

# THE SEVERE VON WILLEBRAND DISEASE (sVWD) PATIENT REGISTRY



## A LONGITUDINAL NATURAL HISTORY AND PATIENT OUTCOMES STUDY

*After years of development, VWD Connect Foundation (VCF) is proud to announce the December 2021 launch of the sVWD Patient Registry. Under the guidance and commitment of Dr. Mrinal Gounder, Chair of the VCF Research Committee, we are ready to begin gathering data concerning the sVWD Patient experience. This is a significant step in providing the necessary information to the scientific community so together we can improve treatment and CURE Von Willebrand Disease.*

### WHAT IS THE sVWD PATIENT REGISTRY?

The sVWD Patient Registry is an IRB approved on-line registry that will collect longitudinal data from patients living with Severe Von Willebrand Disease. Data collected will include patients' experiences with their disorder (like symptoms, treatments, etc.), their quality of life, and medical information related to their disorder (like laboratory values).

### WHY DID VWD CONNECT FOUNDATION SPONSOR THE sVWD PATIENT REGISTRY?

Severe VWD is an ultra-rare disease state, and scientists need to understand sVWD patients' medical and life experiences to be able to move the research needle forward. As the U.S. sVWD National Patient Organization, the Foundation understands the critical importance of gathering this information in a safe, methodical way so we can provide the data to scientists with a robust research proposal.

### WHO IS INVOLVED IN THE DEVELOPMENT OF THE sVWD PATIENT REGISTRY?

The four co-Principal Investigators (co-PI's) are Dr. Mrinal Gounder, Dr. Christopher Walsh, Alice Arapshian and S. Christina (Chrissy) Morgenthaler, MS, MBA. They bring years of experience in both clinical research and systems platform security and design.

A VCF Patient Registry Sub-Committee (PRSC) was formed including the four co-PI's; Jeanette Cesta, Registry Administrator; Stefanie Dugan, Certified Genetic Counselor and advisor; and Johnna Cesta, Research Coordinator.

The VCF International Medical and Scientific Advisory Board (MSAB) was engaged to review and comment on the sVWD Patient Registry throughout each step of development. They will also be responsible for vetting data requests from interested researchers.

Salus Independent Review Board (IRB) has approved this study, and the informed consent document. Salus IRB is a committee of scientific and non-scientific individuals who review, require modifications to, and approve or disapprove research studies by following the federal laws. This group is also required by the federal regulations to provide periodic review of ongoing research studies.

sVWD Patient Volunteers – not only are the majority of PRSC members living with VWD, additional fellow patients volunteered to review, test and comment on the development of the sVWD Patient Registry.

*For more information about the sVWD Patient Registry please see Frequently Asked Questions on the reverse side or contact:*

Alice Arapshian, *co-Principal Investigator*

S. Christina Morgenthaler, *co-Principal Investigator*

Jeanette Cesta, *Study Administrator*

Arapshian@VWDRegistry.org

Morgenthaler@VWDRegistry.org

RegistryAdmin@VWDRegistry.org

## sVWD PATIENT REGISTRY – FREQUENTLY ASKED QUESTIONS

Below are some FAQs regarding the sVWD Patient Registry. If you have further questions, please do not hesitate to reach out directly to registry personnel.

### WHO ARE WE ASKING TO PARTICIPATE?

Anyone who lives with Severe Von Willebrand Disease is invited to participate. Don't worry if you are not sure if you qualify, we will walk you through the study eligibility requirements.

### WHAT WILL HAPPEN IN THE STUDY?

If you are entered into the study, you will be able to start completing questionnaires related to your sVWD in a series of "modules" using an online website. Some modules will be available to you in the Registry website right away, and others will be available in the future. You might be able to complete a module over the phone with Registry staff assistance or also in person during VWD Connect Foundation Inc. annual conferences.

There is no end date to this Registry, and it will remain open for as long as it is collecting data that are useful to the sVWD community. This study will remain open for at least five years. There are no costs to participants for taking part in the Registry.

### HOW ARE YOU PROTECTING MY PRIVACY?

The privacy and safety of the information you choose to share within the sVWD Patient Registry is our highest priority. As many of the people involved in the creation and execution of this Study are patients themselves, we understand your concerns and value your time. Data is maintained in secure locations and access is strictly controlled. Only the co-PI's will have access to your identified data. This means that they will be the only people who can link your identity to your responses. All others involved will only have access to de-identified data, meaning your responses will be linked only to your participant number, no name or contact info would be provided.

Anytime you email a co-PI, only the co-PI's will have access to that email. Staff of the Foundation, the Sponsor of this Study, will not have access to identified data or direct email correspondence between the participants and the co-PI's.

### WHO MAY REQUEST DATA FROM THE SVWD PATIENT REGISTRY?

VWD Connect Foundation believes the only way we can move forward in improving care of and curing VWD is through collaborating with scientists, clinicians and key stakeholders across the world working on research in VWD. The Foundation will collect requests for data and forward them to the VCF Medical and Scientific Advisory Board. A Sub-Committee will then review the request to authenticate a valid purpose and that appropriate patient privacy/safety standards are in place. If approved, the Foundation will then co-ordinate the transfer of the de-identified data.

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*Join us as we all Connect for the Cure*

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