

2024

Rare Disease Week on Capitol Hill



Christine Petty SUMMARY REPORT

It was both such an informative and wonderful experience to join over 700 fellow rare disease advocates across the country at the 2024 Rare Disease Week held on Capitol Hill. Rare Disease Week is an annual event that brings together advocates, patients, and policymakers to both raise awareness and advocate for important legislative initiatives in support of those living with rare disease in the United States.

I had never heard of NPC prior to my son's diagnosis. Since then, Ryan's diagnosis has changed every aspect of our life as a family. While NPC is considered an ultra-rare disease with only an estimated 300 patients in the U.S., rare diseases as a whole are not so rare, with approximately 30 million people in the U.S. who live with rare disease every day. While the needs of each rare disease community are unique, there are powerful common shared experiences that unite us.



"The route to achieving equity will not be accomplished through treating everyone equally. It will be achieved by treating everyone justly according to their circumstances."

- PAULA DRESSEL

I learned about several important rare disease legislative initiatives such as the Interagency Coordinating Committee for Rare Diseases (IACC), the Accelerating Kids' Access to Care Act, the Creating Hope Reauthorization Act, the Safe Step Act and other important legislative initiatives in the works. During the week I also had the opportunity to meet other rare disease advocates within my state and local community as we prepared for meetings with our congressional representatives.



It was a great experience to meet other rare disease community members and hear their stories, some of whom I have been in contact with after leaving DC and who have provided valuable advice on navigating the local healthcare system with a rare disease. I hope to continue to attend Rare Disease Week in future years!

Learn more about the 2024 EveryLife Foundation legislative asks at <https://t.ly/LkJH->.

