



Research Guidelines

The Platelet Disorder Support Association (PDSA) is a nonprofit patient advocacy organization dedicated to enhancing the lives of patients with Immune Thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support. In 2016, PDSA established these Research Guidelines with the goal of funding the most promising research projects to further understand the pathogenesis and management of primary ITP, have the potential to raise the quality of life for ITP patients, and lead to new therapies and a cure.

Scope: Research must be focused on primary ITP. Clinically oriented, observational, and laboratory hypothesis-driven research proposals related to ITP are encouraged. Proposals should include a clear description of a hypothesis-driven investigation that addresses an area of need in the understanding of, or treatment of primary ITP. The research plan must include evidence of consultation with and/or collaboration with patients with primary ITP (alternatively, PDSA's Patient Research Panel). Funding may be allocated to hypothesis-driven research projects showing research for a patient benefit, according to the Patient-Centered Outcomes Research Institute (PCORI) Methodology Report, across the following areas:

- Disease incidence, prevalence, burden, causes, prevention, and management
- Gaps in evidence in terms of biomarkers, clinical outcomes, practice variation, and health disparities
- Potential for new evidence to improve health, well-being, and quality of care, such as patient qualitative studies to clarify symptoms or other quality of life issues of living with ITP
- Patient needs, outcomes, and preferences
- Relevance to patients and clinicians in making informed health decisions

Eligibility and funding: Up to two grants will be awarded annually. Awarded research funds are to be used only to support patient-centered primary ITP research. The maximum amount available for each grant is \$20,000, including institutional overhead and indirect costs of research. Funds can be used for a portion of the applicant's salary and supplies or for partial salary support of a research study coordinator; if the funds are all used for salary, then an outside source to fund the remainder of the study must be demonstrated. Funds cannot be used for equipment without prior approval in writing. Funding is for a maximum period of 12 months. Funding for a second year is contingent on exceptional progress and renewal applications will be assessed along with new applications. Research applications from outside the US are welcomed. There is no restriction on additional sources of support for the position and project, i.e. partial funding from a for-profit institution or another not-for profit source, e.g. American Heart

Association is acceptable. Research involving vertebrate animals is acceptable if approved by the relevant institutional committee on animal welfare.

Application process:

Completed proposals must be submitted to PDSA's Research Program Manager by May 1, 2023 and written for a general audience. Incomplete applications will not be considered. All materials should be submitted as microsoft word/excel files, including "PDSA Proposal Template," "PDSA Budget Template," documentation of approval of other funding sources, and Principal Investigator's CV. In order to effectively determine the most promising and innovative research important to ITP patients, the Proposal Template will include a summary of the proposed research, preliminary data and/or a literature review summary, methods and intended statistical analysis, and a project timeline.

Review process: Applications from investigators will be evaluated by PDSA's Patient Research Panel. The PDSA Research Program Manager will screen proposals for proper adherence to framework guidelines. Proposals will be sent to PDSA Medical Research Advisors to review for feasibility and relevance to ITP, and they will provide comments to investigators. After receiving updated proposals, grants will be awarded based on selection by a review panel selected by the PDSA. Proposals will be evaluated on a point scale established by PDSA's Research Team and will be based on importance, relevance, investigation plan, and interest to the ITP patient community.

Additional information: Written approval by the Institutional Review Board (IRB) for research involving human subjects and written approval for research involving vertebrate animals must be submitted to the Board before funding can begin. A written progress report of no more than two pages must be received by the PDSA Research Program Manager within 6 months of the date of funding for funding to continue. A Final Report on the work accomplished, including a summary report on ALL expenditures made, must be submitted. Applicant agrees to cite support from PDSA in all written and oral communications pertaining to the funded research, and to submit a research abstract to PDSA to include in their quarterly newsletter disseminated to its members. Direct questions about these research guidelines can be directed to PDSA Research Program Manager, Jennifer DiRaimo, at jdiramo@pdsa.org.