



PRESS RELEASE

## **My-State Trek Virtual Event Provides New Opportunity to Support ALS Research While Social Distancing**

*Virtual event provides opportunities to get active at home and raise funds for cutting-edge ALS research at the ALS Therapy Development Institute (ALSTDI).*

**Cambridge, MA (April 29, 2020)** – The ALS Therapy Development Institute (ALSTDI), the world’s foremost drug discovery lab focused solely on finding treatments for ALS, has announced that they are pivoting their annual Tri-State Trek into a new virtual event, the My-State Trek. The My-State Trek invites community members to ride, wherever they are, to support ALSTDI’s mission and raise funds for critical ALS research. In addition to virtually riding, the My-State Trek is offering a new DIY Participation option through which community members can choose to participate through the activity of their choice; be it running, walking, or swimming, for example. With the new My-State Trek virtual format, ALSTDI is hoping to prevent the spread of COVID-19 while also opening the event up to an even larger audience and raising money to fund end ALS.

Now, more than ever, these funds are urgently needed. As a nonprofit biotech, ALSTDI relies on the support the community to continue their cutting-edge research. Due to the COVID-19 pandemic, individual donations are down significantly, and many of the events that the organization relies on to fund their work are being canceled due to the need to socially distance. The impact is real, and the need is urgent. For this reason, ALSTDI is encouraging anyone who is able, to participate in fundraising as part of the My-State Trek.

“Most people with ALS only live three-to-five years after experiencing their first signs of the disease, so fundraising for research is crucial. ALS is not an incurable disease, it’s an underfunded one,” said Steven Perrin, Ph.D., Chief Executive Officer of the ALS Therapy Development Institute. “The new My-State Trek brings together the ALS community not just in the Northeast, but from across the country, to join ALSTDI in our mission to end ALS.”

Distance riders who would like to take part in the My-State Trek event have the option to do the Virtual 270 Mile (traditional 3-day ride), Virtual 200 Mile (traditional 2-day ride), or Virtual 100 Mile (traditional 1-day ride). Participants who choose to ride can do so at home on their own stationary bike or indoor bike trainer, or ride outdoors while practicing social distancing. New this year, ALSTDI will also be offering a DIY Virtual Participant option where participants can choose their distance and pledge a fundraising goal per mile.

The annual Tri-State Trek, which was scheduled for June 19-21, 2020, is a three-day, 270-mile bike from Boston, MA to Greenwich, CT, and is one of the organizations largest fundraisers, attracting over 450 participants last year. The event has raised over \$9 million to date for research at the ALS Therapy Development Institute, and ALSTDI is hoping that the My-State Trek will be equally successful this year. Though the event will be virtual, ALSTDI has plans and tools in place to ensure that the community remains connected and able to share their progress and motivation to end ALS.

“The format has changed this year, but the mission remains the same, end ALS,” said Carol Hamilton, Development Director at ALSTDI. “Many participants have a direct connection to the disease and are riding for loved ones who are battling or have lost the battle to ALS – some riders are even battling the disease themselves.”

Participants have from now until June 21, 2020 to complete their selected mileage at their own pace. Registration for the My-State Trek is open now at [www.tristatetrek.com](http://www.tristatetrek.com).

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PRESS RELEASE

## **ALS TDI Hosts “Gamers vs. ALS” Virtual Livestream Event to Benefit Critical ALS Research**

*Gamers can join the livestream video game event on Tiltify, May 3-9, to raise funds for cutting-edge ALS research at the ALS Therapy Development Institute.*

**Cambridge, MA (May 3, 2020)** – May is ALS Awareness Month and the ALS Therapy Development Institute (ALS TDI) is inviting gamers to get involved by joining their new “Gamers vs. ALS” event, taking place May 3-9. Gamers vs. ALS is a virtual fundraiser aimed at bringing together the gaming community to benefit critical ALS research at ALS TDI. The goal is to raise \$10,000 by getting 100 gamers to each raise 100 dollars.

