

# Prader-Willi Syndrome Scoliosis Study

ID# \_\_\_\_\_ Age: \_\_\_\_\_ Name (optional): \_\_\_\_\_

Please answer all questions below. If you need to explain or add information, please use the back of this page.

1. Has your child (of any age) been diagnosed with:
  - Scoliosis (side to side curvature of the spine)
  - Kyphosis (front to back curvature of the spine - humpbacked)
  - At what age was it first noticed? Scoliosis? \_\_\_\_\_ Kyphosis? \_\_\_\_\_
  - Has your child had any complaint related to their back (e.g back pain, cosmetic dissatisfaction)?
2. Has your child ever been on growth hormone (GH)? Yes or No
  - Was your child's scoliosis/Kyphosis diagnosed **BEFORE** start of GH? Yes or No
  - Was your child's scoliosis/Kyphosis diagnosed **AFTER** start of GH? Yes or No
  - If yes to after start of GH, by how many months (or years)? \_\_\_\_\_
  - Did the doctor think the scoliosis got more pronounced quicker due to growth hormone? Yes or No
3. Has your child ever been braced for the scoliosis? Yes or No
  - At what age was bracing first started? \_\_\_\_\_
  - If bracing was used, what type of brace? If more than one type of bracing was used, number the types below (1 = first type, 2= second type, etc.)
    - \_\_\_\_\_  Nighttime only brace
    - \_\_\_\_\_  Day and night brace
    - \_\_\_\_\_  Plastic body jacket (e.g. Boston, Wilmington)
    - \_\_\_\_\_  Milwaukee style brace
    - \_\_\_\_\_  Other Explain: \_\_\_\_\_
- Is your child still in a brace? Yes or No
  - How compliant are/were they with their brace? Circle one
    - Fully Compliant
    - Most of the time
    - Some of the time
    - Never
  - Comment \_\_\_\_\_
  - Have there been any complications or problems with the bracing? Yes or No
  - Describe: \_\_\_\_\_
4. Scoliosis surgery? Yes or No
  - Degree of curve at time of first surgery? \_\_\_\_\_
  - At what age was the first spine surgery? \_\_\_\_\_
  - How many surgeries for scoliosis has your child had? \_\_\_\_\_
  - What type(s) of scoliosis surgery did your child have?
    - Anterior (front of spine) release and/or fusion
    - Anterior spinal instrumentation (rods and screws in the front of the spine)
    - Posterior spinal fusion with instrumentation (fusing the spine from behind, with rods)
    - Other \_\_\_\_\_
  - How much time between the diagnosis of scoliosis and the first surgery? \_\_\_\_\_
  - Do you consider the surgeries successful? Yes or No
  - If there were complications from the surgery, please describe. (E.G. infections, anesthesia)  
\_\_\_\_\_
  - How long was your child hospitalized after each surgery? \_\_\_\_\_

Thank you!

Return to: PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238