

Prader-Willi Syndrome Association (USA)

Survey #2

Survey #1 must be filled in prior to completion of this survey. Use the back of this form to give further explanation if needed. This survey is an extension of the first. Your ID# was assigned in Survey #1. If you have questions email bmcmanus@pwsausa.org or call 800-926-4797 and ask for Barb- Please fill out online if possible www.pwsausa.org/population or mail to: PWSA (USA), 8588 Potter Park Dr. Suite 500, Sarasota, FL 34238

ID# _____ Child's Date of Birth _____ Child's Name _____ Today's Date _____

Please circle Yes, No or N/A whenever appropriate

Behavior

Has your child ever been diagnosed as having psychosis?
Yes, No or N/A More than once? Yes, No or N/A
If yes, at what age was this diagnosis first made? _____
How long did the symptoms last? _____ days; _____ months

- Has your child ever received medication for:
- Attention problems or hyperactivity?** Yes, No or N/A
 - Behavior problems?** Yes, No or N/A
 - Mood or anxiety disorder?** Yes, No or N/A
 - Psychosis?** Yes, No or N/A
 - Depression?** Yes, No or N/A

If yes to these questions, list top five details below .

Medication Used	Condition Better, Worse or unchanged	Side Effects -if any

Educational Issues

- Your child was/is in school where she/he is in:
- Yes, No or N/A An inclusion classroom (mainstreaming)
 - Yes, No or N/A A special education classroom
 - Yes, No or N/A A combination of special and inclusion
 - Yes, No or N/A In a special education school

Which setting does he/she do best in? _____
(if your child is older, reflect back to High School age)

Does your child have/had a one on one aide? Yes, No or N/A

Food Issues

Has your child ever been preoccupied with food? Yes, No or N/A
 At what age was he/she preoccupied by food? _____
 At what age was the child when food seeking began? _____
 At what age was food locked up? _____
 Has your adult child's appetite decreased? Yes, No or N/A
 If Yes, at what age did you notice the decrease? _____

Respiratory Concerns

Does your child have asthma? Yes, No or N/A
 Prone to lung infections, bronchitis or pneumonia? Yes, No or N/A
 Is your child on a C-pap or Bi-pap? Yes, No or N/A
 Problems with aspiration as an infant? Yes, No or N/A
 Ever been on (circle) oxygen? A respirator? Had a tracheotomy?
 Does your child have Sleep Problems? Yes, No or N/A

Additional Health Questions

Has there been any serous choking episode? Yes, No or N/A
 Was the Heimlich Maneuver ever used? Yes, No or N/A
 What did your child CHOKe on? _____

Did your child ever have seizures? Yes, No or N/A
 Does your child currently experience seizures? Yes, No or N/A
 If yes, what type of seizure does he/she have? (check one or both)
 Subtle changes in behavior or "spacing out"
 Major episodes of involuntary motor activity
 A period where he/she could not be aroused
 Other _____
 Age seizures started _____ frequency _____ day/mth/yr

Does your child have excessive daytime sleepiness? Yes, No or N/A
 Has he/she been diagnosed with narcolepsy – cataplexy

Does your child have Gastrointestinal Problems? Yes, No or N/A
 If yes, check the conditions your child has experienced
 Severe bloating Severe stomach pain
 Impacted bowel Gastroparesis (delayed emptying)
 Chronic constipation Reflux
 Severe diarrhea Regurgitation
 Projectile vomiting Gallbladder crisis
 Oozes out vomit Other _____

If your child has been diagnosis with gastroparesis, list any prescribed medications that were helpful

Does your child's normal body temperature fall into these categories? Circle one:
 95 to 96 degrees, 96 to 97 degrees, 97 to 98 degrees, 98 to 99 degrees

Has your child ever been tested for Thyroid conditions? Yes, No or N/A

If yes, was there a diagnosed condition? Yes, No or N/A
 Was it hypothyroidism? Yes, No or N/A
 If he/she has hypothyroidism, was it diagnosed before or after starting growth hormone? (circle one): Before; after; not on GH
 If not hypothyroidism, what was the condition? _____

Has your child ever been diagnosed with another syndrome or serious disease? Yes, No or N/A
 If yes, please list syndrome/disease at the end of this form

Picking concerns?

