Careful Steps – 2 Years

Happy Birthday!

Below is a "To Do" list of things that should be done during this next year to make sure your child continues to thrive. Please don't feel overwhelmed and remember, we are here to support you, your family and your child. Please reach out with any questions you may have.

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Brooke Ramos – Family Support Coordinator brookeramos@upwsa.org

Zeinab Bahsoun– Medical Care Coordinator zeinab.bahsoun@hsc.utah.edu

Annabelle Wilcox– Genetics Physician Assistant annabelle.wilcox@hsc.utah.edu

Doctors to See

- **Attend PWS Medical Clinic** – Zeinab Bahsoun or Annabelle Wilcox should contact you with the time you are next scheduled to attend the clinic.
- **Endocrinologist**
    - **Check for Hypothyroidism** –tested by a simple blood draw
    - **Check Growth Hormone Dose** – tested by simple blood draw
    - **Update Prior Authorization for Insurance**
    - **Follow up visit with Endocrinologist** – Your child should see an endocrinologist 2x a year (every 6 months)
- **Pulmonologist/Sleep Specialist**
    - **Follow up Sleep Study**
        - **If Moderate to Severe Obstructive Sleep Apnea is detected in first study**:
            - Child to be seen by ENT for tonsil and adenoid evaluation
            - Child has had an evaluation by pulmonologist
            - If CPAP is needed, infant should be successfully using CPAP as instructed by pulmonologist
- **Pediatrician**
    - **Discuss Supplements with Medical Provider**
        - Iron supplement
        - Vitamin supplementation
        - Fish Oil
        - CoQ10
        - Levocarnitine
        - MCT oil
    - **Child current on Vaccinations**
    - **Examined for Constipation** – Likely, there will be no obvious signs of constipation. If needed oral laxative is being administered.
    - **Monitor for Bladder Infections** – Again, typical signs of bladder infection (such as crying in pain or fever) may not be present.

- **Pediatric Dentist** – dental issues are very common in individuals with PWS so it is important to develop a relationship with a good pediatric dentist in your area and have regular checkups and cleanings.

Testing to be Done

- **Follow up X-ray for scoliosis**
    - **If scoliosis is detected**:
        - Growth Hormone is not generally stopped
        - If degree of curve is 30 degrees or greater, address bracing with orthopedic physician

Therapy to Enroll In

- **Yearly IFSP with Early Intervention Program** –This IFSP should include physical, occupational, vision, and feeding/speech services.
- **Cognitive Therapy** (If available)
- **Physical Therapy** – through early intervention, an outpatient program, or both
- **Occupational Therapy** – through early intervention, an outpatient program, or both
- **Speech Therapy** – through early intervention, an outpatient program, or both
    - Explore the option of PROMPT speech therapy if available if your area.
    - Feeding Issues Addressed – access to feeding therapy if needed
- **Explore Preschool Options in your District** – Your early intervention team should be able to point you to the preschool in your school district they feel would be best for your child. However, like with any child, it is your choice to place your child in the public school system or to explore a private schooling option for preschool education.

Applications to Complete

- **Pfizer Bridge Program** – this program helps cover the cost of growth hormone if insurance approval is delayed for any reason. Your endocrinologist should be able to help you through the application process for this program.
- "**Katie Becket Waiter"** – In Utah this program is known as "DSPD" and is administered through the Health Department. This program is not income based and provides a Medicaid card as well as monetary support based on the need of the child.
- **Medicaid Waiver** – This program IS income based
- **Social Security Benefits** - Income based for children under 18
- **National Parks Pass** – Ask your pediatrician for an application and letter. This pass allows free admission into any national park for the vehicle carrying the person with disability.
- **Handicapped Parking Pass** – Received from your pediatrician
- **Create a Special Needs Trust** – Lisa Thornton is an attorney and can help get you started

Sources of Support to Connect With

- **Receive a copy of the booklet "Nutrition Care for Children with PWS, Infants and Toddlers"** – Can be found on PWSA(USA) website
- **Become a member of PWS(USA)**
    - Receive all publications helpful for toddler stage of development
    - Access the parent-to-parent 0-5 list through pwsausa.org and know how to submit questions for the parent board to answer
    - Receive a Parent Mentor
- **Become a member of Utah Prader Willi Syndrome Association**
- **Become a member of the Facebook group "UPWSA – Parent's Only"**
- **Become a member of the Facebook group "PWSA | USA Birth to Three"**
- **Become a member of the Facebook group "PWS Caterpillars"**

If you have questions or get "stuck" at any point in this checklist, please don't be afraid to reach out. We are here to help!