**RESOURCES LIST**

**Websites:**

* PWSA l USA: [www.pwsausa.org](http://www.pwsausa.org)
* PWS News: <https://praderwillinews.com/>
* Foundation for Prader-Willi Research: [www.fpwr.org](http://www.fpwr.org)
* International Prader-Willi Syndrome Organization: [www.ipwso.org](http://www.ipwso.org)

**Handouts:**

* **Quick reference and general overview on Health Issues in Children and Adults with PWS;**
	+ [Prader-Willi Syndrome (vkcsites.org)](https://iddtoolkit.vkcsites.org/physical-health/health-watch-tables-2/prader-willi-syndrome/)
	+ [Medical Home Portal - Prader-Willi Syndrome](https://www.test.medicalhomeportal.org/diagnoses-and-conditions/prader-willi-syndrome)
* **Medical Care Overview (IPWSO)**
	+ **Infants (0-3 yrs.) -** [IPWSO-CSAB-Overview-and-Evaluation-for-Infants-with-PWS-Aged-0-3yrs-May-2019.pdf](https://ipwso.org/wp-content/uploads/2020/10/IPWSO-CSAB-Overview-and-Evaluation-for-Infants-with-PWS-Aged-0-3yrs-May-2019.pdf)
	+ **Children (3-12 yrs.) -** [IPWSO-CSAB-Overview-and-Evaluation-for-Children-with-PWS-Aged-3-12yrs-February-2019.pdf](https://ipwso.org/wp-content/uploads/2021/02/IPWSO-CSAB-Overview-and-Evaluation-for-Children-with-PWS-Aged-3-12yrs-February-2019.pdf)
	+ **Adolescents –** [IPWSO-CSAB-Overview-and-Evaluation-for-Adolescents-with-PWS-February-2019.pdf](https://ipwso.org/wp-content/uploads/2021/02/IPWSO-CSAB-Overview-and-Evaluation-for-Adolescents-with-PWS-February-2019.pdf)
	+ **Adult -** [IPWSO-CSAB-Overview-and-Evaluation-for-Adults-with-PWS-January-2018.pdf](https://ipwso.org/wp-content/uploads/2020/10/IPWSO-CSAB-Overview-and-Evaluation-for-Adults-with-PWS-January-2018.pdf)
* **Medical Alert Booklet -** [Medical-Alerts-Booklet\_3.8.22Final.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Medical-Alerts-Booklet_3.8.22Final.pdf) (www.pwsausa.org)
* **GI Chart -** [GI-Algorithm-Chart-2022.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/GI-Algorithm-Chart-2022.pdf) (www.pwsausa.org)
* **Comprehensive Overview of GI Issues in Persons with PWS:** [GI-issues-Scheimann-final-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/GI-issues-Scheimann-final-2022.pdf)
* **Gastroparesis:** [Understanding-Gastric-Motility-and-Gastroparesis-in-PWS-2022.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Understanding-Gastric-Motility-and-Gastroparesis-in-PWS-2022.pdf) (www.pwsausa.org)
* **Hidden Swallowing Problems:** [Swallowing-Problems-in-PWS-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Swallowing-Problems-in-PWS-2022.pdf)
* **Swallowing Problems in Infants:** [Swallowing-and-Silent-Aspiration-in-Infants-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Swallowing-and-Silent-Aspiration-in-Infants-2022.pdf)
* **Respiratory Problems -** [Respiratory-problems-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Respiratory-problems-2022.pdf)
* **Medications and Respiratory Issues -** [Medication-combinations-warning-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Medication-combinations-warning-2022.pdf)
* **Medical Necessity for Food Security -** [Medical-Necessity-for-Food-Security-Statement.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Medical-Necessity-for-Food-Security-Statement-2022.pdf) (pwsausa.org)
* **Anesthesia -** [Anesthesia-and-PWS-Loker-2022-1.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Anesthesia-and-PWS-Loker-2022-1.pdf)
* **Postoperative Monitoring -** [Postoperative-monitoring-of-patients-2022.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Postoperative-monitoring-of-patients-2022.pdf) (www.pwsausa.org)
* **Postoperative Monitoring Pediatric Patients-** [Postoperative-monitoring-of-pediatric-patients-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/03/Postoperative-monitoring-of-pediatric-patients-2022.pdf)
* **Skin Picking -** [Skin-Picking-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Skin-Picking-2022.pdf)
* **Skin Picking -** [The Pittsburgh Partnership (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2015/10/Skin-Picking.pdf)
* **Skin Picking –** **N-Acetylcysteine** [Picking-and-N-acetylcysteine-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/Picking-and-N-acetylcysteine-2022.pdf)
* **Hypothermia -** [Hypothermia-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/03/Hypothermia-2022.pdf)
* **Allegations of Abuse -** [AllegationsofAbuse-2022.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2022/02/AllegationsofAbuse-2022.pdf)
* **Food Security – Locks -** [Food-Security-Locks-and-Alarms-ED-2022.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Food-Security-Locks-and-Alarms-ED-2022.pdf)(pwsausa.org)
* **PWS Mental Health Guidebook -** [PWS-Mental-Health-Guidebook-download (fpwr.org)](https://www.fpwr.org/hubfs/Landing_Pages/PWS-Mental-Health/PWS-Mental-Health-Guidebook-download.pdf?utm_campaign=Mental%20Health%20Guidebook&utm_medium=email&_hsmi=95744843&_hsenc=p2ANqtz-_gqpVAY0b1wCjLEBREVthwlU__xNFMLiSCwD8iVKsebi2km92-61Ixapu7Gd_JQAO59vQhuRRNzFKe5Y36WrEJnDh0bg&utm_content=95744843&utm_source=hs_automation)
* **Mental Health -** [The-Mental-Health-of-People-with-PWS-T-Holland.pdf (pwsausa.org)](https://www.pwsausa.org/wp-content/uploads/2018/01/The-Mental-Health-of-People-with-PWS-T-Holland.pdf)
* **Mental Health – Information for Psychiatrists** - [Psychiatric-information-for-psychiatrists.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Psychiatric-information-for-psychiatrists-_C-2018.pdf) (www.pwsausa.org)
* **Mental Health –** **Behavior Changes** - [Mental-Health-and-Behavior-Updated.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Mental-Health-and-Behavior-Updated-2018_MA-121.pdf) (www.pwsausa.org)
* **Psychotropic Medication Tip Sheet for Health Care Professionals -** [Psychotropic-med-tip-sheet-2022.pdf](https://www.pwsausa.org/wp-content/uploads/2022/03/Psychotropic-med-tip-sheet-2022.pdf) (www.pwsausa.org)
* **Mental Health Handout (1 page) -** [Serious-Mental-Health-Problems-In-Prader-Willi-Syndrome.pdf (fpwr.org)](https://www.fpwr.org/hubfs/Pillar_Pages/mental-health/Serious-Mental-Health-Problems-In-Prader-Willi-Syndrome.pdf?utm_campaign=Mental%20Health%20Guidebook&utm_medium=email&_hsmi=85478267&_hsenc=p2ANqtz--GBAEg_clTF2GHM2OrreUfmQNJZlQJ5PO3N2uqVEvjankTc3fL0h1weGRTP_TB3oNcceEHSrcInRNFcMQm8NsG28zWfQ&utm_content=85478267&utm_source=hs_automation)
* **Handbook for Parents of Young Children -** [Prader-Willi\_Syndrome\_First\_Steps\_online.pdf (hubspot.net)](https://cdn2.hubspot.net/hubfs/2105275/Offers/Prader-Willi_Syndrome_First_Steps_online.pdf)
* **Health Supervision for Children with PWS:** [Health Supervision for Children With Prader-Willi Syndrome | Pediatrics | American Academy of Pediatrics (aap.org)](https://publications.aap.org/pediatrics/article/127/1/195/30016/Health-Supervision-for-Children-With-Prader-Willi)
* **Recommendations for the Diagnosis and Management of PWS (Good Medical Resource to Share with Primary Care Health Professional):** [2008clinicalGuide.pdf (fpwr.org)](https://research.fpwr.org/hubfs/FPWR_April2018/Docs/2008clinicalGuide.pdf)
* **The Importance of Growth Hormone:** [Growth-Hormone-Therapy-for-PWS-Fact-Sheet.pdf (fpwr.org)](https://research.fpwr.org/hubfs/Offers/Growth-Hormone-Therapy-for-PWS-Fact-Sheet.pdf)

