NM PRADER-WILLI SYNDROME PROJECT

MARCH 2020

PWSA (USA) Coronavirus Statement to the Prader-Willi syndrome (PWS) Community

March 3, 2020

PWSA (USA) is aware that the threat of illness is always a potential danger to those with PWS, their families and community. We advise our families to be extra vigilant in their efforts to prevent the spread of viral illness especially at this time when the Coronavirus is likely to be present in their communities at some point. Below is the link to the CDC website where you can get the facts and answers to many of your questions.

https://www.cdc.gov/coronavirus/2019-ncov/community/index.html

It is also important to remember that persons with PWS do not always present with typical symptoms when ill, and they may be at higher risk for timely identification of illness because of this. Arbitrary things such as subtle changes in behavior, sleeping patterns or increase in anxiety can indicate an impending illness. Your health care provider should have a high level of suspicion if any symptoms of the virus occur. Remember to have your Medical Alert Booklet with you when seeking medical care in any setting. If you need an updated copy download it here:

https://www.pwsausa.org/wp-content/uploads/2018/04/MedicalAlert-April2018.pdf

More medical information can be found on our website at:

https://www.pwsausa.org/medical-issues-a-z/

What can you do right now?

Practice everyday preventive actions now. Remind everyone in your household of the importance of practicing everyday preventive actions that can help prevent the spread of respiratory illnesses:

Practice good personal health habits and plan for home-based actions:

- Avoid close contact with people who are sick.
- Stay home when you are sick, except to get medical care.
- Cover your coughs and sneezes with a tissue.
- Clean frequently touched surfaces and objects daily (e.g., tables, countertops, light switches, doorknobs, and cabinet handles) using a regular household detergent and water.
 - If surfaces are dirty, they should be cleaned using a detergent and water prior to disinfection. For disinfection, a list of products with Environmental Protection Agency (EPA)-approved emerging viral pathogens claims, maintained by the American Chemistry Council Center for Biocide Chemistries (CBC). Always follow the manufacturer's instructions for all cleaning and disinfection products.
- Wash your hands often with soap and water for at least 20 seconds, especially after going to the bathroom; before eating; and after blowing your nose, coughing, or sneezing. If soap and water are not readily available, use a hand sanitizer that contains at least 60% alcohol. Always wash your hands with soap and water if your hands are visibly dirty.

16TH ANNUAL FAMILY LEADERSHIP CONFERENCE

APRIL 30-MAY 1, 2020 ALBUQUERQUE, NEW MEXICO



LEADERSHIP INSTITUTE APRIL, 29, 2020

Developing the Dream (The IFSP Process)

Date/Time

Date(s) - Apr 8, 2020 10:00 am - 12:00 pm

Location

Parents Reaching Out

Categories No Categories

- · Learn skills to advocate for you and your family
- · Find out about your rights and responsibilities
- Learn about Early Intervention and what it means for your family
- Discover how the Individual Family Service Plan build on strengths to support goals for your child and family
- Find out about the roles and responsibilities of service providers



CELEBRATE WORLD DOWN SYNDROME DAY!

SATURDAY, MARCH 21, 2020

ON THE BALLOON MUSEUM LAWN

| 7:00AM - 9:00AM

BALLOON INFLATIONS • CREWING • TETHERED RIDES • WHEELCHAIR ACCESSIBLE GONDOLAS ON SITE (Weather Permitting)

8:00AM - 11:00AM

BREAKFAST TAILGATE FESTIVAL • FOOD TRUCKS
MUSIC • ACTIVITIES • RESOURCE BOOTHS
SHINING STARS ART EXHIBIT BY DOH

BALLOON MUSEUM • 9201 Balloon Museum Dr. NE • ABQ, NM 87113 • www.cabq.gov/balloon • Call: 311 or 505.768.6020 (Relay NM or 711)















