## NM Prader-Willi Syndrome Project

## JANUARY 2021

Happy New Year everyone! I hope you've enjoyed the holidays and that your 2021 is off to a good start. I wanted to take this opportunity to update you on some new developments within the NM PWS Project. Thanks to the previous PWS Coordinator along with ARCA's Foundation and Training Departments, you can access info about the Project on our website at: <a href="https://www.arcaopeningdoors.org/arca-pws/">https://www.arcaopeningdoors.org/arca-pws/</a>

In an effort to make things more efficient and reduce our paper use, you can now subscribe and receive our monthly newsletters straight to your email. Simply go to the website above, click on the PWS News Archive on the left-hand side, and enter your name and email information in the boxes provided.

Additionally, PWS trainings are now available online! Click on the training tab and select one of the links based on whether you are working with an adult or child.

These trainings are intended for three different circumstances:

- The trainee has already received the PWS training but is needing a refresher (usually completed annually)
- 2. There is a sudden change in staff and the trainee and the trainer are unable to coordinate a virtual/ in-person training prior to the start date
- 3. You or someone you know is interested in learning more about PWS! We encourage natural supports (those are not paid) to take the training as well.

\*\*It is still advised that new staff schedule a virtual/in-person training as it is more comprehensive and allows for questions and discussion\*\*

Thank you for all you do, and please don't hesitate to reach out if I can help!

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Please flip over for a PWSA statement about the Covid-19 vaccine

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The following was taken from the PWSA website:

Statement from Members of the Clinical Advisory Board (CAB) Regarding People with PWS and COVID-19 Immunization

December 15, 2020 PWSA | USA

The types of vaccines now available against COVID-19 use mRNA technology. This type of vaccine has been under development for many years and, unlike other immunizations, does not place a weak or inactive germ into the body, but instead teaches cells in our body to make an immune response that then produces antibodies which provide protection if exposed to COVID-19.

Given the scale of the pandemic with the impact upon lives and long-term health, experts from the US (FDA, CDC) and Europe (MHRA, EMA) have carefully reviewed data from very large clinical studies conducted by the vaccine developers and provided emergency authorization approval to expedite availability to the public. Reported side effects from the vaccines currently available (Pfizer and Moderna) are rare, but their use in those with a history of severe allergies should be discussed with a medical adviser and possibly avoided. Studies are currently underway looking at the safety of the vaccine in children.

PWSA | USA understands that decisions regarding COVID-19 vaccination is a personal/family decision, but advocates for vaccination, <u>particularly</u> among those with Prader-Willi syndrome who are at an increased potential risk for COVID-19 complications (i.e., those individuals with severe obesity, sleep apnea, diabetes and cardiovascular disease).

To learn more about the Covid-19 vaccination and to register, please visit: https://cv.nmhealth.org/covid-vaccine/