**Webinars / Presentations:**

* **Advocating for the Person with PWS in the Emergency Department (Dr. Dan Beaver MD):** <https://m.youtube.com/watch?v=VoiIklGDq-A>
* **Optimal Nutrition for People with PWS (Melanie Silverman)** [Here is your video: Optimal Nutrition For People With PWS (fpwr.org)](https://www.fpwr.org/here-is-your-video-optimal-nutrition-for-people-with-pws?submissionGuid=f8aa5f7b-7210-4230-8e8f-4276a89524bf)
* **Standards of Care for Adults and Children with PWS (Dr. Jessica Duis)** [Here is your video: Dr. Jessica Duis Standards of Care for Adults and Children with PWS Video (fpwr.org)](https://www.fpwr.org/here-is-your-video-dr-jessica-duis-standards-of-care-for-pws?submissionGuid=054ff38f-d616-487e-b395-736371cc5e8d)
* **Scoliosis and PWS (Dr. Van Bosse and Janice Agarwal)** [Here is your video: Dr. van Bosse Orthopedics, Scoliosis and PWS Presentation (fpwr.org)](https://www.fpwr.org/here-is-your-video-dr-van-bosse-orthopedics-scoliosis-and-pws-presentation?submissionGuid=a47dfead-66d7-434b-a7df-a8f67a8cd007)

**Blogs:**

* Behavior, Mental Health and PWS (Lauren Schwartz Roth, PhD.) [Psychologist Lauren Roth on Behavior, Mental Health and PWS [PODCAST] (fpwr.org)](https://www.fpwr.org/blog/psychologist-lauren-roth-on-behavior-mental-health-and-pws-podcast)