust Limited to begin designing a regimen in the trial. The regimen will evaluate the investigational drug Monepantel.

[Read More](#)



We are in discussions with several other pharma and bio tech companies about the next regimens for the HEALEY ALS Platform Trial.

[Learn more about how to join the trial here](#)

Over 475 Participants

48 Active Clinical Sites

20 Investigational Products

Expanding Access to Experimental Therapies

We are committed to ensuring individuals living with ALS across the U.S., who may not be eligible for clinical trials can access investigational products. [Visit our EAP webpages](#) to learn more about Expanded Access.

For the latest updates on Expanded Access, read our [EAP quarterly newsletter](#)

HEALEY ALS Platform Trial & EAP Webinar Series

Join us on Thursday, September 12th at 5 pm EST to hear the latest expanded access protocol updates from Dr. Suma Babu.

[Register](#)

Media Coverage

A full list of media coverage is available on our [website](#)



Massachusetts ALS Advocacy Day

On Thursday, May 2, Sabrina Paganoni, M.D., Ph.D., spoke at the State House as part of the first ever Massachusetts ALS Advocacy Day. The event was attended by patients and their families, ALS advocates and Healey & AMG Center staff. Dr. Paganoni spoke about the progress being made in the clinical and research spaces around ALS, as well as encouraging legislative support for ALS treatment.

[Read More](#)

Combination Therapy Showed Favorable Safety Profile in ALS

Merit Cudkowicz, M.D., M.Sc. discussed the combination therapy of ciprofloxacin and celecoxib (Prime C, NeuroSense) demonstrating a favorable safety profile for those with ALS. "The combination treatment was safe, the discontinuation rates were similar between the groups and the side effects were rare, often mild and did not lead to drug discontinuation."

[Read More](#)

NBC Boston Visits MGH Neurology and Highlights African Bridge Network Program, Healey & AMG Center for ALS

NBC Boston recently featured the African Bridge Network Program (ABN), which works to help immigrants struggling to find work in an appropriate field connect with the programs and training they need for a successful career in the U.S. Featured in the segment is Ludjie Jean Pierre, who joined the Healey & AMG Center for ALS in 2022 as an ABN fellow.

[Watch the Full Segment](#)



From the Bench

The Mass General Institute for Neurodegenerative Disease (MIND) is an open laboratory space where researchers focusing on a particular neurodegenerative disease – Alzheimer’s, Parkinson’s or ALS – share ideas and find common connections, accelerating discoveries and therapeutic development across all of these diseases.

This month, we visit the Wainger Lab.

[Read More](#)

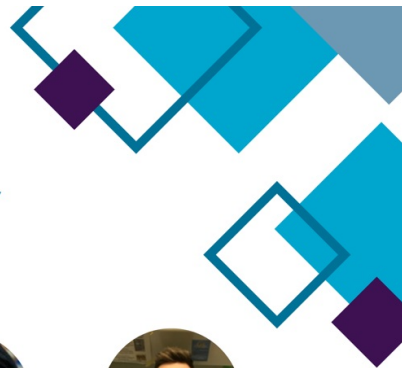
Recent Publications

The dedicated efforts of physicians and researchers at the Healey & AMG Center have led to significant breakthroughs in the fight against ALS. Publications are the result of rigorous investigation and research that offer valuable insights into the nature of this disease.

[See the full list of publications on our website](#)

Read our Team’s Latest Publication

*Allogeneic B Cell Immunomodulatory
Therapy in Amyotrophic Lateral
Sclerosis.*



Read the
Article

In The Community

The success of the Healey & AMG Center for ALS would not be possible without the valuable contributions from the ALS community. The year so far has brought together extreme athletes, support from the Major League Baseball & National Football League Associations, and reinvigorated the spirit of the Ice Bucket Challenge, ten years later.

Together, we’re making waves of change and moving closer to a future without ALS.

Visit our [Community Support](#) page for information about upcoming and past campaigns.

