



## Foundation for Ichthyosis & Related Skin Types, Inc. 2023 Research Grant Application Packet

### Contents:

- Research Priorities
- Guidelines for Submission of Proposals
- Proposal Application Forms (see list of forms in Table of Contents, page 2)
- Terms and Conditions of Awards

### Schedule for Applications:

- April 14, 2023 - Letters of intent are due to FIRST
- May 8, 2023 - Invitation to submit full application emailed to investigators
- June 16, 2023 - Full grant application due to FIRST
- August 31, 2023 - Notification of award

Please download the application packet in PDF format. Complete the application and return to the Foundation for Ichthyosis & Related Skin Types<sup>®</sup> (FIRST) by email to [cwassel@firstskinfoundation.org](mailto:cwassel@firstskinfoundation.org). Please include any relevant attachments.

### *Electronic submissions are required.*

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### For more information:

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### **Introduction**

The Foundation for Ichthyosis & Related Skin Types® (FIRST) research grant program was established in 2006 to encourage and support investigation into the causes, treatments, and potential cures for ichthyosis. FIRST supports both **Pilot Grants** (up to \$15,000, not renewable) that support generation of new ideas for study and simple projects that provide definitive information within 1 year, and **Research Grants** (up to \$50,000 for one year, with the potential for a second year of funding upon demonstration of progress and availability of funds) that will lead to ongoing, self-supporting programs in ichthyosis research. Different types of ichthyosis research will be considered. Research may include focused basic science projects addressing keratinocyte biology and differentiation, genetics, biology of skin inflammation, itch or other ichthyosis-related areas. Clinical research is also encouraged and may address improving diagnosis and/or quality of life, defining quality of life measures, expanding knowledge about topical or systemic treatments, or specific aspects of the disease. Investigators are encouraged to utilize the National Registry for Ichthyosis and Related Skin Disorders when appropriate.

Surveys of the ichthyosis community, specifically individuals affected with ichthyosis and their families, have indicated that research is their primary area of interest and their top priority for funds donated to FIRST. In response to this, FIRST initiated an expanded program to promote promising avenues of research by investigators who have a new or established interest in the ichthyoses.

The genetic basis of most types of ichthyosis is now known. Recent advances in knowledge about epidermal structure, function, and physiology have provided insights into the pathogenesis of several of the ichthyoses. A variety of new approaches to molecularly targeted therapy for genetic disease have been developed by the scientific community. FIRST and its stakeholders are determined to promote the use of this knowledge and to encourage its translation into more effective therapies. Special interest exists for research with relevance to autosomal recessive congenital ichthyosis (ARCI), epidermolytic ichthyosis and keratitis-ichthyosis-deafness (KID) syndrome.

Research priorities used by the research committee for funding decisions reflect the interests of FIRST members and advice of the FIRST MSAB and are reviewed annually by FIRST's CEO and Board of Directors.

### **About FIRST**

FIRST is a vibrant, growing foundation connected to its members and families by the special skin and unique management needs of individuals and families with ichthyosis and related skin types. Our mission is to improve lives and seek cures for those affected by ichthyosis and related skin types, such as palmoplantar keratoderma, erythrokeratoderma, KID syndrome, Darier disease and other inherited disorders of cornification.

