

WELCOME

Thank you for enrolling in the PATH for PWS study! The information you share as part of the study will help us better understand serious medical events in PWS over a 4-year period, as well as evaluate how PWS related behaviors change over time. The data from this study is intended to inform the development and clinical trial design of potential new treatments. As a reminder, there are no clinic visits during the study – all study data will be collected online through internet surveys.

If you are eligible for and have agreed to participate in the optional sub-study, you will receive a separate email with instructions for the blood test.

In this Welcome Kit you will find a variety of resources, including:

- **PATH for PWS brochure**
- **Checklist of surveys** to complete online
- **Refrigerator magnet** with key information about reporting serious medical events
- **Fact sheet** on how to recognize the signs and symptoms of blood clots
- **Calendar reminder stickers** to help you remember to complete the online surveys every 6 months – and earn e- gift cards!

There are also additional resources available online at www.PATHforPWS.com, including FAQs about the study, social media content to consider sharing through your PWS community networks, and more.

The strength of those living with PWS and their families is an inspiration daily as we work to advance research and potential therapies, and your participation in the PATH for PWS will provide valuable insights toward these goals.



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* |

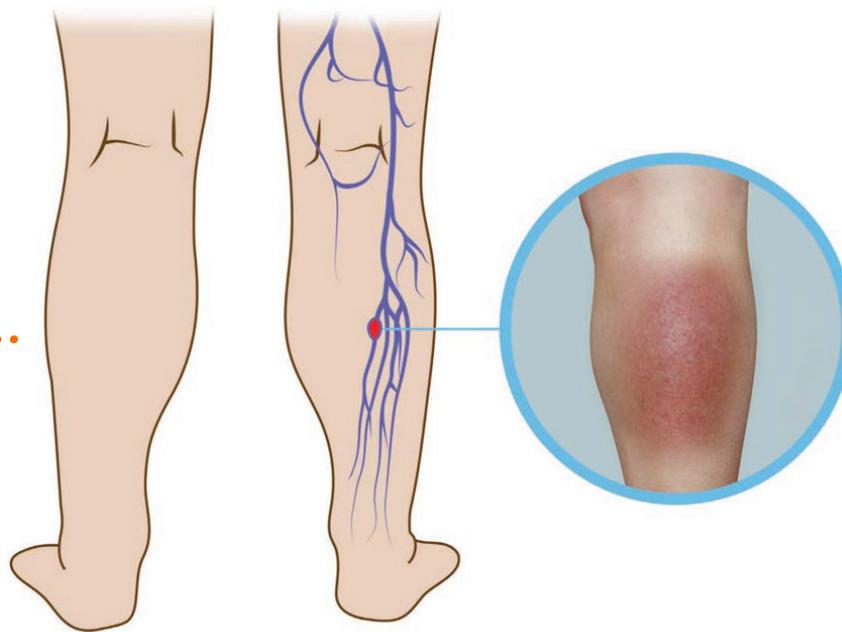
| | SURVEY NAME |
|--------------------------|------------------|
| <input type="checkbox"/> | PWS Profile* |
| <input type="checkbox"/> | Research Trials* |

Signs and Symptoms of Blood Clots

Thank you for participating in this important research study. As one of the objectives for the study, researchers are trying to understand if PWS patients are at a higher risk of developing dangerous blood clots (deep vein thrombosis and pulmonary embolism). This handout provides information on how to recognize signs and symptoms related to these events. You should seek medical attention if you see or experience any of these signs and symptoms.

What is deep vein thrombosis and what does it look like?

Deep vein thrombosis (DVT) happens when blood clots form in the deep veins of the legs.



The most common symptoms of DVT include:

- Swelling in the affected leg
- Pain in the affected leg (may feel like cramping in the calf)
- Affected area feeling warm and tender
- Redness or other changes in skin color, such as the skin turning paler or having a bluish tint

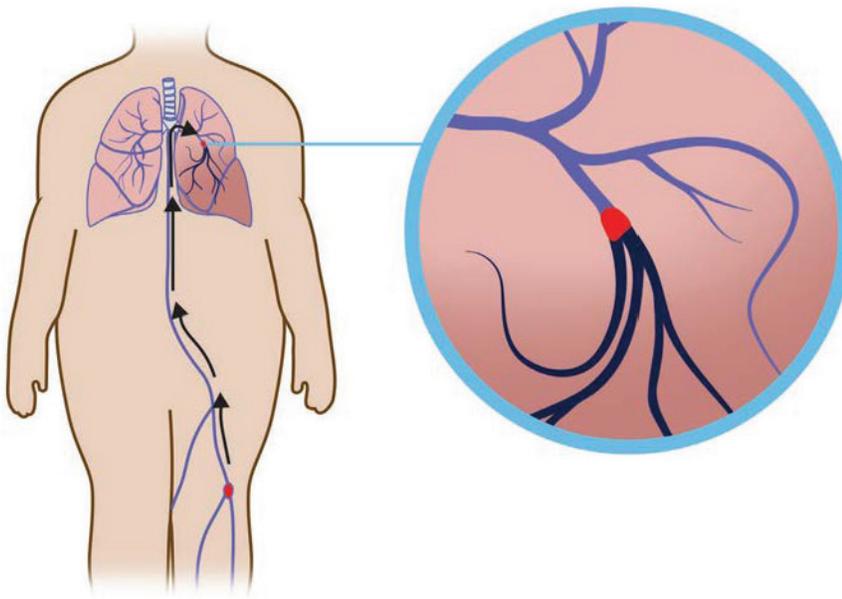
If you have any concerns or questions about these
risk factors, discuss them with your doctor.



Signs and Symptoms of Blood Clots

What is pulmonary embolism and what does it feel like?

Pulmonary embolism (PE) develops when a blood clot in the deep veins of the leg (DVT) breaks loose, travels through the bloodstream, and becomes lodged in the lungs.



Symptoms of PE include:

- Shortness of breath
- Problems breathing
- Coughing up blood
- Light-headedness, fainting, and unconsciousness
- Sharp chest pain that worsens after taking a deep breath

Symptoms of PE can occur very suddenly and without warning. These symptoms need medical attention at once. If you experience signs/symptoms of PE over a weekend or you cannot get in contact with your doctor, do not wait.

CALL 911 OR GO TO THE EMERGENCY ROOM IMMEDIATELY.

There are some factors that may increase your chances of developing dangerous blood clots. They include:

- Genetic blood clotting disorder
- Smoking
- Being overweight or obese
- Sitting or lying still for a prolonged period of time
- Hormonal birth control or hormone replacement therapy
- Surgery or severe bruising (injury to the veins)

If you have any concerns or questions about these risk factors, discuss them with your doctor.



PATH for PWS™

What types of serious medical events should be reported through the PATH for PWS study?

- Required hospitalization
- Required an emergency room (ER) visit
- Were considered life-threatening
- Were considered medically significant, such as blood clots, pneumonia, major infections, psychosis, significant self-injury, extreme aggression, suicidal thoughts, seizures, extreme food consumption in a short amount of time, severe edema

What information should be captured and shared as soon as possible after a serious medical event?

- Date of the event
- Description of the event including clinical symptoms, contributing factors or events
- Medication changes
- Medical records such as lab reports, imaging reports, clinician's notes, and discharge summary

For more information, please visit www.PATHforPWS.com or contact info@PATHforPWS.com