

NM PRADER-WILLI SYNDROME PROJECT

JULY 2020

Summer Fun In The Sun!

Summer is the perfect opportunity to spend time with your family, have fun, and de-stress. Whether you are hiking near a remote waterfall, camping in your own backyard, riding bikes through the neighborhood, or running through the sprinkler, doing it as a family makes it more fun and helps create life-long memories.

Individuals with Prader-Willi syndrome can take part in summer fun too, but because children and adults with the syndrome often have difficulty regulating body temperature (and can then overheat easily), parents and caregivers must take certain precautions to protect their loved one. Here are some tips to help make summer fun for everyone:

- Capitalize on the cooler temperatures in the early morning and evening and plan your outdoor activities during those times.
- Carry an umbrella with you to block out the sun's direct rays.
- Always wear sunscreen!
- Always keep frozen water bottles or cold drinks with you.
- Cool your car down before getting into it.
- Keep battery operated fans in your car and larger fans in your home.
- When traveling, keep a cooler with ice packs, wet towels, and water bottles with you in case of a heat-related emergency.
- Technology is advancing and that includes body cooling technology. Invest in a cooling vest, frogger towel, or cooling gel pads which can all found in your local sporting goods store.

Despite taking precautions, your loved one may experience a heat-related problem such as heat exhaustion or heat stroke. Heat exhaustion is an urgent situation that includes heavy sweating, rapid pulse, dizziness, fatigue, goose bumps, and often nausea and headache. A person with PWS might not experience all these symptoms, so look for red cheeks, exhaustion, and fatigue. If you suspect your loved one is having heat exhaustion you must work quickly to cool them down. Move them into a cool place with good air circulation, remove any wet clothing, and use cold, wet towels to cool the skin. Focus on the arm pits, neck, and groin as the largest blood vessels are in those areas.

Heat stroke is an emergency and requires immediate medical assistance. Call 9-1-1! When someone is suffering from heat stroke they are no longer sweating, and they might be confused and even collapse. While waiting for first responders to arrive, continue all efforts mentioned above to rapidly reduce body temperature.

Contributed by Stacy Ward, Director of Family Support, PWSUSA

Project Updates:

- Project team members are available for consults and trainings but will continue to adhere to Covid-19 restrictions set by DDS and DOH.
- Trainings will take place over the phone or via online webinar only at this time. Please reach out to Hillary to schedule.
- Project team members are available to participate remotely in IDT or IEP team meetings as needed.
- The Project is working towards developing an engaging and interactive web platform to better stay connected with you, your family, and your teams. Please be sure to keep an eye out for upcoming changes and updates!
- We hope all of our individuals and families are staying safe and healthy!

NM Prader-Willi Syndrome Project Team Members

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