Careful Steps – 1 Year

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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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**
    - **Monitor Oxygen Saturation Levels** – Oxygen levels need to be monitored consistently, especially during sleep, feedings and upper respiratory illness. If oxygen SATs drop below 93, oxygen is to be administered to bring oxygen levels up to at least 96, or as advised by a pulmonologist. This should be done for at least the first 6 weeks of growth hormone treatment and if possible, for the first 2 years of life.
    - **Follow up Sleep Study**
        - **If Moderate to Severe Obstructive Sleep Apnea is detected in study**:
            - Child to be seen by ENT for tonsil and adenoid evaluation
            - Child has a GI evaluation for reflux (which can cause sleep apnea)
            - Child has had an evaluation by pulmonologist
            - If CPAP is needed, child should be successfully using CPAP as instructed by pulmonologist
- **Pediatrician**
    - **Synagis shots** – for prevention of RSV during RSV season. Debbie can assist in providing letters proving need if insurance denies coverage.
    - **Continue to Monitor Child for Estropia (or Strabismus)** – This is a condition where one or both eyes cross inward looking "cross eyed"
    - **Discuss Supplements with Medical Provider**
        - Iron supplement

        - Vitamin supplementation
        - Fish Oil
        - CoQ10
        - Levocarnitine
    - **Child current on vaccinations**
    - **Regular Weight Checks** – height and weight should be charted at regular intervals using standard growth charts. It does not matter where your child falls on the chart but you are looking for a consistent growth curve just like any other child.
    - **Discuss G-tube 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.

Testing to be Done

- **Follow Up Swallow Study** – if child is still on thickened liquids
- **Baseline X-ray for scoliosis** – This should be done as soon as the infant is able to sit solidly and independently
    - **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
    - Feeding Issues Addressed – access to feeding therapy if needed
- **Oral Hygiene Strategies** – use soft foam toothbrushes and wetting solutions to care for gums and teeth as soon as they start appearing.

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** - 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 infant 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"**

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!