During this period of social distancing, gamers can participate in “Gamers vs. ALS” by joining the event on Tiltify, a fundraising platform geared to livestream video game play on Twitch, Mixer, Smashcast, Facebook, or YouTube. Viewers can then support ALS TDI and donate through the gamers’ livestream.

From world-class streamers to new gamers, “Gamers vs. ALS” allows video game enthusiasts of all levels to make a significant impact on the future of ALS treatments, which is in critical need of fundraising due to impact from the COVID-19 pandemic.

“ALS TDI is being financially impacted given that our cornerstone fundraising events have had to be postponed or cancelled,” said Steven Perrin, Ph.D., Chief Executive Officer of the ALS Therapy Development Institute. “With social media and gaming at its height, we hope the virtual impact of ‘Gamers vs. ALS’ will provide excitement and activities for our supporters during this at-home period, while at the same time helping fulfill the funding needed in order to continue the pace of research.”

Through this virtual fundraiser, the ALS and gaming community can help to support the continuation of ALS TDI’s cutting-edge ALS research from the safety of their home.

For more information and to register to participate in “Gamers vs. ALS,” please visit [fundraise.als.net/gaming](https://fundraise.als.net/gaming).

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PRESS RELEASE

## **ALS TDI Collaboration with Google's Project Euphonia Highlighted in Documentary Series Featuring former NFL Player Tim Shaw**

*"The Age of A.I." Hosted by Robert Downey Jr. Premieres Today on YouTube*

**Cambridge, MA (December 18, 2019)** – The ALS Therapy Development Institute (ALS TDI), the world's foremost drug discovery lab focused solely on finding treatments and cures for ALS, today proudly announced that it is featured in episode two of "The Age of A.I.," a new YouTube Originals documentary series that takes an immersive look at artificial intelligence and its potential to change the world. The new learning series is hosted by Robert Downey Jr. and available to stream beginning today on [YouTube.com/Learning](https://www.youtube.com/learning). Episode 2 features former NFL linebacker Tim Shaw, who is battling ALS, as he works with a team at Google to help restore his ability to communicate, testing the prototype of Project Euphonia for the first time. Through Project Euphonia, Google and ALS TDI partnered to develop technology that can help ALS patients with speech impairments, like Tim, communicate using their smartphone.

Project Euphonia was initiated thanks to data collected from people with ALS through ALS TDI's Precision Medicine Program (PMP). The PMP at ALS TDI is the most comprehensive and longest running translational research study in ALS. Through PMP, researchers at ALS TDI partner with people with ALS around the world to share and gather data on voice, movement, lifestyle, medical and family histories, genetics, biomarkers, and patient tissue samples to better understand the disease. PMP grew from 25 to 300 participants in 2014 largely due to funds raised through the Ice Bucket Challenge. Now, five years later, the program has enrolled over 600 people with ALS. In 2018, ALS TDI partnered with Google to leverage their expertise in artificial intelligence to analyze the "big data" collected from the Precision Medicine Program, making significant strides towards the development of unbiased, quantitative and sensitive measures of ALS disease progression.

"Google's technology and expertise has allowed us to draw insights from our Precision Medicine Program data that would otherwise not have been possible," said ALS TDI's Chief Scientific Officer, Fernando Vieira, M.D. "Through the Project Euphonia collaboration we are now able to see how these data can be used to not only increase our understanding of ALS, but to also build technologies that can help people with ALS, and other speech impairments, communicate in new ways."

The mission of Project Euphonia is to leverage research initiatives at Google to help people who have difficulty speaking because of neurologic conditions, like ALS, communicate and gain independence. The premise is that existing speech recognition tools have not been trained on enough ALS-affected voices yet to optimize an algorithm to recognize them. Now, as a part of Project Euphonia, many participants in the PMP have recorded hundreds or thousands of specific phrases in order to train these algorithms – allowing mobile phones, computers, and other smart devices to more reliably recognize, transcribe, and respond to the phrases expressed. This research could eventually allow people with ALS to independently send text messages or to generate spoken commands using Google Home devices. In Tim Shaw's case, additional recordings of his voice taken from the years before the onset of ALS were able to further train a text to voice program to read his words in his "original" voice, providing for a moment of particular emotional resonance in this episode of "The Age of AI."

