Careful Steps – 5 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.

Lisa Thornton – President of UPWSA lisathornton@upwsa.org

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** – Annabelle Wilcox (annabelle.wilcox@hsc.utah.edu) or Zeinab Bahsoun (zeinab.bahsoun@hsc.utah.edu) 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, child 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**
  - **Discuss Gtube Removal** (if needed)
  - **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 check ups and cleanings.
- **Ophthalmologist** – vision trouble is very common in kids with PWS often times require corrective lenses. Strabismus is also very common, sometimes requiring corrective surgery. Eyesight should be regularly checked.

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

- **Final IFSP with Early Intervention Program** –This IFSP should provide you with a list of services they suggest continue through the school system.
- **Cognitive Therapy** (If available)
- **Physical Therapy** – through the public school system, an outpatient program, or both
- **Occupational Therapy** – through the public school system, an outpatient program, or both
- **Speech Therapy** – through the public school system, 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
- **IEP/Transition Meeting for Kindergarten** – Contact Michelle Holbrook (michelle.holbrook@msn.com) for help navigating the school system and making sure your child gets the accommodations they need.

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 Waiver"** – 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** - Based on parents income 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 Three to Five"**

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!