

NM Prader-Willi Syndrome Project

DECEMBER 2020

Hello everyone!

I hope you are healthy and well. It's hard to believe we are in the holiday season and quickly approaching the new year. This time last year I was helping at ARCA's Annual PWS Holiday Party, where I was able to first meet some of the amazing individuals in our program, along with their families and staff. I really wish we were celebrating together this year, and I look forward to the next time we are able to do so.

This year has been...unlike anything we've experienced. It's been challenging, anxiety-inducing, and sometimes heartbreaking. And we have gotten through it. We've learned new skills, we've adapted to the ever-changing world around us, and we've *grown*. We've been reminded over and over again that what we really need more than anything is each other.

Here is to our families, friends, laughter, a good book, Netflix, snow days, and time to hit pause. And here is to the new year ahead and remaining hopeful.

The NM PWS Project wishes you the best.

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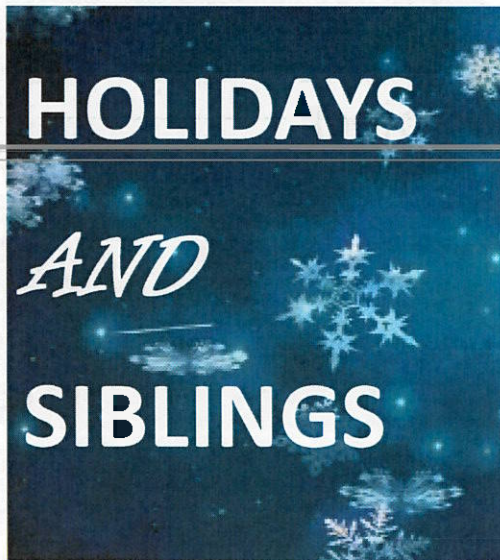
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More on the back :)

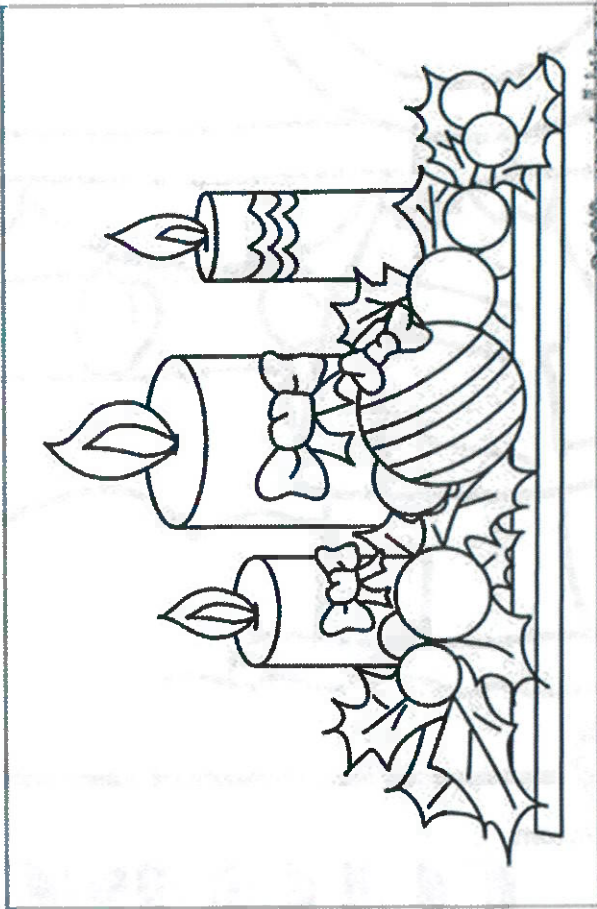
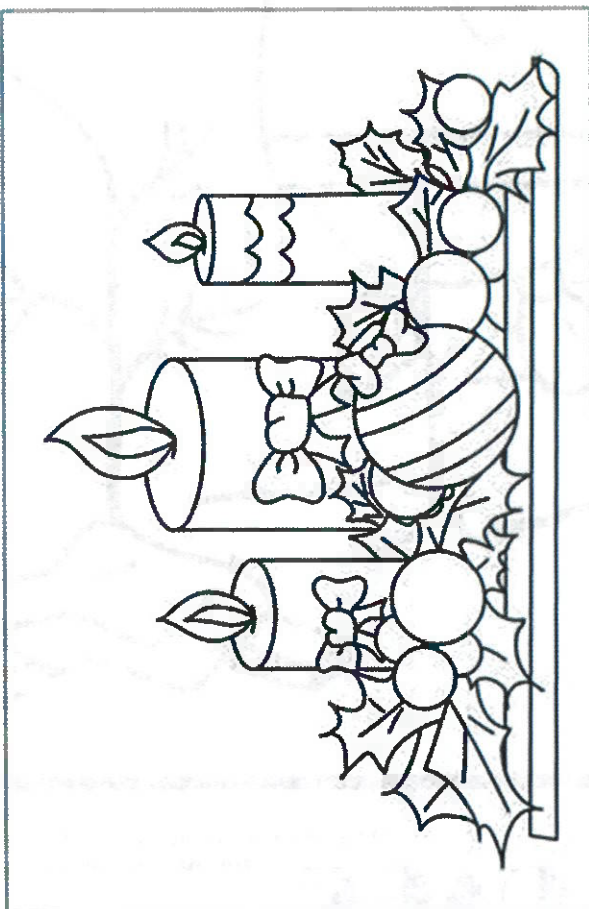


