

2026

Rare Disease Week on Capitol Hill



Christine Petty SUMMARY REPORT

What an incredible opportunity it was to attend my second Rare Disease Week on Capitol Hill. I attended my first Rare Disease Week in 2024, shortly after Ryan’s diagnosis. I was unable to attend in 2025, but this year I wanted to bring Ryan, my NPC hero, and give him the gift of meeting the incredible community of fierce advocates that attend Rare Disease Week and share his story. I’m so glad I did.

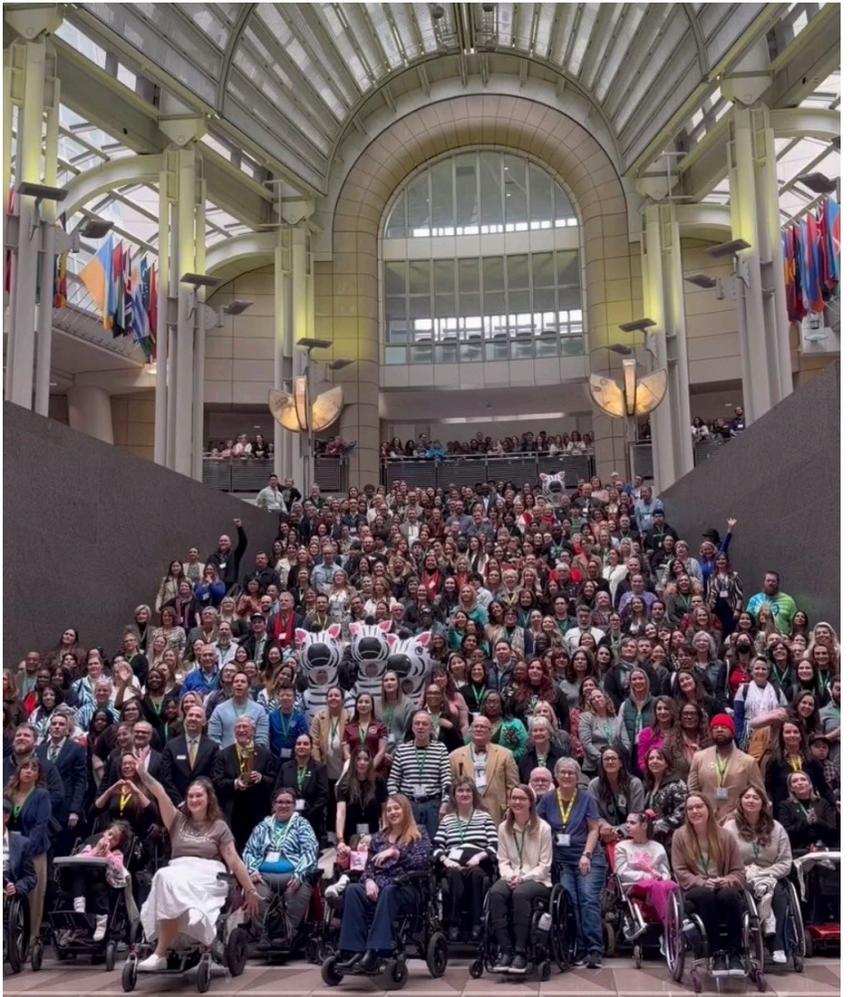
Rare Disease Week kicks off with a day where various speakers educate the attendees on current rare disease legislative initiatives and priorities. From there, advocates meet their fellow constituents who will be participating in the Hill meetings taking place later in the week. Admittedly, Ryan didn’t find the panels as exciting as I do, but he loved seeing the fun people in zebra costumes and visiting the photo booth.



Ryan took time leading up to his congressional meetings to practice his introduction. He was especially excited to tell everyone his nickname from taekwondo (Super Star Rocking Jay). When it was Ryan’s turn to speak, he introduced himself and handed out his special “Cure NPC” bracelets. He had a blast and felt so special. Not only that, but he shared his story and showed exactly why lives like his are so important. I’m so proud of him. More importantly, he’s proud of himself too.

For more information on various legislative initiatives currently underway to help our community, please go here: <https://everylifefoundation.org/rare-advocates/advocacy-tools/policy-primers/>

Christine Petty
Mom of Ryan, NPC



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