

KDVS Foundation Grant Request Process

Supporting Research, Advocacy, and Community Impact

The mission of the KdVS Foundation is to improve the lives of individuals and families affected by Koolen-de Vries syndrome through research, advocacy, education, support services, and meaningful community connection. As the Foundation continues to grow, a thoughtful and transparent grant process helps ensure that resources are invested strategically, responsibly, and in ways that create measurable impact for the KDVS community.

Research & Funding Priorities

The KdVS Foundation seeks to support innovative, early-stage, translational, and patient-centered initiatives that advance scientific understanding and improve outcomes for individuals living with KDVS. The Foundation is especially interested in projects that demonstrate strong scientific merit, collaboration, measurable milestones, and long-term therapeutic potential.

Priority areas include:

- Advancing understanding of *KANSL1* biology and KDVS mechanisms
- Exploring therapeutic development and treatment pathways
- Supporting translational and clinical research
- Strengthening patient registries and natural history studies
- Developing biomarkers and clinical trial readiness
- Improving quality of life and functional outcomes
- Supporting educational, behavioral, and family-centered interventions
- Encouraging collaboration and open scientific exchange

While earlier research efforts focused primarily on defining and characterizing KDVS, the field is now entering a new phase centered on therapeutics, translational science, and cure-oriented research. Through intentional funding cycles and strategic investment, the Foundation seeks to help move discoveries from the laboratory toward meaningful clinical impact.

Proposal Evaluation Criteria

Grant proposals are evaluated based on:

- Scientific merit and rigor
- Innovation and creativity
- Feasibility and readiness
- Potential patient and family impact
- Collaboration and data sharing
- Long-term translational potential
- Responsible stewardship of funding

Grant recipients are expected to provide progress updates every six months to the Foundation's Medical Advisory Board to promote transparency, accountability, and shared learning across the KDVS research community. We will provide a template progress report and continued funding payments or dispersals could be delayed if the reports are not received in a timely manner.



Review & Approval Process

The KdVS Foundation Board of Directors is responsible for reviewing and making all final decisions regarding grant funding requests. Proposals are evaluated based on mission alignment, measurable impact, feasibility, financial stewardship, collaboration opportunities, and long-term benefit to individuals and families affected by KdVS.

Submission Timeline

Grant applications are accepted on a rolling basis throughout the year; however, applicants are strongly encouraged to submit proposals by **November 1** for primary consideration during the Foundation's annual funding review cycle. The majority of grant allocations for the upcoming calendar year are typically determined and awarded by the end of November. Projects submitted after November 1 may still be considered based on available funding, emerging research opportunities, and strategic priorities identified by the KdVS Foundation and its Medical Advisory Board. Please submit to Ashley Point, President, KdVS Foundation at ashley@kdvsfoundation.org. Feel free to contact Ashley with any questions.

KdVS Grant & Funding Application
(Application must be submitted in English)

(Notes – Build into website, google form, to email + store all data electronically in a spreadsheet for easier sorting, reading)

Applicant Information

1. Name of Organization or Individual Applying
2. Biosketch/CV of applicant
3. Primary Contact Name
4. Primary Contact Title
5. Primary Contact Email,
6. Primary Contact Phone Number
7. Organization Website (if applicable)
8. Is your organization a nonprofit, academic institution, medical provider, or independent initiative?
9. Please provide any applicable tax-exempt or organizational documentation.

Project Information

9. Project Title
10. Requested Funding Amount
11. Total Project Budget
12. Has KdVS Foundation previously supported this project? If so, please provide the total amount awarded/given. (50 words or less)
13. Briefly describe the project or initiative. (100 words or less)
14. What specific need within the KDVS community does this project address? (100 words or less)

Impact & Outcomes

15. Who will directly benefit from this project? (100 words or less)
16. Approximately how many individuals or families will be impacted?
17. What outcomes or results do you hope to achieve? (200 words or less)
18. How will success or effectiveness be measured? (200 words or less)
19. What is the anticipated project timeline? (200 words or less)

Mission Alignment

20. How does this project support the mission of the KDVS Foundation?
21. Does this initiative involve collaboration with researchers, clinicians, organizations, or community partners?
22. How this project will lead to treatments and cures for KdVS?

23. If you received previous funding for this project or any other project, have you supplied the KdVS Foundation with an update over the past year? (YES/NO/ NA

Financial Information

22. Please provide a detailed project budget. (attachment)
23. What additional funding sources, if any) are supporting this initiative? (100 words or less)
24. Specifically, how will KDVS Foundation grant funds be used? (200 words or less)

Long-Term Vision

25. What long-term impact could this project have on individuals and families affected by KDVS? (200 words or less)
26. Could this initiative continue beyond the initial funding period? If so, how? (200 words or less)

Final Reflection

27. Is there anything else the KDVS Foundation Board should know when considering this request?