

#RareDiseaseDay
FEBRUARY 28, 2025

15 WAYS TO RAISE AWARENESS FOR PWS



Prader-Willi Syndrome Association | USA

1. SHARE PWSA | USA'S RARE DISEASE DAY GRAPHICS & YOUR OWN PHOTO

Download one of our [PWS-specific Rare Disease Day graphics](#) and post it on social media with a message of support. Encourage friends and family to do the same!

2. READ & SHARE "IT STARTS WITH HELLO: KATIE'S STORY ABOUT PRADER-WILLI SYNDROME"

[Buy Dr. Destiny Pacha's book](#) and donate it to a local library, school, or medical office to help educate others about PWS. Alternatively, you can share the [YouTube video](#) of Dr. Pacha reading "It Starts With Hello" with your loved one's school or on social media.

3. LIGHT UP FOR RARE!

Encourage local landmarks, businesses, or buildings to shine in Rare Disease Day colors—purple, pink, blue, and green—on February 28. [Click here](#) to learn more about NORD's official "Light Up for Rare" campaign.

4. REQUEST A RARE DISEASE DAY PROCLAMATION

Ask your local or state government to officially recognize Rare Disease Day and highlight the importance of PWS awareness. Click on the links below to read how other PWS families navigated this process.

[Sheri & Lyra's Story](#)

[Sue & Shealynn's Story](#)

[Leslie & Corey's Story](#)

5. SHARE YOUR STORY OR A RARE DISEASE DAY POST ON SOCIAL MEDIA

Use the hashtags #RareDiseaseDay, #PWSAwareness, and/or #PWSProud and share a personal message, a fact about PWS, or a post from PWSA | USA.

6. LISTEN, SHARE & REVIEW "PWS UNITED" PODCAST

Help PWSA | USA's podcast, [PWS United](#), reach more listeners! Share an episode with friends or write a review on Apple Podcasts, Spotify, or your favorite podcast platform.

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7. WEAR YOUR SUPPORT – PWSA | USA’S BONFIRE STORE

Purchase and wear PWS-specific clothing to raise awareness. Check out [PWSA | USA’s Bonfire store](#) for exclusive designs!

8. HOST A "WEAR JEANS FOR RARE GENES" EVENT

Encourage a school, workplace, or community group to wear jeans on Feb. 28 in support of rare diseases like PWS. [Click here to find more information.](#)

9. ORGANIZE A RARE DISEASE DAY FUNDRAISER

Host a Hope United fundraiser in honor of Rare Disease Day! The process is easy and fun and provides friends, family, and everyone in your circle a chance to make a difference for your loved one with PWS. When you go to our [Hope United website](#), you will see a button to host a “Rare Disease Day” specific fundraiser! Simply select “fundraise” in the “Rare Disease Day” box. You will be prompted to create a page, which you can then share with your community. If you have any questions, email us at hopeunited@pwsausa.org.

10. DOWNLOAD AND CUSTOMIZE OUR PWS IDENTIFICATION CARD

To help our communities better understand Prader-Willi syndrome, how it affects those diagnosed, and what symptoms require immediate medical attention, PWSA | USA has created a [customizable PWS Health Identification Card](#). This Health ID card can be printed and shared with anyone in your community, e.g. school officials, medical providers, family members, etc.

11. WRITE TO YOUR ELECTED OFFICIALS

Email or call your representatives to advocate for PWS research, medical care, and disability rights. Every voice matters! [Click here](#) to find letter templates on our Advocacy webpage.

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12. WEAR YOUR ZEBRA PRINT!

Zebras are the official symbol of Rare Disease Day because, in medicine, “when you hear hoofbeats, think horses, not zebras” is a common saying—meaning doctors are trained to look for common conditions first. But for rare disease families, zebras are our reality. Wear zebra print clothing, accessories, or ribbons on Feb. 28 to stand in solidarity with the rare disease community! Snap a photo and share why zebras represent Prader-Willi syndrome and Rare Disease Day.

13. START A CONVERSATION

Talk to friends, coworkers, and neighbors about Prader-Willi syndrome and why Rare Disease Day matters. Education starts with a simple hello!

14. GET CREATIVE – CHALK YOUR WALK OR PAINT A ROCK

Decorate your driveway or sidewalk with a Rare Disease Day message, or paint a rock with a PWS awareness symbol and leave it in a public space!

15. MAKE A RARE DISEASE DAY DONATION TO PWSA | USA

Support families affected by PWS by making a donation in honor of Rare Disease Day. Every gift fuels research, advocacy, and life-changing support! [You can make a donation by clicking here.](#)

