



PWSA | USA's 2024 D.C. FLY-IN IMPACT REPORT

MAY 13 - 15, 2024 |
WASHINGTON, D.C.



SUMMARY

Between May 13th and 15th, PWSA | USA held its second biennial D.C. Fly-In to celebrate PWS Awareness Day. This event was a resounding success, drawing 139 dedicated advocates from 31 states. Together, these advocates attended a remarkable total of 131 Congressional meetings, highlighting the widespread support and commitment to advancing our cause.

Our advocates engaged in meaningful discussions, ensuring the voices of those affected by Prader-Willi syndrome were heard loud and clear on Capitol Hill. We gathered congressional support for adding Prader-Willi syndrome to the Department of Defense Peer Reviewed Medical Research Program, gathered co-sponsors for the Promising Pathway Act, and obtained congressional support for PWS research and development with the FDA.

131

Congressional
Meetings



- Congressional meetings: 131
- Member level meetings: 13
- Attendees: 139
- States represented: 31
- Senate meetings: 67
- House meetings: 64
- Democrat offices: 74
- Republican offices: 55
- Independent offices: 2



139

Attendees

31

States &
Districts
Represented



TESTIMONIALS



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If there's a silver lining with all this, it's all the amazing people we've met. Coming to events like this, we're just surrounded by people that get it.

- David D. (NY)
Dad to Zahra (6), living with PWS



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We met with senators and representatives to discuss PWS. If I'm being honest, it was scary, it was intimidating, but I think overall it felt really good.

- Kenna G. (KS)
Mom to Lucca (9), living with PWS



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I've been to D.C. before, but this is my first time advocating. I really think I made an impact. It felt great getting my voice out and telling the representatives and senators what it's like living with the syndrome and how desperately we need treatments, especially for adults. My biggest goal was to share how complex PWS is and how difficult it is for the whole family. Some people think I'm absolutely normal because I'm so intelligent, but behind the picture, they don't know what I'm living through.

- Conor H. (43) (IL), living with PWS



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I was talking with all the Minnesota representatives and senators. It was very cool. This was my first time ever doing this, and I think it was very successful.

- Alex G. (MN)
Sibling to John (18), living with PWS

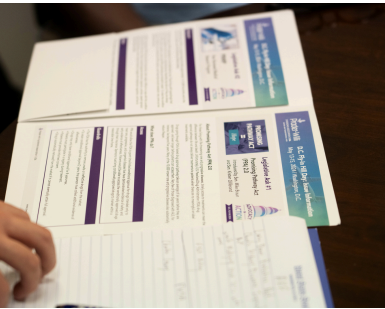


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Having the chance to speak with people who are in a position to affect change for my daughter and all of her PWS buddies, there's just nothing, nothing more important I could be doing.

- Melanie M. (NH),
Mom to Josephine (5), living with PWS

Find more 2024 D.C. Fly-In recap information at www.pwsausa.org/events/dc-fly-in-2024



[CLICK HERE TO VIEW THE D.C. FLY-IN PHOTO GALLERY](#)



D.C. FLY- IN RECAP VIDEO

Click the image to watch!

THANK YOU, SPONSORS!



On behalf of PWSA | USA, I extend my heartfelt gratitude for your generous support in funding our 2024 D.C. Fly-In advocacy event. Your contributions were instrumental in making this event a resounding success. With your help, we were able to bring together dedicated advocates and policymakers to advance crucial initiatives for those affected by Prader-Willi syndrome. Thank you for your unwavering commitment to our cause and for helping us make a significant impact in the lives of individuals and families within the PWS community.

We are excited to announce that our next Fly-In event will be held in May 2026. Please save the date and consider sponsoring this important event again. Your continued support will be invaluable in bringing families and individuals affected by PWS to Washington, D.C., where they can advocate directly to lawmakers for their unmet needs.

Sincerely,

A handwritten signature in cursive script that reads "Stacy Ward".

Stacy Ward, MS, BCBA
CEO, PWSA | USA

