

The End.

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

December 1, 2021

Edition 3

Life is so much brighter when we focus on what truly matters...



The Jim Heller Fund Grants Another \$100,000 to ALS TDI to Continue New Drug Lead

As I reported in my last newsletter, all of you helped ALS TDI to bring, in house, a new animal (mouse) model of ALS. Animal models of disease are critical, as they have the biological systems (circulatory, immune, respiratory, etc.) that cells do not.

To remind you of what was stated in the last newsletter, the ALS TDI science team first discovered a new drug 'target' in the major form of genetic ALS (a mutation of the C9orf72 gene). Next, they invented and synthesized molecules to hit that target, and continue to test those molecules in cellular models. Concurrently, the new mice brought in to further test the effects of these molecules (needed to see any downstream issues these molecules may cause on the biological systems mentioned above) must be validated and further bred to ensure an enduring, reliable model. All of this, as you may be able to decipher on the flow chart schematic included as page 4 of this newsletter, is work that is happening now. These experiments will take months, and I will report back to you on their progress, including the overall progress



ALS TDI's biotech lab in Watertown, MA

on the project as new sections of the flow chart have begun.

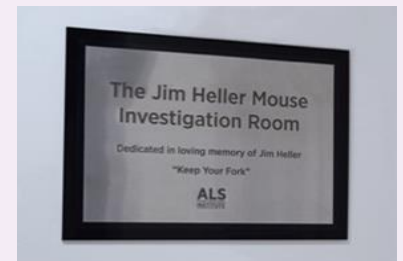
Drug discovery and testing, as I've learned, is a very difficult and tedious process, with many more failures than successes. But the science must continue, and we must not stop until treatments are found for all those currently living with ALS and those yet to be diagnosed. It could be you or one of your loved ones next.

What is ALS?

Amyotrophic lateral sclerosis (ALS) is a progressive nervous system 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 weakness in a limb, 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.

ALS TDI Lab Room Dedicated in Memory of Jim Heller

In recognition of the support provided by The Jim Heller Fund, ALS TDI chose to name a room of the lab in honor of Jim. The dedication was done on November 5th, 2021 in conjunction with the 2021 ALS TDI Summit held in Boston, MA. Pictured left to right: Carol Hamilton, Sr. Director of Development, Lori Larson Heller, Fernando Vieira, Chief Scientific Officer and CEO.



"Over and over, every day, scientists work in this room with the urgency this disease requires. Jim Heller's legacy will be a future in which ALS is a treatable disease. I am so grateful to his family, friends, and colleagues who are allowing us to affect that legacy faster."

- Carol O. Hamilton,
Sr. Director of Development,

Fund Update

*While asking for money is always a bit uncomfortable, I am so dedicated to finding a cure for this horrible disease that it has almost become second nature for me. For many of you, you gave a generous donation last year, and we can't thank you enough. (Some have even given one or more donations already this year ... thank you!). However, here is where I remind you that this is a new tax year, and your donations go straight to a 501(c)3, giving you a 100% charitable deduction for this year's taxes. With your help, we can continue to be a part of the answer in curing ALS. **PLEASE consider a donation in memory of Jim.***

\$252,375 raised via hundreds of individual donations-8/20-11/21

(\$50,000) granted to ALS TDI for PMP Program-12/20

(\$10,000) granted to Team Gleason for ALS Patient Equip.-12/20

\$225,000 donation from The Opus Group-3/21

(\$150,000) granted to ALS TDI for Therapeutic Development-4/21

(\$10,000) grant to Team Gleason for ALS Patient Equipment - 4/21

(\$20,000) granted to I Am ALS for advocacy work -7/21

(\$100,000) granted to ALS TDI for Therapeutic Development - 8/21

(\$25,000) granted to ALS TDI for Gala Sponsorship - 8/21

(\$15,000) granted to ALS TDI for Therapeutic Development - 10/21

\$ 97,375* Balance

To date, we have raised a total of **\$477,375 in Jim's memory with your help. THANK YOU!!*

www.givemn.org/jimheller/story

Free Fallin'

I wish I could say that I enjoyed my own *free fallin'* experience recently as much as I enjoy the song by Tom Petty. But that would be a lie. I thought I would share the irony of the timing as well as the lessons learned from a fall I took in May (which helps explain the delay in getting my newsletter out).

I had decided to head to Atlanta to spend the first anniversary of Jim's passing with Bryan, Jeff and their families, hoping to help each other through what I knew could be a tough weekend. On my first night there (note: hadn't even unpacked my suitcase yet) as I was heading upstairs to go to bed, I managed to lose my balance about half-way up and "free fall" back down. We are not talking about a tumble down the stairs, but rather a tree falling in the forest. Having turned around to see what I had dropped, I literally felt like I was having an out-of-body experience as I watched myself slam down on my entire right side. Boom. Don't get me wrong, the steps were beautiful, but they were wooden ... and hard. I broke my femur, hip and humerus on the right side of my body. Thank God for Bryan, Jen and the girls, as they watched me try to figure out how I felt and then called 911. They continued to be there for me throughout the ordeal. I spent the better part of two weeks in a Trauma 1 hospital in Atlanta, followed by a medical flight back to Minneapolis and another three weeks in a transitional care unit here in Minneapolis. What was supposed to be a healing weekend for all turned into a pretty rough five weeks away from home.



