

After several meetings and many discussions, it was clear that Dr. Eichler and the CRND would be the ones to help us accomplish these goals. By November of 2019 we had provided the Year-1 capital needed for the CRND to create the assets needed and begin the research. Three years and a global pandemic later, we have found another patient with the same variant, and we are in awe of what the CRND has accomplished most importantly, publishing the FIRST medical journal manuscript ever written on Avery's variant on January 31, 2023. In addition, they have developed vectors and are testing delivery routes for potential gene therapy treatments. We hope that this means the variant will be redesignated as pathogenic and that in turn, our patient population will grow.

The team and this work has changed our lives in the most magical ways and this experience is a testament to the power of philanthropy to drive scientific discovery that directly impacts the lives of patients and families like ours."

