

The End.

Everything that has a beginning has an end. Let's close the book on ALS. The End.

January 23, 2023

Edition 4

to be
inspired is great,
to
inspire
is
incredible



Our Continued Support to ALS TDI is in Good Hands

A Letter from ALS TDI CEO & Chief Scientific Officer, Fernando Vieira:

Thanks to all of your generous support, we at the ALS Therapy Development Institute (ALS TDI) have been able to accomplish so much during the past several months!

First, you've allowed us to complete studies that are a true force multiplier to results of landmark study, the [ALS Precision Medicine Program](#) (PMP), that we initiated in 2014. Through this study, we learn about ALS directly from people living with ALS. Much like we now understand that cancer is not one single type of disease with one single type of cause or single type of treatment, we are learning that ALS is not one single disease. It will take multiple treatment strategies to end ALS. The most important way to learn which treatment strategies will work best for each person with ALS is to learn everything we can about each person's ALS. Through the PMP, we learn which people have associated types of ALS, and then we work to invent drugs for each type of ALS. Thanks to you, we have started a study that will measure 20,000 different molecules in each person's



ALS TDI's biotech lab in Watertown, MA

blood samples. By measuring each molecule, we learn what processes are different in a person with ALS compared to healthy people or compared to other people with ALS. Then, we'll invent medicines to shift those processes to hopefully produce a more healthy person.

Secondly, your support has allowed us develop transgenic mice - or designer mice. These mice are designed to develop symptoms that match specific types of ALS described above. If we can invent treatments that make the mice live better and longer lives, then we have quite possibly invented treatments that will make people with similar types of ALS live better and longer lives. This is a necessary step in the discovery of ALS medicines. Thanks to you, we are developing three entire new breeds of mice for this purpose.

Your support means so much to me and to rest of the scientists working each day at ALS TDI to end ALS. You unlock our potential. Thank you.

--Fernando Vieira, M.D.



We were pleased to host an Ales for ALS event at Insight Brewery in August 2022. All proceeds went directly to the ALS Therapy Development Institute (ALS TDI). We had live music, food, a great venue, and guest speakers Kevin Geraghty and Lynn Giovannelli who are battling ALS as we speak. Even the dogs supported us! Oh, and we had lots of beer, particularly our featured beer, Hazy Heller. Look for more of these events to come.

What is ALS?

Amyotrophic lateral sclerosis (ALS) is a progressive disease that affects motor neurons in the brain and spinal cord, causing loss of muscle control. ALS is often called Lou Gehrig's disease, after the baseball player who died from it in 1941. It often begins with muscle twitching and limb weakness, or slurred speech. Eventually, ALS affects control of the muscles needed to move, speak, eat and breathe. There is no cure for this fatal disease and currently no effective treatments. Let's change this.

Fund Update

**To date, we have raised a total of \$850,000 in Jim's memory with your help. THANK YOU!*

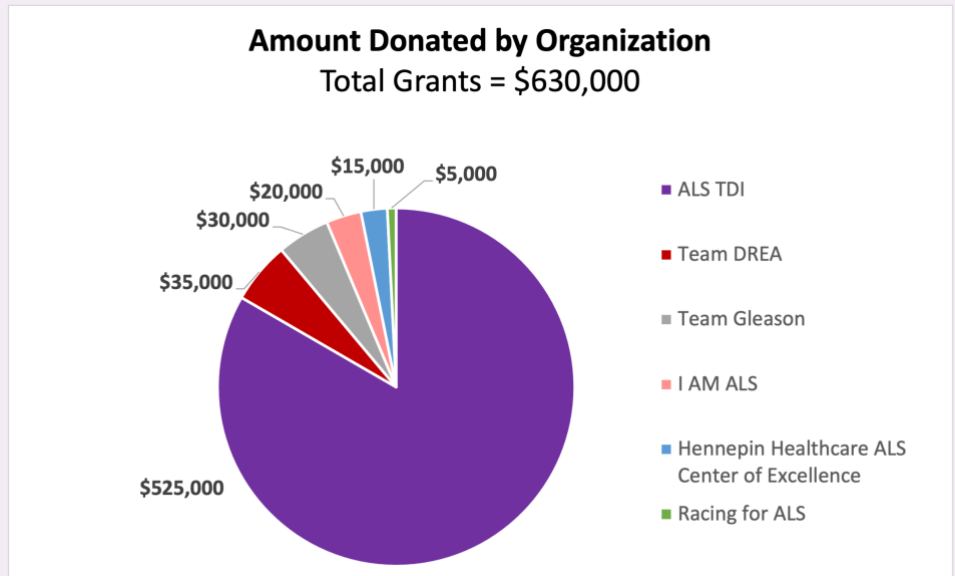
Our Fund has continued to grow through the contributions of many of you. Words cannot express how thankful I am for the support of family and friends to help find a cure for this terrible disease.