The holidays can be a challenging time for individuals with PWS and their families for many reasons, and it is important to keep in mind the ways that siblings may be negatively impacted by the added stress in the home. Below are some ideas from Jane Thornton. You can access her full blog on the PWSA website at:

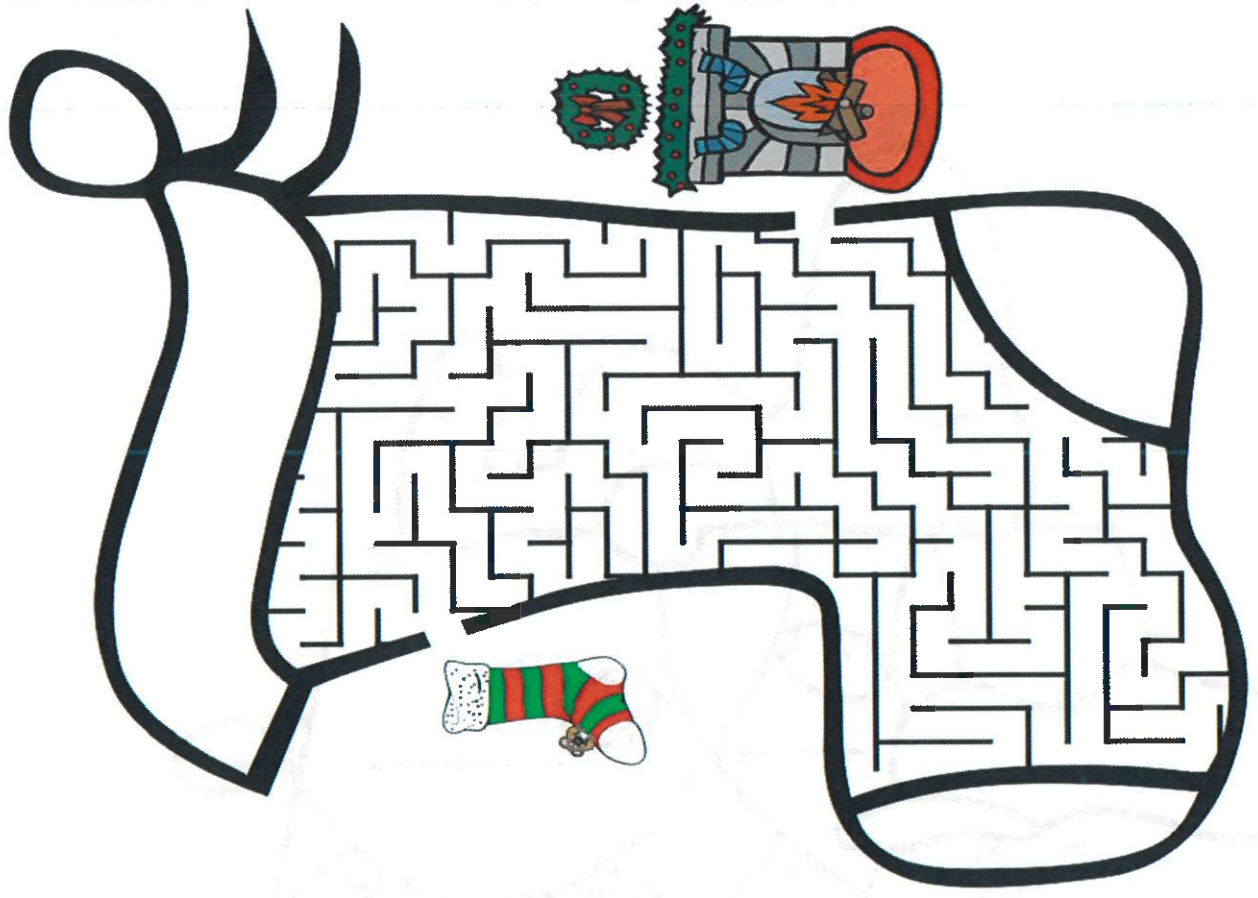
www.pwsausa.org/holidays-and-siblings/

- Plan some wonderful family nights during the holidays with meaningful conversations, games, and connection (along with fun food and treats) after the member with PWS goes to bed.
- Give siblings time away from their family member with PWS. Holidays usually mean a lot of time as a family. However, it is hard as a sibling to be with their family member with PWS for long periods of time as it is often tiring and stressful. Allow siblings times to be by themselves or with friends or family away from their family member with PWS.
- As part of this effort to give siblings needed breaks, make sure the siblings have a space to unwind and revitalize away from their sibling with PWS. This will allow them time to recharge and be more prepared to deal with stress.
- If possible, siblings should not share a room with the child with PWS. Research shows it is better for healthy children to share a room with multiple other siblings than with a child with PWS (Murphy, Thornton & Thornton, 2019). Sharing a room with the child with PWS eliminates almost any chance for the sibling to reboot after the stressful events of the day have depleted their resources and resilience. If it is not possible for the siblings to have a room away from their family member with PWS, make sure they have some type of private haven in the home.
- Remember that hearing the child with PWS tantrum and yell can be an enormous stressor for siblings, even if they are not responsible for calming them down or cannot see them. Sound disturbance greatly decreases the benefits of having a safe space to regain strength. To combat this, consider providing noise-cancelling headphones or room soundproofing. This can be a pre-Christmas gift! For instance, the Boltune BT-BH010 Black Bluetooth Wireless Over-Ear Headphones (noise cancelling) are currently \$28.87 on Amazon.com and they compare in quality to the \$300 Bose noise cancelling headphones.
- Consider purchasing a safe for the siblings to keep in their room or keypad/lock for the siblings' doors so the siblings can have privacy and perhaps keep a snack stash.
- In family gatherings, siblings are often tasked with watching their family member with PWS. As one sibling said, "five eyes need to be on her (the individual with PWS) at all times" (Murphy, Thornton & Thornton, 2019). Make sure, if you must have the sibling take shifts, that the time frame is short, and their responsibilities are well-defined. If the sibling makes mistakes, refrain from harsh criticism. This is a hard job for adults, let alone children.