"People with dysarthria and other physical limitations should be able to have access to written and spoken communication - email, the internet, social media, options for independent access to reading, television operation, and more," said Google's Michael Brenner, PhD. "We're excited our partnership with ALS TDI has the potential to one day help thousands of ALS patients communicate with their loved ones."

To see more of Tim's story and the work Google's Project Euphonia is doing to restore his voice, you can watch the episode visit [www.als.net](http://www.als.net) or [www.als.net/news/project-euphonia](http://www.als.net/news/project-euphonia).

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PRESS RELEASE

## Robert Downey Jr. Explores World-Changing Technologies in New YouTube Learning Series

*"The Age of A.I." hosted by Robert Downey Jr. Premieres December 18 on [YouTube.com/Learning](https://www.youtube.com/learning)*

**Los Angeles, CA (December 12, 2019)** – Today, YouTube Originals is releasing the official trailer for “The Age of A.I.” – an all-new learning series hosted by Robert Downey Jr. This new eight episode series takes a deep dive into the fascinating world of the most transformational technology in the history of humankind. Robert Downey Jr. brings his irreverent enthusiasm and curiosity to the screen as the series takes an immersive look at artificial intelligence and its potential to change the world. “The Age of A.I.” launches December 18 on [YouTube.com/Learning](https://www.youtube.com/learning).

How is artificial intelligence reshaping our world? Can machine learning enhance the human experience? Can artificial intelligence help level the playing field for people with disabilities? Increase our physical performance? Help us save lives? These are just a few of the questions explored as “The Age of A.I.” looks at the technology that will impact our world for years to come.

In each episode, viewers will meet the people on the front lines of A.I. – the scientists, innovators, and dreamers who are shaping the future and the real people whose lives may be forever changed as technology races to tackle some of the world's greatest challenges.

The premiere episode follows co-founder of Soul Machines, Mark Sagar, an Oscar-winning special effects artist who has created some of the most sophisticated avatars, as he builds an autonomously animated digital version of Grammy-award winner will.i.am. Future episodes will feature prominent figures, including former NFL linebacker Tim Shaw, who is battling ALS, as he works with a team at Google to help restore his ability to communicate, testing the prototype of Project Euphonia for the first time.

**Watch the official trailer [here](#).**

*Press interested in embedding the trailer directly into their stories can use this [link](#).*

Episodes will release weekly starting Wednesday, December 18. YouTube Premium subscribers will have access to binge the first 4 episodes starting December 18 and will be able to binge episodes 5-8 on January 15, 2020.

The series is produced by Network Entertainment with Team Downey in association with Sonar Entertainment. Sean Foley, Yon Motskin, Emily Ford, Cory Lanier, Tom Lesinski, Paul Gertz, and Derik Murray serve as executive producers alongside Robert Downey Jr. and Susan Downey. Will.i.am is a consulting producer with Evan Moore serving as a

co-producer on the series. Susanne Daniels is Global Head of Original Content for YouTube. Nadine Zylstra, Head of Learning for YouTube Originals along with Ian Roth and Laurel Stier on the Learning Development team will oversee the project for the global platform.

“The Age of A.I.” joins a growing slate of YouTube Originals focused on learning. Other projects include the platform’s monthly book club, “BookTube” featuring prominent authors like Malcolm Gladwell; “Could You Survive the Movies?” hosted by Vsauce3’s Jake Roper; “Mind Field: What is the Scariest Thing?” with Vsauce creator Michael Stevens; “Glad You Asked” from Vox Media Studios, and Retro Tech with Marques Brownlee. Upcoming Originals include “Creators for Change: The Series” premiering next year.

