

The VEDS Movement Research Policy

Guidelines for Announcement of Research Studies That Require Human Subject Volunteers

As a division of The Marfan Foundation, The VEDS Movement's mission is to provide up-to-date medical information and support to our membership. The Foundation Research Program supports and promotes both basic and clinical studies in order to encourage new therapies and eventually find a cure for VEDS. However, the Movement is faced with a dilemma when researchers and physicians interested in pursuing novel therapies for our membership approach the Movement for help in recruiting volunteers to participate in research studies. While we want to encourage and promote research, our responsibility as a volunteer health organization is to maintain the privacy of our membership. We cannot, therefore, directly solicit our membership to participate in any research study. In order for research to advance, the Movement is willing to provide information about research studies to our membership through different media avenues but will not actively get involved in the recruitment process or endorse any specific study.

Please use the following guidelines to request media coverage of research studies through The VEDS Movement:

1. A letter of intent (1-2 pages) outlining the research proposal must be submitted to the Chief Scientific Officer.
 - The goal and significance of the study must be clearly expressed. A short study announcement that can be used on our website, newsletter or sent through our e-mail network must be provided. Included in that announcement should be information on how patients can participate (i.e. contact information for study investigator, link to survey etc.).
 - If only patients diagnosed with VEDS are requested, it must be explicitly stated.
 - The scope of patient participation must be fully and accurately described.
 - The significance of how this study will move research forward should be explained.
 - The required number of patients needed to fulfill the research goal must be estimated.
 - Proposed methods for publicizing research study to the membership should also be included (i.e. booth at conference, questionnaire, notice in newsletter, website).
 - The fate of any tissue or medical records must be clearly expressed (i.e., destroyed, stored, or returned).
 - Personnel who will have access to the medical records or tissue must also be clearly defined.
2. Investigator must be working actively in the proposed research area and show evidence of prior experience by supplying a biographical sketch along with the letter of intent.
3. Investigators must also submit proof of Institutional Review Board (IRB) approval of human subjects for the proposed research study in addition to approval from appropriate review boards such as thesis advisor or doctoral committee etc. The Movement may require changes to the IRB application.
4. Proposed research topic must be related in substance for the VEDS population.
5. Names, medical history, family history, and genetic diagnosis information must be kept completely confidential and stated in both the IRB forms and the consent forms.

6. Participants are not to incur any costs due to participation in the study.
7. No membership mailing list will be provided.
8. A report describing the conclusion of the study should be provided to the participant if requested.

All requests and documentation must be forwarded to:

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