

NM PRADER-WILLI SYNDROME PROJECT

AUGUST 2020

Running for Research

PWSA USA is happy to announce its partnership with Running for Research, a diverse group of runners dedicated to raising funds for the Prader-Willi Syndrome Research Fund at the University of Florida and Dr. Jennifer Miller's work to identify effective treatments for children and adults with Prader-Willi syndrome (PWS). Since its founding in 2018, the group has nearly tripled in the number of runners and now includes runners of all ages and abilities, from across the world, running local and virtual races in support of the cause.

The group's founder, Kelly Guillou, says, "Running for Research has entered into a partnership with Prader-Willi Syndrome Association USA, a national nonprofit organization dedicated to serving the PWS community. With the support of PWSA USA, RFR will be able to expand its reach and raise more money to support PWS research at the University of Florida. And, because PWSA USA is a recognized 501(c)3, RFR will now be able to offer sponsorships to corporations. Any sponsorship money received will be split evenly between RFR and PWSA. In addition, PWSA USA will help raise awareness about RFR by advertising it in its weekly and quarterly newsletters, as well as on its social media accounts. Other than the split of sponsorship revenue, all money raised by RFR will continue to be for the SOLE benefit of the UF PWS Research Fund."

The group's fundraising goal for the 2021 Walt Disney World Marathon (January 6 – 10, 2021) is \$40,000. Any donations or sponsorships received will help fund two studies: Medication to help reduce hair pulling and skin picking, and probiotic use in infancy and the progression of PWS. All donations are welcome and appreciated, and gifts at the \$1,000 level above will be recognized in pre- and post-race marketing, as well as on race t-shirts worn by the Running for Research team. To learn how you can support the Running for Research team, please contact Kelly Guillou at kelly@guillou.biz, or Paige Rivard at privard@pwsausa.org.

Members of Running for Research come from a variety of backgrounds but are united in their determination to help find treatments for the most debilitating aspects of PWS. With your support, we can create a future in which children with PWS is better, happier, and healthier than ever before.



5 in 15 – Rare disease Advancement, Research, and Education (RARE) Act

Wed, Aug 12, 2020 10:30 AM - 11:00 AM MDT

[Show in My Time Zone](#)

<https://register.gotowebinar.com/register/293655775084060684>

Join PWSA | USA for a mini webinar series on the issues you care about. During these 15-minute live webinars, you will learn about the various ways you can advocate for our current federal policy priorities and how you can make a lasting and sustainable impact for those affected by PWS.

H.R. 5115: Rare disease Advancement, Research, and Education (RARE) Act of 2018

The RARE Act would provide much-needed investment in rare disease research; direct the Centers for Disease Control and Prevention (CDC) to increase its efforts in tracking and quantifying rare diseases; require the Agency for Healthcare Research and Quality (AHRQ) to implement rare disease outreach and awareness campaigns for physicians; and commission additional analysis and recommendations from the National Academy of Sciences on how to accelerate rare disease therapeutic development.

Early Literacy by Zoom

Date/Time

Date(s) - Sep 8, 2020

6:00 pm - 8:00 pm

Categories No Categories

- Find out about the development of language and literacy skills.
- Identify literacy opportunities that reflect your family's strengths.
- Learn how to give your child an early start in reading.
- Discover how to use daily routines to develop literacy.

Please RSVP and receive Zoom information to 505-247-0192 or jianneci@parentsreachingout.org

NM Prader-Willi Syndrome Project Team Members

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