Brief Video Message re: FDA Decision on Bardoxolone Methyl

Video Recording Link: https://youtu.be/_CrWR3PAfG0

Hello, I'm Lisa Bonebrake, Executive Director of Alport Syndrome Foundation. I am also an Alport syndrome patient, and parent of a patient. The board and staff of ASF want to be sure that our membership and community of patients and families hear directly from us about the FDA's recent decision not to approve bardoxolone methyl as a treatment for Alport syndrome.

We remain in touch with the study sponsor, Reata Pharmaceuticals, and will do all we can to update you as the company makes decisions about the future of bardoxolone methyl. If you have questions about the FDA's decision, please direct them to info@alportsyndrome.org. If ASF does not have the information available to answer your question, we will share it with Reata Pharmaceuticals to gain answers so that we can respond to you appropriately and accurately.

Though the outcome is not what we anticipated or hoped for as the result of the first-ever clinical trial in Alport syndrome, it is really important for us to put in context the following:

- This is how science and clinical trials work. It can be a long and arduous path, but it is our only way forward to better treatments and possible cure.
- We need to remember that progress was still made in getting this far and all that's been learned over 4 years, including the study being a catalyst for a new and more accessible genetic testing option that led to thousands of patients being accurately diagnosed and becoming aware of their specific genetic mutation.
- This is not the only current clinical trial in Alport syndrome. Others are available as potential options, and this is extremely valuable and not often the case with a rare disease.

ASF wants to remind you all of how important it is that we not lose momentum for innovation or for science.

Please know the reason why ASF is investing directly in a new patient registry, in partnership with the National Kidney Foundation, and a new ancillary study to collect bio-samples and natural history data with Neptune at the University of Michigan, is because these major projects provide exactly the kinds of data that directly support a regulatory pathway for potential new drug therapies. This is the data that pharmaceutical companies depend on as they design clinical trials, and as they prepare their cases to

the FDA about new drug therapies. As we roll out and launch these new projects over the next few months, we encourage you to participate, if possible.

Together, as ASF membership grows, our voices get stronger. Many patients are making use of our educational resources and engaging in opportunities to participate in research and data collection. At ASF, we remain focused every day on improving the lives of Alport syndrome patients through education, empowerment, advocacy, and directly investing in research. We remain diligent and hopeful in our vision to conquer Alport syndrome.

As we learn more from the study sponsor, Reata Pharmaceuticals, we will update you as soon as we can.

In the meantime, on behalf of the board and staff of Alport Syndrome Foundation, we extend our deepest gratitude to the patients who participated in the Cardinal and Eagle Studies and the doctors who participated as principal investigators, only adding to their own workload with no compensation, to help move research forward for patients.

You all proved Alport patients are willing to participate in clinical trials, and that the doctors who treat us are willing to selflessly oversee clinical trials and sites to enroll patients like us. This is a huge hurdle to overcome in a rare disease community and we are grateful.

Thank you for your interest and support and for your continued willingness to help us change the stories and outcomes for Alport syndrome patients and families. Thank you so much.