HOLIDAY FUN

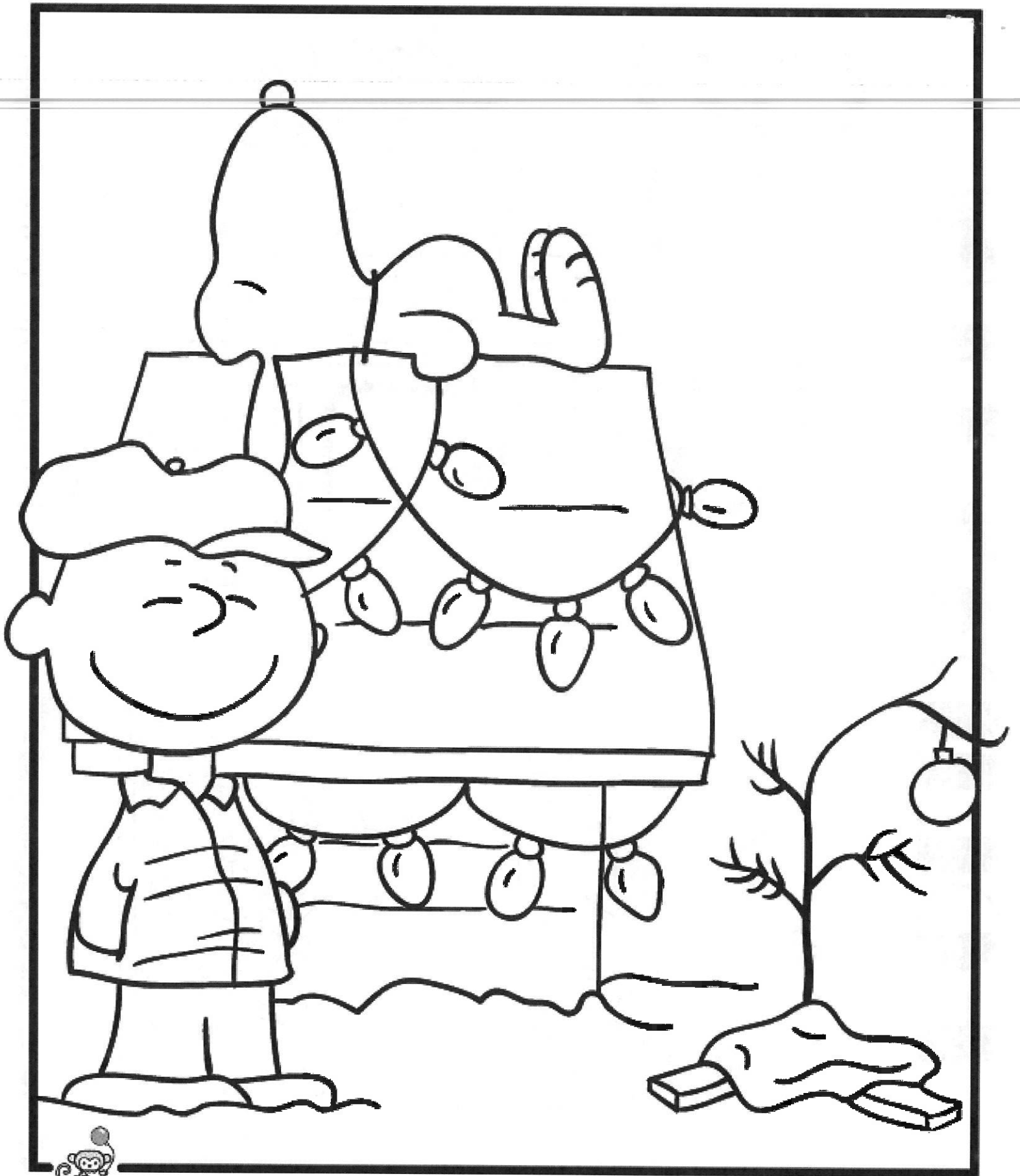


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