So, the irony here is that my fall happened one year to the day that we were told Jim was dying and wouldn't make it through the night. Weird, right? As for lessons, my first lesson learned is to keep one hand free for the railing when on the stairs instead of loading yourself up with sixteen things and no ability to brace a fall. My second lesson is more of a life lesson. Did you know the right side of our bodies is our "male" side? I basically broke the right side of my body, had to learn to walk again and stand on my own two feet. Symbolic? How about the fact that I've told my therapist many times that Jim and I were "joined at the hip"? And now Jim is gone and I'm getting my hip put back together with titanium rods? I am reminded that things don't happen **to** us, they happen **for** us. Is it possible that I needed to also be reminded to slow down, that I can do this, that I am strong, and I will survive?



"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.**



Important ALS Legislation

We in the ALS community are hopeful that this is the year we can get a bill passed in both the House and the Senate for the Accelerating Access to Critical Therapies for ALS Act ("ACT for ALS"). This bill will make \$100,000,000 available each fiscal year from 2022-2026 to build new pathways to fund early access to ALS investigational therapies, accelerate ALS and other neurodegenerative disease (such as Parkinson's) therapy development through a public-private partnership, and increase research on and development of interventions for rare neurodegenerative diseases through a new Food and Drug Administration (FDA) research grants program. I have been part of a grassroots effort to call on Senators and House members to support and co-sponsor these bills. To date, we have 330 co-sponsors in the House and 50 co-sponsors in the Senate. These numbers have put the ACT for ALS bill in the Top 100 co-sponsored bills in the **history of the U.S. Congress** (pretty impressive for a grassroots movement). I was pleased to report that we were able to get a clean sweep of support for this bill in MN ... all eight House members and both U.S. Senators are co-sponsors! My fingers are crossed that I can report the passing of this bill in both chambers as well as signature by the President in my next newsletter.

Going Back to College? Sort of.



What did I do with my time as I sat around in my wheelchair this summer, you ask? Remember that I reported in my last newsletter that I had received a scholarship to take an online college course. Talk about timing ... at a point in my life where I couldn't do much else, I returned home from the "fall" incident on June 18th and the class started the following week. The course was offered by a collaboration of NYU and The University of Arizona Law School and was entitled "Access to Investigational Medical Products: Clinical Trials, Expanded Access, and Right to Try." I am so grateful that I had the opportunity to participate in this, and I left the class well educated on the complexities of expanded access to clinical trials. Despite these complexities, we must make headway in this area, since less than 10% of people living with ALS will actually qualify for a clinical trial. Without the ability to join a clinical trial or participate via an expanded access pathway, ALS patients literally have no hope and are simply left with the horrible words often heard at diagnosis ... "get your affairs in order".

A Cruel Connection - Veterans and ALS

Did you know that America's military veterans are approximately twice (if not more) as likely to develop ALS than other segments of our population? Scientists have yet to find a cause. The U.S. Department of Veterans Affairs recognizes ALS as a service-connected disease and provides financial and medical support to those with at least 90 continuous days of military service. If you qualify for these benefits, they can provide significant assistance in obtaining medical care, assistive devices, and financial support.

Study after study continues to demonstrate this to be true: If you serve in the military, regardless of the branch of service, regardless of the war, and regardless of whether you served during a time of peace or a time of war, you are at a greater risk of dying from ALS than if you had not served in the military.

The Mayo Clinic guesses that reasons for the connection "may include exposure to certain metals or chemicals, traumatic injuries, viral infections and intense exertion" but says that "exactly what about military service may trigger the development of ALS is uncertain."

The disease continues to stump scientists in general, much less trying to figure out the connection to military service. ALS/Lou Gehrig's Disease was first seen in 1869, more than 150 years ago, yet the prognosis is the same today as it was then: a terminal disease with death in an average of 2 to 5 years. We owe it to our veterans and active military to do more studies to understand why those who are protecting our freedom by putting their lives at risk are also more likely to die from this monster.



Senator Lisa Murkowski, center

I had the opportunity to spend some time in Washington, D.C. in late September to get together with other ALS advocates who have become great friends (a blessing in disguise, I think they call it). We were honored to be able to spend some time with Senator Lisa Murkowski (R-Alaska). Lisa is a champion in the ALS arena and is the co-chair of the ACT for ALS bill in the Senate, along with co-chair Christopher Coons (D-Delaware). We are so pleased that this bill has bipartisan support and are thankful to have both sides of the aisle working together in both the House and the Senate.

