

More room needed? Attach additional sheet

Date form filled in: _____

Person with Prader-Willi Syndrome			Parent or Other Contact Person (<i>address if different</i>)		
Last Name		First Name	Last Name		First Name
C/O – Company/Organization			Contact (s) or Parent(s) occupation		
Address 1			Address 1		
Address 2			Address 2		
City	State	Postal Code	City	State	Postal Code
Country			Country		
Date of Birth		Sex	Home Phone		Work Phone
Current Height		Current Weight	Email		Fax
Contact's Relationship to person with PWS:					
Do You Wish to be Contacted About Research Opportunities? (Yes/No)					
Are You Willing to Help by Completing Future Questionnaires? (Yes/No)					
Type of Prader-Willi Syndrome (<i>circle one</i>)					
Paternal deletion – Maternal uniparental disomy (UPD) – Imprinting defect – PWS Like – Translocation – Unknown					
Date of Diagnosis:					
Method of Diagnosis: (<i>circle one</i>) Clinical (by symptoms only) – or – Blood Testing					
Blood Testing Type (<i>circle all that apply</i>)- chromosomal analysis, FISH, molecular/DNA(e.g. methylation) or unknown					
List Hospitalizations/Surgeries					
Primary Doctor for PWS Management (e.g., primary physician, endocrinologist) (name, address, phone)					
Growth Hormone (Yes/No) Start Date:			End Date:		
Prescribed Medication (Yes/No) Detailed Explanation of Condition Including Medication:					
Major Medical Concerns –Current or Past: (check all that apply)			<input type="checkbox"/> Diabetes – age at onset _____ Treatment- insulin __, oral hypoglycemic agents __ or diet control __		
<input type="checkbox"/> Weight related <input type="checkbox"/> Sleep apnea <input type="checkbox"/> Aspiration <input type="checkbox"/> Other respiratory complications <input type="checkbox"/> Heart problems <input type="checkbox"/> Osteoporosis <input type="checkbox"/> Curvature of the spine (scoliosis, kyphosis) <input type="checkbox"/> Fractures – explain _____ <input type="checkbox"/> Hip dysplasia <input type="checkbox"/> Other bone problems – explain _____ <input type="checkbox"/> High pain tolerance <input type="checkbox"/> Severe skin picking <input type="checkbox"/> Mitochondrial disorder - explain _____ <input type="checkbox"/> Seizure – age at onset _____ <input type="checkbox"/> Autistic behavior – explain _____			<input type="checkbox"/> Hypothyroidism – age at diagnosis _____ <input type="checkbox"/> Pubic or axillary hair before age 8 <input type="checkbox"/> Hormone replacement therapy (e.g., estrogen/ testosterone) <input type="checkbox"/> Gall bladder disease <input type="checkbox"/> Pancreatitis <input type="checkbox"/> Gastric/intestinal disorders Birth <input type="checkbox"/> Twins – identical <input type="checkbox"/> Twins - fraternal <input type="checkbox"/> Assisted reproductive techniques- explain _____ <input type="checkbox"/> Breech <input type="checkbox"/> Premature - Number of weeks _____ <input type="checkbox"/> Emergency c-section <input type="checkbox"/> Tube feeding – Number of weeks _____		
<input type="checkbox"/> DO NOT give my contact information to my PWSA state chapter			Eye - <input type="checkbox"/> Strabismus <input type="checkbox"/> Patching <input type="checkbox"/> Other If Other Explain _____		