



Smith-Kingsmore SYNDROME FOUNDATION

REQUEST FOR PROPOSALS 2026 RESEARCH GRANT PROGRAM

Smith-Kingsmore syndrome (SKS) is a rare neurodevelopmental disorder with a limited but growing number of identified patients worldwide. The condition is caused by de novo, gain-of-function mutations in the MTOR gene, leading to hyperactivation of the mTOR signaling pathway. SKS is characterized by a spectrum of clinical features including macrocephaly, developmental delay, intellectual disability, seizures, disordered sleep and behavioral challenges such as autism spectrum features. There are currently no approved therapies specifically indicated for SKS, and clinical development efforts remain limited.

Eligibility Criteria

This grant program is open to research investigators affiliated with an academic institution, hospital system, industry/pharma, non-profit institution, or other accredited research institutions based in the United States (U.S.) or internationally. Eligible applicants include post-doctoral fellows, clinical fellows, researchers, physicians, or other associated research professionals with faculty appointments or research positions.

Research Priorities

The Smith-Kingsmore Syndrome Foundation is specifically interested in the following areas of research but is open to any applications addressing the needs of the Smith-Kingsmore patient population. In order to respond to this RFP, investigators will need to note the suite of SKS-associated mutations they plan on investigating. For a full list of mutations, reach out to the SKS Foundation at susan.dando@smithkingsmore.org.

- Analysis of mTOR pathway dysfunction resulting from SKS-related genetic mutations
- Research into SKS-related seizures
- Development and evaluation of therapeutic interventions for SKS
- Studies to address behavioral, communication, sleep, and feeding difficulties in SKS patients

If interested, please reach out to the Smith-Kingsmore Syndrome Foundation to set up an informational meeting.

Budget

Applicants may request up to \$50,000 in direct costs for a 12-month project. Indirect costs will not be considered. There may be opportunities to apply for more funding for the most promising projects after the first year of funding.



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2026 Grant Program Dates

Program opens	July 2026
LOI due	August 28 th , 2026
Announcement of those selected for full application	September 23 rd , 2026
Full applications due	November 20 th , 2026
Anticipated award announcements to applicants	January 29 th , 2027

Application Review Process

Applications will be reviewed by the SKS Foundation Board of Directors and scientific advisors. The grant selection process is unbiased and independent; awards are based on scientific merit, feasibility, potential impact, and expected contribution to the body of knowledge about SKS. Advisors and board members with a conflict of interest will not participate in voting for those specific applications.



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Letter of Intent Application Instructions

Letters of Intent (LOIs) will be accepted on or before August 28th, 2026. Submit to susan.dando@smithkingsmore.org and include the following:

1. Application form: signed by principal investigator and institutional official (if needed at LOI stage per institution policy).
2. Research proposal: 2-page maximum, single-spaced, 11-point Arial font, 1-inch margins all around, and page numbers in the bottom margin.

Include the following sections: title of project, abstract, specific aims, background, significance, research design and methods, and timeline.

Full grant application details will be provided to those applicants selected for full submission.

Application Submission

A PDF copy of the LOI should be electronically submitted to susan.dando@smithkingsmore.org.

All documents should be merged as one PDF file. Documents requiring signatures can either be digitally signed or ink signed, scanned, and merged. The PDF file should be saved as "investigator first and last name_institution_2026." An example would be to name the file "Jane Doe_University of State_2026".

Questions regarding these guidelines should be directed to susan.dando@smithkingsmore.org.

Those selected to submit full applications will be notified by email. Full applications are due by November 20th 2026. Final decisions on grants selected for funding will be determined following review by advisors but no later than January 29th 2027. All decisions about grant applications made by Smith-Kingsmore Syndrome Foundation are final and are not subject to appeal.

Terms and Conditions

Please note, this is a partial list of our terms. A complete list of the full terms and conditions will be forwarded to grant recipient(s) upon notification of grant approval.

Reporting: progress report and virtual update at 6 months and a final project report due at 12 months (3-page maximum) will be required. With the virtual update and the final project report, submit a simple summary in writing, of either study progress or study findings, that can be understood by a non-scientific audience.

Publication Policy: it is expected that the results of research supported by the Smith-Kingsmore Syndrome Foundation will be published as soon as practical, as conference abstracts and/or in



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relevant PubMed-indexed, peer-reviewed journals. Acknowledgment of funding support, either in whole or in part, from the Smith-Kingsmore Syndrome Foundation Research Grant Program is required. The responsibility for publication lies exclusively with the principal investigator and does not require prior review by the Smith-Kingsmore Syndrome Foundation. Electronic copies of presented conference posters, conference presentations, and published manuscripts (whether during the term of the grant or after it has ended) should be promptly forwarded to the Smith-Kingsmore Syndrome Foundation.

Publicity: the Smith-Kingsmore Syndrome Foundation shall be permitted to use the principal investigator's name, image, and likeness, as well as the name of the affiliated institution, in connection with all statements, printed materials, or electronic media related to the grant. The principal investigator will provide career bio and headshot to the Smith-Kingsmore Syndrome Foundation.

Conference Attendance: the researcher will be encouraged to present their findings at the Smith-Kingsmore Syndrome Foundation Family Conference.

Tool sharing: Grantee shall make reagents (e.g., animal models, expression plasmids, antibodies, permanent cell lines) and detailed protocols available, upon request, to qualified scientists at academic institutions and to other organizations working with the Foundation, exerting best efforts to make these available as quickly as possible, as well as post any related protocols on the Smith-Kingsmore Syndrome Foundation website, upon request.

Data sharing policy: Data generated from funded research shall be shared with the Smith-Kingsmore Syndrome Foundation Board.



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2026 RESEARCH GRANT PROGRAM APPLICATION FORM

Title of Project

Principal Investigator Name (First, MI, Last)

Title and Degree(s)

Institution and Division/Department

Mailing Address

E-mail and Phone

Co-Investigator Name (First, MI, Last)

Title and Degree(s)

Institution and Division/Department

Co-Investigator Name (First, MI, Last)

Title and Degree(s)

Institution and Division/Department

Co-Investigator Name (First, MI, Last)

Title and Degree(s)

Institution and Division/Department

Co-Investigator Name (First, MI, Last)

Title and Degree(s)

Institution and Division/Department



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2026 RESEARCH GRANT PROGRAM APPLICATION FORM

If research is to be conducted at a different site, Institution and Division/Department

Mailing Address

E-mail and Phone

Funding requested (\$50,000 maximum)

I hereby certify that the information provided in this LOI is, to the best of my knowledge, true and correct. I have not knowingly withheld any facts or circumstances that would otherwise affect consideration of this LOI. I agree to accept responsibility for the scientific direction and conduct and financial and legal oversight of this project.

I certify that I have read the Smith-Kingsmore Syndrome Foundation Research Grant Program Terms and Conditions and understand the grant requirements if awarded funding by the Smith-Kingsmore Syndrome Foundation.

Applicant Name

Applicant Signature

Date

Institutional Official Name

Institutional Official Signature

Institutional Official Title

Date
