



What is Thrombotic Storm...

Most people who develop a blood clot in their vein have either a deep vein thrombosis (DVT) or a blood clot in their lung (pulmonary embolism). A very small number of people who develop blood clots have more serious and often life-threatening symptoms. Some of these people have what is called Thrombotic Storm (TS). TS is characterized by more than one blood clot in a short period of time. These clots occur in different, and sometimes unusual, locations in the body. This very aggressive and serious form of blood clotting is often difficult to treat.

TS may be associated with an existing condition or situation that predisposes a person to blood clots such as cancer, infections, or pregnancy. It has also been seen in patients with Antiphospholipid Syndrome (APS). In this situation, the condition is called 'catastrophic antiphospholipid syndrome', or catastrophic APS. Thrombotic Storm has been seen in patients of all ages.



More information about Thrombotic Storm can be found at www.thromboticstorm.com.



A LOOK INSIDE Thrombotic Storm

Ultimately, we hope that data from this research will lead to improvements in prediction, diagnoses, prevention, and treatment of this serious disorder.

For more information about this research or Thrombotic Storm, please go to www.HIHG.org or call 305-243-2365 during business hours, or toll free 24 hours a day at 1-877-740-7744. Our email address is HIHGTS@med.miami.edu.

Medical questions pertaining to Thrombotic Storm may be directed to:

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RESEARCHERS AND FAMILIES WORKING TOGETHER TO LEARN ABOUT THROMBOTIC STORM

WHAT IS OUR RESEARCH GOAL?

The goal of this research is to learn more about Thrombotic Storm syndromes and track the clinical course of people with this disorder over time. This includes genetic research.

Genetic research means research on genes. Genes control heredity from parents to children. Genetic research is necessary for many important reasons including:

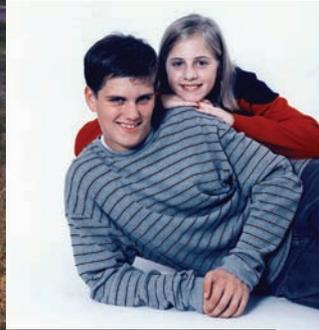
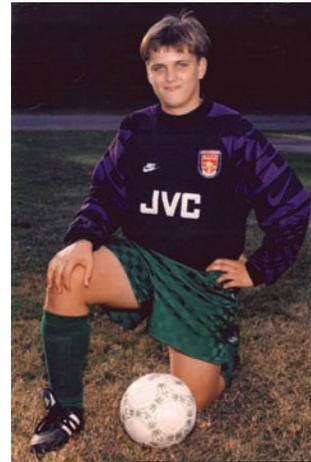
- a) to increase medical knowledge about TS
- b) to predict who is at risk for the disease
- c) to improve diagnosis
- d) to develop new drugs and treatments

If we apply these goals to our Thrombotic Storm study, we hope to eventually identify genetic factors that contribute to this rare, but incredibly serious syndrome.

In addition to helping patients with Thrombotic Storm, this research will also advance the field of genetics by hopefully finding any inherited patterns for thrombotic complications or autoimmune disorders in families where Thrombotic Storm syndromes are present.

HOW CAN YOU HELP?

All individuals who have been diagnosed with Thrombotic Storm or catastrophic APS are welcome to take part in this study. These disorders are characterized by more than one blood clot in a short period of time and in different, and sometimes unusual, locations in the body. Some people who qualify may not have been given a formal diagnosis of TS or catastrophic APS. If you think you may qualify or would like more information, please contact us.



REMEMBERING AN EXTRAORDINARY PERSON

This research project has developed due to the legacy of a kind, compassionate and intelligent 14-year-old boy, JJ Vance, who was stricken with Thrombotic Storm in 1998. His death profoundly affected his friends, school and his family, including his parents Margaret A. Pericak-Vance and Jeffery M. Vance. The Vances are the investigators of this study.



WHAT DOES PARTICIPATION INVOLVE?



- Reading and signing a consent form
- Giving a detailed family and medical history
- Providing a blood sample
- Providing updated information on a yearly basis

STUDY PARTICIPATION FACTS

- Participation is voluntary
- There is no cost to you
- All information is kept strictly confidential
- Participation will not affect health care

RESEARCH TEAM

To make this research project a success, we need many people with different areas of expertise. Families, physicians and human geneticists are all working together to find the genes that cause TS.

Margaret Pericak-Vance, PhD, is the Director of the John P. Hussman Institute for Human Genomics (HIHG) and the principal investigator of this study. Thomas Ortel, MD, PhD, a hematologist from Duke University, is the lead clinical investigator.

HIHG faculty have led the field in identifying the genetic variants that underlie common human disease. They have identified genes for more than 60 human illnesses, including neurological disorders, cardiovascular diseases, and eye diseases.

CALL OUR TOLL-FREE NUMBER:
1-877-740-7744

