Medical Research: It's About Max

"Every 3 weeks I get really angry and groggy and tired, and I get sick. And it happens every 3 weeks."

When he was just 22-months-old, Max Hasenauer was diagnosed with X-linked agammaglobulinemia (XLA), a very rare genetic condition where the body does not produce the antibodies necessary to maintain a functioning immune system. In order to survive, he takes antibiotics daily and receives infusions of new antibodies every three weeks. In the days leading up to his infusion, he feels fatigued and ill as the old antibodies wear off. Despite his treatments, XLA can quickly become life-threatening. Max has even had to miss school during flu season to avoid contact with very ill people, who could jeopardize his health.

While new treatments are certainly needed to improve Max's quality of life, he would not be alive today without the research that made his infusions possible. The National Institutes of Health (NIH) has also launched the "Therapeutics for Rare and Neglected Diseases program," a collaboration between NIH researchers, nonprofit organizations and pharmaceutical and biotechnology companies to accelerate the development of new treatments for many rare diseases.

Approximately 7,000 different rare diseases affect 30 million Americans. From 1983-2013, over 2,900 potential rare disease treatments entered the research pipeline.[1]

We've made progress. But the funding to sustain it is eroding.

Congress: harness your compassion, gather your will, and fund the National Institutes of Health at $32 billion in FY15.

Do it for Max.

www.researchamerica.org

[1] www.rarediseases.org