## Guidelines for Submission of Proposals

1. A letter of intent containing an abstract of the proposal must be **received** by **April 14, 2023**. After review of the LOI, the Foundation will invite applicants to submit a full application.
2. Grant proposals must be **received** in the Foundation office **by 5pm EST on June 16, 2023**
3. Only electronic submissions will be considered. Please use a minimum of 11 point Arial font.
4. **Pilot grants** are available for funding for 1 year, **Research grants** are available for funding for up to a total of 2 years, pursuant to acceptable progress reports after one year and availability of funds.
5. The narrative portion of the application may not exceed **5 pages**, and references are limited to **1 page**. Brief narratives are encouraged for Pilot Grants.
6. Proposals must include
  1. A starting date for the project and a proposed ending date. Use the appropriate space on the form entitled *Proposal Application Form*.
  2. A summary of the proposed project. Use the attached form titled *Project Abstract*. Please use **lay language** to the extent possible.
  3. A detailed budget. Use the form entitled *Detailed Budget for Initial Budget Period*. Provide a one-year budget up to \$15,000 for Pilot grants, and up to \$50,000 for Research Grants with a 2-year budget.
  4. The budget is not to include funding for equipment greater than \$2,000.
  5. Payments will be made to the financial officer of the principal investigator's institution, who will be responsible for administering the funds. Any unexpended funds shall be returned to the Foundation upon completion of the funding period unless an extension is approved by the Foundation.
  6. The Foundation does not fund indirect costs.
  7. Complete biographical information on the principal investigator, co-investigators, and any other significant personnel. Please use the form entitled *Biographical Sketch*, page 9, it may not exceed four pages. Alternatively, NIH biosketches may be used and attached to the proposal.
    - a) Personal Statement - Briefly describe why your experience and qualifications make you particularly well-suited for your role (e.g., PD/PI, mentor, participating faculty) in the project that is the subject of the application. Within this section you may, if you choose, briefly describe factors such as family care responsibilities, illness, disability, and active duty military service that may have affected your scientific advancement or productivity.
    - b) Positions and Honors - List in chronological order previous positions, concluding with the present position. List any honors.
    - c) Selected Peer-reviewed Publications - FIRST encourages applicants to limit the list of selected peer-reviewed publications or manuscripts in press to no more than 15.

Do not include manuscripts submitted or in preparation. The individual may choose to include selected publications based on recency, importance to the field, and/or relevance to the proposed research. When citing articles, provide the PubMed Central (PMC) reference number (e.g., PMID234567).

- d) Research Support – List both ongoing and completed research projects for the past three years (Federal or non-Federally-supported). Begin with the projects that are most relevant to the research proposed in the application. Briefly indicate the overall goals of the projects and responsibilities of the key person identified on the Biographical Sketch. Do not include number of person months or direct costs.
8. A detailed description of your research plan including hypothesis or hypotheses, proposed methodologies, expected results, and strengths and potential pitfalls of the project. Please consult page 10 for a suggested format.
9. A description of the facilities available, including a Letter of Commitment from your institution or department head.
10. Letters of Commitment to collaborate from other research institutions or facilities that will participate in the project.
11. Future plans for the project, including plans for future funding, if applicable.

#### **Use of Human Data/Biological Specimens**

Research that involves the use of human data or biological specimens is considered human subjects research and must be approved by the Human Subjects Review Board of the applicant's parent institution. Provide the status of IRB approval process or approval number and date of expiration.

#### **Use of Animals in FIRST-Funded Biomedical Research**

Animals shall be used in biomedical research only when no other means of obtaining scientifically sound, valid and useful results are available. The minimum number of appropriate animals required to obtain and validate results shall be used. The acquisition, care and use of animals must be in accordance with all applicable federal, state and local laws and regulations and must be approved by the institutional animal care and use committee (IACUC). Provide a separate Vertebrate Animal section, if applicable.

Certifications must be received from research facilities prior to being approved for a research grant that each involved animal facility, its researchers, and employees adhere to the Animal Welfare Act, National Research Council Guide for the Care and Use of Laboratory Animals, and any appropriate U.S. Department of Agriculture or National Institutes of Health regulations and standards. In cases requiring the death of an animal, only the most appropriate and humane form of euthanasia shall be used consistent with the purpose of the research.



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**Project Application**

*Investigator.*

Project Title:	
Date of Application:	
Principal Investigator: Degree: Position: Address:  Phone Number: Fax: Email:	
Sponsoring Institution / Department  Grants Contract Administrator, Name:  Address:  Phone: Fax:	
Endorsing Chairman of the Department: Chairman's Phone Number:	<i>Signature:</i>
Total Funds Requested:	
Dates of Proposed Project Period:	
Site of Project:	
Principal Investigator Signature:	

- Animal use
- Human subject use
- IACUC approval status pending / approved (*circle*)
- IRB approval status pending / approved (*circle*)