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PRESS RELEASE

## **ALS Therapy Development Institute Reflects on the Impact of Pete Frates and the Ice Bucket Challenge**

*Pete was a leader in the ALS community and the inspiration for the Ice Bucket Challenge, which helped raise millions of dollars for ALS research and awareness.*

**Cambridge, MA (December 10, 2019)** – On Monday it was announced that Pete Frates passed away due to complications from ALS. Pete was a leader in the ALS community and the inspiration for the Ice Bucket Challenge, which helped raise millions of dollars for ALS research and awareness. Though it has been five years since the Challenge, Pete’s legacy will continue to live on through the impact of these funds on organizations like the ALS Therapy Development Institute (ALS TDI).

“All of us at ALS Therapy Development Institute is devastated by Pete’s passing. Pete meant so much to many of us, personally, and meant the world to the ALS community. His leadership during the Ice Bucket Challenge allowed ALS researchers, including those at ALS TDI, to advance treatments and learn more about this hideous disease,” remarked Carol Hamilton, Sr. Development Director at ALS TDI.

As a non-profit biotech company dedicated to the discovery and development of effective treatments for ALS, ALS TDI relies on awareness and generosity to make its mission possible. Pete, through his work as a tireless advocate and community leader, was instrumental in helping to spread the word about this disease and inspiring people around the world to help support the search for cures. The \$4 million that ALS TDI was able to raise through the Ice Bucket Challenge was invaluable, creating opportunities that allowed the organization to greatly expand its research and drug discovery efforts.

ALS TDI was able to immediately invest these funds to advance its work to end ALS, and today the value of that investment is clearly demonstrated. Of the \$4 million, ALS TDI invested \$2 million into a potential treatment that was discovered in their lab, anti-CD40L antibody development, now called AT-1501. In November of 2018, AT-1501 entered a phase 1 clinical trial, making ALS TDI the first nonprofit biotech in any disease to develop a potential treatment and bring it from their own lab, through FDA review and into clinical trial.

On November 18, 2019, Anelixis Therapeutics, a for-profit clinical stage development company that brought the drug through trial, announced the successful completion of a Phase 1 safety and pharmacokinetic study of AT-1501 in healthy subjects and people living with ALS. This milestone represents evidence that a non-profit research institute, fueled and funded by the ALS community, can discover targets and invent drugs with real potential to impact this devastating disease.

In addition to funding AT-1501, the Ice Bucket Challenge funds also allowed ALS TDI to rapidly expand its Precision Medicine Program (PMP) from 25 to 300 participants in 2014. Through the PMP, researchers at ALS TDI partner with people with ALS around the world to share and gather data on voice, movement, lifestyle, medical and family histories, genetics, biomarkers, and patient cell biology to better understand the disease and track disease progression. Now, five years later, PMP has enrolled over 630 people with ALS and is the most comprehensive and longest running translational research study in ALS.

In 2018, ALS TDI partnered with Google to leverage their expertise in artificial intelligence to analyze the “big data” collected from the Precision Medicine Program, making significant strides towards the development of unbiased, quantitative and sensitive measures of ALS disease progression.

In 2019, ALS TDI’s Precision Medicine Program launched a new initiative to validate and discover blood-based biomarkers for ALS. This next step in the evolution of the world’s first translational research program for ALS has potential to dramatically enhance the understanding of how ALS works and to better

recognize when treatments are effective in people with ALS – without ever asking participants to leave their homes.

“Pete’s efforts were instrumental in allowing us to expand our research and they have helped us to make significant strides in our work to end ALS”, said Steve Perrin, CEO of ALS TDI. “ALS TDI’s discovery and development of a potential treatment, AT-1501, and the expansion of our Precision Medicine Program, were made possible thanks to the money raised through the Ice Bucket Challenge.”

The ALS TDI lab is headquartered in Cambridge, MA and is open to all community members who would like to come tour the space, learn more about their work to end ALS, and see firsthand how Pete Frates’ legacy lives on through the research his efforts helped make possible.

To learn more about the research being done at the ALS Therapy Development Institute, or to schedule a tour, visit [als.net/research](https://als.net/research).

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