Dear Friends,

Thank you for the invitation to join you at this year’s University of Minnesota College of Pharmacy Rare Disease Day. I want everyone to know how thankful I am for the unrivaled dedication of the researchers, advocates, students, families, and patients here today. You all are leaders in the rare disease community, working every day to make breakthroughs that will help us better understand the human body, identify treatments and cures, and save lives.

Throughout my time in the Senate, I have consistently pushed my colleagues to support the National Institute of Health (NIH) and enhance medical research funding in budget and appropriations negotiations. But funding isn’t the only answer. We must also continue elevating the needs of patients and their families and making sure they have a better seat at the table when the FDA is reviewing new treatments. Patients and families need greater clarity about the process for approving these drugs and their input should be valued every step of the way.

Passing the 21st Century CURES Act just over three years ago was an important milestone for getting patient experience into the drug approval process. But that is just the start. That is why I have continued working with Mississippi Senator Wicker to ensure the FDA consider patient experience or patient-focused drug development information as part of the risk-benefit assessment.

Moving forward, there is still a lot of work to do, but I am working across the aisle – because members of both parties know how important research is and how many families are counting on the ability to access the treatments and cures that are the result of the work going on at the NIH. And I am confident that together, we will accomplish some truly remarkable things. We will find treatments and cures. And we will save lives. So thank you for everything you do for rare disease patients, and keep up the great work!

Sincerely,

Amy Klobuchar
United States Senator