Together we have raised \$850,000 since the fund was started in mid-2020 when Jim lost his battle with ALS. In addition, through the generosity of my dear friend, Becky Finnigan, who passed away in May 2022 from cancer, the Fund will be receiving another \$60,000 that has been left to us by Becky to support this endeavor.

The pie chart shown here will continue to inform you of where our money is hard at work in research, advocacy, and aide to those in need.

If you can, please help us reach a \$1 million milestone, donated to finding effective treatments and a cure that are so long overdue. Thank you, thank you, thank you!!!

www.givemn.org/jimheller/story



\$ 213,000* Balance

*Includes payment of \$7K of expenses over 3 years.

Save the Date

Please join us on April 14, 2023 as we honor and remember all those affected by ALS and raise funds for treatments and a cure. Remember: ALS is not an incurable disease – it's an underfunded one.

Feel free to contact me at lori.larson2@comcast.net or visit the website for more information.



“Keep Your Fork”

Remember when you were a kid and your mom was clearing the table after dinner but told you to “keep your fork” because dessert was coming? Well, Jim and I decided during our battle with ALS that the fork would be our symbol. It was a reminder to us that the best is yet to come. Only God knows what and when that will be for each of us. I would encourage those living with ALS and their families/caregivers to keep the faith. For some of you, the fork may symbolize the eventual cure to this disease, and maybe to others you will feel the same assurance of eternity and sense of peace from the fork that we did. In any event, please remember that **the best is yet to come.**

Racing for ALS

Two amazing brothers, David and Scott Lloyd, have put a new spin (no pun intended) on raising funds for ALS research and drug discovery. David was diagnosed in October 2017 after being perfectly healthy, in his late 40's, and raising two children along with his wife. David and his brother, Scott, who both always had a passion for racing and fast cars, purchased a 2019 Hendrick's Motor Sports Track Attack car and the rest is history.

This car has been raced by Kasey Kahne, Chase Elliot and William Byron over several seasons. Now, the brothers have raised over \$400,000 by hosting race fundraisers, and they are just getting started. I had the opportunity to meet Scott and see the car first-hand, and I am honored that Jim is right along with them each time they hit the track and "race to end ALS."



These pictures allow you to see Jim's name on the roof of the car, and Scott also wanted me to know that Jim went 180 mph with him recently (pic of speedometer to prove it)! Thank you, Lloyds ... keep up the good work, and we are praying for you, David.

Being a Voice for Change

I continue to look for new ways to help in the fight against ALS, beyond just financial support. The research organizations, clinical trials and pharmaceutical companies have come a long way in recognizing that the patient's (or caregivers's or advocate's) voice is important in workingtogether to solve the puzzle that is ALS. In that regard, I have been asked and agreed to participate in several endeavors:

- Biogen Pharmaceuticals Patient Advisory Committee
- Clene Pharmaceuticals Patient Advisory Committee
- Northeast ALS Consortium (NEALS) Patient Advisory Committee
- HEALEY ALS Platform Trial @ Mass General Patient Advisory Committee
- Northeast ALS Consortium (NEALS) Research Ambassador

I remain committed to contributing whatever advice, knowledge, wisdom or brainstorming ideas I may have that can help us all end ALS.

