

April 17, 2019

Robert and Mary Ann Blais  
Blazeman Foundation for ALS  
172 Marnoch Drive  
Seekonk, MA 02771-3812

Dear Bob and Mary Ann,

This past February 27<sup>th</sup> the Maryland Brain and Tissue Bank attended a Rare Disease Day symposium hosted by the Frank H. Netter M.D. School of Medicine at Quinnipiac University in Connecticut. We were pleased to attend and to represent not only the Bank, but the Blazeman Foundation for ALS as well. As you know, Rare Disease Day occurs at the end of February and has taken place internationally for the past 12 years. Specific events are held in cities and research institutions throughout the world to bring attention to the thousands of identified rare diseases which, in America, affect approximately 1 in 10 individuals. The medical students at Quinnipiac University have taken the initiative to organize a symposium for the past four years. It was a delight to participate and support their efforts on behalf of the Blazeman Foundation at this event attended by researchers, physicians, advocates, and patients.

It was particularly meaningful to attend this meeting given Jennifer Hansen's involvement. As you are both well aware, Jenny has been a highly devoted and successful fundraiser for the Blazeman Foundation for ALS and is currently a medical student at Quinnipiac University. She participated in this year's organizing efforts and made the initial invitation for us to attend the meeting. Our representative at Rare Disease Day was one of our Project Managers, Shea Lawson. She was able to spend a lot of time with Jenny who made her visit there pleasant and productive. Our attendance at Rare Research Day where we promoted research on ALS would not have been possible without the support of the Blazeman Foundation for ALS and we remain grateful for your continued sponsorship and confidence in the Maryland Brain and Tissue Bank.

As we approach ALS Awareness Month in May I would also like to update you on our activities made possible through the Blazeman Foundation for ALS's generous funding of the "Expansion of the Blazeman ALS Tissue Collection" project. These funds are used primarily to recruit and recover post-mortem tissue from ALS tissue donors for use



in biomedical research, and to attend meetings to increase awareness about the University of Maryland Brain and Tissue Bank among ALS patients and researchers.

Once again, this funding made it possible to attend the annual Neuroscience meeting where over 30,000 physicians and scientists from around the world meet to learn about recent advances in neuroscience research. We believe attendance at this meeting is highly beneficial. ALS is ranked number one in terms of the number of samples we have shipped from neurologic and developmental disease tissue for the second year in a row. We have already shipped almost 300 ALS tissue samples to multiple investigators this fiscal year. Although we are only seven months into our NIH contract year this is already higher than for any year in our current NIH contract initiated in 2014.

We look forward to continued success and to working together with the Blazeman Foundation for ALS. Participating in the fight against ALS gives our activities added meaning and we are honored to help further Jonathan's wish to promote and facilitate ALS research, ...*so others may live*. Thank you again for your continued support and allowing the University of Maryland Brain and Tissue Bank to partner with you in this most worthwhile of missions.

Sincerely,



Thomas Blanchard, Ph.D.  
Director, University of Maryland Brain and Tissue Bank