NFL rivALS Game 2024

The NFL will be hosting the 2nd annual rivALS game which aims to raise funds for ALS by honoring Tim Green (Tackle ALS) and Steve Gleason (Team Gleason). Funds will be raised through a 50/50 raffle when the teams face each other this season. New

Orleans Saints vs. Atlanta Falcons in Atlanta on Sept. 29 and in New Orleans on Nov. 10. Those living in Georgia and Louisiana can purchase raffle tickets online!

See additional details [here](#).

Tackle ALS Season 2 supports repair and regeneration. Create a Team or support Tackle ALS [here](#).



Team Jimmer

Supported by colleagues, family and friends Jimmer Szatkowski will be taking on the "Loop the Lake" The Great New York State Marathon in Syracuse, NY on October 21.

Support Jimmer's race through his Tackle ALS fundraising page [here](#).



Ride to Endure

After caring for his uncle who had ALS, Miron Golfman an ultra-endurance athlete, was motivated to raise awareness and funds for ALS by taking on extreme physical challenges in honor of those who can't. The Ride to Endure film follows Miron's journey along the 1,600-mile Baja Divide route in Mexico to raise funds and awareness for the ALS community. Since the Baja Divide attempt in January of 2022, Miron has cycled the 1,000-mile Iditarod Trail in Alaska in March 2023 & 2024 raising funds for the Sean M. Healey & AMG Center at Mass General. The Ride to Endure Documentary premiered at the [Greenpoint Film Festival](#) in Brooklyn, NY on August 8th.

[Watch the trailer here.](#)



Ariella's Two Thumbs Up Climb for ALS

Inspired by his mother's passion for hiking, Yossi Nasser decided to undertake an immense physical challenge to raise awareness for ALS in his mother, Ariella's honor. In early July he and other ALS community champions completed their first peak, Mt. Kilimanjaro with a plan to climb further peaks in the future.

To learn more and support Yossi in his climbs, visit the fundraising page [here](#).

Ice Bucket Challenge 10th Anniversary

On August 1 the Peter Frates Family Foundation hosted an Ice Bucket Challenge at Fenway Park celebrating the 10th anniversary of the event and honoring one of its founders, Pete Frates. Dr. Merit Cudkowicz along with Nancy Frates, Governor Maura Healey, Red Sox President Sam Kennedy and other local sports legends shared remarks on Pete's legacy and progress made in the field of ALS.



The 2014 Ice Bucket Challenge raised over \$100 million dollars, which has translated to over \$1 billion dollars of funding towards ALS research and care efforts in the following years.

[Watch the ESPN Segment](#)



Pictured: Staff from the Healey & AMG Center for ALS at Fenway Park in Boston On Lou Gehrig Day 2024

MLB Lou Gehrig Day 2024

Major League Baseball Commissioner's Office, in partnership with the Lou Gehrig Day Committee, selected the Healey & AMG Center for ALS as the beneficiary of their 2024 Lou Gehrig Day fundraising efforts. This year, \$60,000 in proceeds from the MLB's online auction and funds raised through the Lou Gehrig Day donation link benefited the Expanded Access Protocol (EAP) Program.

Bourque Family Foundation Captain's Ball

On Thursday, September 19th, 2024 at the SoWa Power Station, the Bourque Family Foundation will host the 3rd annual Captain's Ball in honor of Pete Frates. The night will include delicious food, live music and auctions raising funds to support the Bourque Family Foundation, The Frates Family Foundation and the Sean M. Healey & AMG Center for ALS.

Purchase tickets [here](#).



Impact of Philanthropy

Our work at the Sean M. Healey & AMG Center for ALS combines outstanding, multidisciplinary care with clinical and basic research informed by the needs of our patients. Philanthropy allows us to accelerate the pace of discovery and make a meaningful difference to our patients and their families. Your support helps to fuel breakthroughs and discoveries in the field of ALS and ensure everyone with ALS can access effective treatments and therapies. We are determined to find the cures and we are confident your partnership will get us there. Thank you for your consideration.

If you have questions or would like to learn more about how you can support the Sean M. Healey & AMG Center for ALS, please contact Emily Monteiro at emonteiro7@mgh.harvard.edu or visit <https://www.massgeneral.org/neurology/als/support/>.

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