Project Abstract

*Investigator.*

Project Title:	Please do not exceed this page length. Use lay language to the extent possible.
Abstract:	<p><i>Objective:</i></p> <p><i>Aims:</i></p> <p><i>Methods:</i></p> <p><i>Key idea of proposal (how is it an advancement):</i></p> <p><i>Relevance to the mission of the Foundation for Ichthyosis &amp; Related Skin Types:</i></p>



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Project Budget - List Direct Costs Only

Investigator:

Project Title:		
Detailed Project Budget From:	Through	Type of

Personnel (Applicant organization only):	Dollar amount requested:
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Name	Title/Position	% Effort	Salary	Fringe Benefits	Totals
	Principal Investigator				

Subtotals:			
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Supplies (please itemize):	
Other:	
Total Request:	\$





**Biographical Sketch**

Please provide the following information for the key personnel and other significant contributors in alphabetical order following the principal investigator. Follow this format for each person. Do not exceed **four** pages.

Investigator:

Project Title:	
Name	Position / Title

Education/Training (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training).

Institution and Location	Degree	Month/Year(s)	Field of Study

Please refer to the Guidelines for Submission of Proposals in order to complete sections 7 a through d of the Biographical Sketch.

## Research Plan

### Suggested Format:

Project Title:

Principal Investigator:

- I. Hypothesis:
- II. Goals, Objectives and Aims:
- III. Significance: How is this project relevant to advancing an understanding of or treatment for ichthyosis?
- IV. Background / Preliminary Data
- V. Experimental Design/Methods:
- VI. Potential Pitfalls/Alternatives:
- VII. References:

*Please do not exceed 5 pages, exclusive of references. References limited to 1 page.*

### Resources/Facilities Description

Specify the facilities to be used for the proposed project. Indicate the performance sites, capacities, pertinent capabilities, and relative proximity to and availability to the project PI and other investigators. Under “Other,” identify relevant support services and indicate the extent to which they will be available to the project.

#### **Resources**

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Laboratory:

Clinical:

Animal:

Other:

#### **Major Equipment**

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List the most important equipment items readily available for this project, noting the relevant capabilities and location of each:

## Terms and Conditions of Awards

1. Duration: Grants are funded for up to a total of 1 or 2 years, pursuant to acceptable progress reports after year one and availability of funds.
2. Changes of Status of Principal Investigator: If the named principal investigator changes affiliations, the award will follow only after approval of the transfer from the Foundation. If the named principal investigator ceases work on the project for which the award was made, the award will terminate and the remaining balance will be returned to the Foundation.
3. Site of Project: Awards are for study at public or private universities, colleges, hospitals, and biomedical research institutions. The principal investigator will make all arrangements for the conduct of the proposed project.
4. Publications: All discoveries resulting from work supported by the Foundation for Ichthyosis and Related Skin Types should be made available to the public and the scientific community through peer reviewed publications and national meeting presentations. Publications and presentations must acknowledge the support of the Foundation. A full PDF of each publication must be forwarded to the Foundation.
5. Publicity: The Foundation for Ichthyosis & Related Skin Types 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 award or related to the Foundation's research program. The principal investigator will provide appropriate photographs and biographical information at the Foundation's request.
6. Realistic Goals: Prior to making awards, applicant will be asked to provide a timetable with realistic goals for every 6 months of support. Such information will form the basis of progress reports, which will be important in determining future years of support.
7. Progress and Financial Reports: All grantees will be required to submit a brief technical progress report and a financial report at 9 months after the start of the project, and a final report no later than 30 days after the end of the granting period. The final 10% of the total award sum will be distributed after the final summary report has been received by FIRST.
8. The Foundation expects that all investigators supported by the Research Grant Program will cooperate to the maximum feasible extent with other scientists who are studying ichthyosis, including sharing notice of any patent applications related to Foundation-funded research.

## Application Checklist

- ❑ Project Application
- ❑ Project Abstract
- ❑ Project Budget
- ❑ Biographical Sketches
- ❑ Other Support
- ❑ Research Plan
- ❑ Facilities Description
- ❑ Letters of Commitment from Division/Department Head/Chair
- ❑ Letters of Commitment from Collaborators
- ❑ Institutional certification of adherence to standards for use of animals or humans in biomedical research by Division/Department Head/Chair