- No picking Yes, No or N/A
- Mild skin picking? Yes, No or N/A
- Severe skin picking? Yes, No or N/A
- Rectal picking? Yes, No or N/A
- Hospitalization or surgery needed for the picking? Yes, No or N/A

What was the age of mother at time of birth? _____
 Does your daughter with PWS have periods? Yes, No or N/A
 Does you daughter with PWS take contraceptives? Yes, No or N/A

Living Arrangements

Does your child reside in a supportive living home? Yes, No or N/A

If yes, pick type below:

- Large group home Yes, No or N/A
- Small supported living home (4 or less) Yes, No or N/A
- Own apartment with supports Yes, No or N/A
- The above is PWS specific Yes, No or N/A
- The home is mixed with other disabilities Yes, No or N/A
- Level of satisfaction with the arrangements
 Unsatisfied neutral Very Satisfied

If no, is he/she on a waiting list or hoping for placement soon? Yes, No or N/A

Alternative Medicine

Has your child taken CoQ10? (more questions below)

Never - Discontinued using it – Currently using it

Has your child taken Carnitine

Never - Discontinued using it – Currently using it

Has your child taken Fish Oil

Never - Discontinued using it – Currently using it

If CoQ10, Carnitine or Fish Oil is used, please rate by putting an "X" here:

	Un-satisfied	Somewhat un-satisfied	No comment	Somewhat satisfied	Very satisfied
CoQ10					
Carnitine					
Fish Oil					

Additional Survey Questions

1. If your child is currently on Co-enzyme Q10 what length of time has it been used? _____
2. Did your child previously take Co-enzyme Q10 what length of time was it used? _____
3. Does your child plan to take Co-enzyme Q10 in the future? Yes, No or N/A

If you responded Yes to Question 1 and 2

4. What is/was the dose of Co-enzyme Q10? _____;

5. What other components are included with the Co enzyme Q10 (such as Vitamin C, Vitamin E etc.)

6. Do you think the Co-enzyme Q10 has made a difference in your child's muscle tone? Yes, No or N/A

Please indicate from scale of 0-5 by circling one (0 No benefit and 5 impressive improvements):

0 1 2 3 4 5

Explain _____

7. Do you think the Co-enzyme Q10 has made a difference in your child's energy level? Yes, No or N/A

Please indicate from scale of 0-5 by circling one (0 No benefit and 5 impressive improvement):

0 1 2 3 4 5.

Explain _____

7. Do you think the Co-enzyme Q10 has made a difference in your child's appetite? Yes, No or N/A

Did the appetite increase? Yes, No or N/A

Please indicate from scale of 0-5 by circling one (0 No increase - 5 impressive increase):

0 1 2 3 4 5.

Did the appetite decrease? Yes, No or N/A

Please indicate from scale of 0-5 by circling one: (0 No decrease- 5 impressive decrease):

0 1 2 3 4 5.

Explain _____

8. Has your child previously had a muscle biopsy? Yes, No or N/A

9. If Yes to the above question was there an abnormality? Yes, No or N/A

10. If there was an abnormality please include details: _____

11. Did the abnormality identified in the muscle biopsy delay the diagnosis of Prader-Willi in your child?

Yes, No or N/A

Explain _____

12. Was your child diagnosed with a mitochondrial disorder? Yes, No or N/A; If yes, what type? _____

13. If yes to Question 12 what treatment did your child receive: _____

14. Did your child benefit from the treatment for a mitochondrial disorder? Yes, No or N/A

Explain _____

Use this area to further explain sections of this survey: