

[Your Name]
[Your Address]
[City, State, ZIP Code]
[Your Email]
[Your Phone Number]

[Date]

The Honorable [Legislator's Name]
[Office Address]
[City, State, ZIP Code]

Dear [Legislator's Name],

I hope this letter finds you well. My name is [Your Name], and I am a constituent from [Your City/Town]. I am reaching out to introduce you to Prader-Willi syndrome (PWS), a rare and complex genetic disorder that affects approximately 1 in 15,000 births. PWS is characterized by low muscle tone, cognitive challenges, developmental delays, and an unrelenting feeling of hunger that leads to serious health risks. The challenges of living with PWS place a tremendous burden on families, requiring constant vigilance and access to specialized care and services.

As an advocate for the PWS community in Texas, I am working alongside families, our Texas PWSA Chapter and PWSA | USA to promote policies that will significantly improve the lives of those affected by this condition. Our advocacy efforts in Texas are focused on increasing access to critical medical care, expanding support services for individuals with rare diseases, and ensuring that individuals with PWS have access to the resources they need to thrive.

We are particularly interested in discussing legislative initiatives that would eliminate the IQ barrier for individuals with PWS to qualify for waiver services. Currently, many individuals with PWS are denied access to crucial support programs simply because their IQ does not fall below the required threshold, despite their significant functional limitations. Removing this outdated and inequitable requirement will ensure that eligibility is based on actual need rather than an arbitrary IQ score. We believe this change will provide much-needed support for individuals with PWS and other rare diseases, granting them access to essential services such as Medicaid waivers, disability benefits, and long-term care options.

I would greatly appreciate the opportunity to meet with you or a member of your team to discuss how we can work together to support the PWS community in Texas. Your leadership and support can make a meaningful difference in the lives of individuals and families affected by this rare disease.

Please let me know a convenient time for us to meet. I look forward to your response and to working together to create positive change for the PWS community. Thank you for your time and consideration.

Sincerely,
[Your Name]
[Your Contact Information]
[Your Affiliation, if applicable]