Greetings,

My name is Christopher Haberman, and I'm writing on behalf of my whole family – my wife of 16 years, my 10 year old daughter, and my 7 year old son.

Our son was diagnosed with Pompe Disease at age 3, and since February 28, 2017 he has received enzyme infusions every other Tuesday. This was a life-changing diagnosis for our family, and not just because this meant spending far more time in doctors' offices or hospital rooms than we'd prefer. This diagnosis has made us fierce advocates for those who have muscle diseases.

We stand on the shoulders of those who came before us. Our son Isaac is walking, running, jumping, rock climbing, and skiing because those who came a generation before us funded research that brought a treatment for Pompe Disease to the market. We are determined to make the world a better place for the next generation of children born with muscle disease.

This makes adding muscle diseases to the newborn screening panel an important issue for us. In the world of muscle disease, time is muscle. Early detection is key, because you can't get back muscle that has been lost. You can strengthen existing muscle, but you can't regain lost muscle. Learning your newborn has a muscle disease can be a difficult thing for new parents, but that information is powerful and can lead to treatment before a child loses critical muscle.

We can only imagine what an earlier diagnosis would have meant for our son. We do know what it means for those who have infantile-onset Pompe Disease. It means life instead of death. We have friends who lost their daughter before she was able to celebrate her first birthday. Had she been diagnosed at birth she would be with us today because there is an effective treatment for even the worst cases of Pompe.

Today we ask that you add Pompe to Iowa's newborn screening panel for the sake of children in Iowa and around the country. We are seeing a wave of momentum in adding conditions like Pompe to the newborn screen. Each state that adds it paves the way for others to do the same.

Thank you for your consideration.

Christopher, Margaret, Jordan, and Isaac Haberman