

SURVEY CHECKLISTS

STUDY ENROLLMENT

To complete the initial set of surveys required at study enrollment, please visit www.pwsregistry.org and login to your account. You will find the list of surveys under the tab “Surveys Not Taken” **marked with an asterisk ***.

Although the time it takes to complete the surveys may depend on the amount of medical history that a study participant has, these surveys are expected to take approximately 2 to 3 hours to complete. The surveys do not need to be completed all at once. You can save partially completed surveys online and come back later to complete and submit the surveys online and come back later to complete and submit the surveys.

	SURVEY NAME
<input type="checkbox"/>	Getting Started*
<input type="checkbox"/>	Contact Information*
<input type="checkbox"/>	Participant Demographics*
<input type="checkbox"/>	Diagnosis*
<input type="checkbox"/>	Research Trials*
<input type="checkbox"/>	General Medical History*
<input type="checkbox"/>	Thrombosis Risk History*

	SURVEY NAME
<input type="checkbox"/>	Psychological and Mental Health*
<input type="checkbox"/>	Neurological History*
<input type="checkbox"/>	Vision History*
<input type="checkbox"/>	Thrombotic and Serious Medical Events*
<input type="checkbox"/>	Hyperphagia / Food Behavior*
<input type="checkbox"/>	Food Safe Zone*
<input type="checkbox"/>	PWS Profile*

EVERY 6 MONTHS

To complete the set of surveys required every 6 months, please visit www.pwsregistry.org and login to your account. You will find the list of surveys under the tab “Surveys to Retake” **marked with an asterisk ***.

Although the time it takes to complete the surveys may depend on the amount of information or serious medical events that a study participant has, these surveys are expected to take approximately 1 to 2 hours to complete. The surveys do not need to be completed all at once. You can save partially completed surveys online and come back later to complete and submit the surveys.

	SURVEY NAME
<input type="checkbox"/>	Thrombotic and Serious Medical Events*
<input type="checkbox"/>	Hyperphagia / Food Behavior*
<input type="checkbox"/>	Food Safe Zone*

	SURVEY NAME
<input type="checkbox"/>	PWS Profile*
<input type="checkbox"/>	Research Trials*