



Request for Application: Research Grant

Overview

Gorlin syndrome (GS) is a rare, autosomal dominant disorder that can manifest in nearly every organ system. The disease burden on afflicted individuals and their loved ones is tremendous. The mission of the Gorlin Syndrome Alliance (GSA) is to thoughtfully support, comprehensively educate, and aggressively seek the best treatments and a cure for those affected by GS. In this light, we are offering a competitive research grant program.

Background

The GSA conducted a survey with an international cohort of affected individuals in 2020, creating the most comprehensive look at the impact of Gorlin syndrome across the world. That work revealed that the absence of a cure, or way to eliminate the frequency of symptoms, is the most universally challenging aspect of the disease, followed closely by the cumulative impact of scarring on their appearance. In 2025, the GSA followed up on these results to determine where improvements in care would deliver the highest improvement in quality of life. Respondents told us that curing basal cell carcinomas (BCC) associated with Gorlin syndrome would significantly reduce or eliminate the challenges of GS in their daily lives. Results also indicated a strong desire to see improvements in treatment options for odontogenic keratocysts (OKC).

Because the community has articulated a strong desire for relief from the challenges of OKC recurrence rates and the accelerating BCC burden over their lives, we encourage projects that advance this aim.

Proposed research projects submitted for review:

- Should be designed to result in the improvement of the quality of life of individuals affected by GS.

- Should address patient priorities
- May relate to repurposing existing drugs or products.
- May be intended to provide localized or systemic benefit to GS patients.
- May involve pre-clinical or clinical trial work.
- May relate to developing research-enabling tools, such as data collection and analysis platforms, to accelerate clinical trials.

Amount of Funding Offered

\$2,000.00 to \$30,000.00

Grants awarded will provide project funding for one year. Multi-year research applications should include a proposed timeline and milestones. There is potential for grants to be renewed. The GSA may award more than one grant annually, if there are multiple, equally meritorious submissions.

Application

Applications must be submitted to: research@gorlinsyndrome.org

Each application must be sent as a single pdf and include:

1. Front page with grant title, investigator(s), institution, departmental affiliations, contact information
2. Cover letter including why Gorlin syndrome research is important to the investigator(s), how it relates to patient priorities and the relevance of the proposed research
3. Abstract (300 word maximum)
4. Layman's Summary of Project (300 word maximum)
5. Project proposal which must include:
 - a. Specific aims
 - b. Background and rationale
 - c. Project Description
 - i. Methods and experimental study design
 - ii. Primary and secondary outcome measures (if applicable)
 - iii. Statistical analysis plan (if applicable)

- d. Potential obstacles / pitfalls
- 6. Budget – A detailed budget with justification and explanation of any anticipated or actual overlapping funds. Plans for support beyond the award period must also be included if applicable.
- 7. Funds should not be requested for honoraria, seminars/meetings, retreats.
- 8. Biographical sketches – A biographical sketch for the Principal Investigator and, if any, Co-Investigators, must be provided. This should follow the NIH style of biographical sketch.
- 9. Letter(s) of Support - While not mandatory, it is recommended that letters of support from co-Investigators, key collaborators, and department chairs be submitted.

Review

Applications will be reviewed by members of GSA's Medical and Scientific Advisory Committee and others they choose to assist in this process.

These evaluations will be based on the following:

- 1. Potential impact on reduction of Gorlin syndrome disease burden and improvement in
- 2. quality of life of affected individuals
- 3. Innovation
- 4. Clarity and readability of proposal
- 5. Feasibility and depth of approach
- 6. Investigator(s) experience and research environment (including mentorship, if applicable)
- 7. Appropriateness of budget

The lay summaries of the applications will be subject to a review by a committee of affected community members. Applications will be prioritized based on their combined scores.

Eligibility

Applicants do not need to be fully trained in their specialty but must be in the process of such training. If in training, the applicant must have a documented mentor to receive funding. They must be eligible to apply for grants under existing guidelines of the host institution. Evidence of IRB approval is required for all studies where relevant.

Award

Applicants may apply for up to \$30,000.00 for one year (direct costs only). If needed, grant recipients may be eligible to apply for a second year of funding through a competitive process prior to the end of their project term. *Award recipient(s) must acknowledge the support provided by the GSA in all publications and at all meetings.* The award recipient(s) may be required to include the Gorlin Syndrome Alliance in future intellectual property negotiations.

Important Dates

All Applications Due by: March 1, 2026

Award Announcement(s): May 30, 2026

Earliest start date: July 6, 2026

Progress report due every 6 months until award completion.

Questions

For additional information about patient priorities or questions about the grant, please email Meredith Weiss at MWeiss@gorlinsyndrome.org