



CYSTINOSIS RESEARCH FOUNDATION (CRF)

Autumn 2014

Call for Research Proposals and Postdoctoral Research Fellowships

The ultimate goal of the Cystinosis Research Foundation is a cure for cystinosis. Global calls for grant applications will be made twice each year. Research and fellowship grants are awarded for 1-3 years.

Currently, the Cystinosis Research Foundation has **\$1,000,000** available for research and fellowship grants. The number of awards and their value will depend on the number of outstanding proposals and the funds available at the time.

The deadline for the Autumn 2014 grant proposals and fellowship applications is Wednesday, October 15, 2014. The successful grant applicants will be notified by the end of January, 2015. Please note that the earliest start date for research projects submitted for this cycle is February 1, 2015.

The CRF issues grants for academic research and will not accept applications from commercial, for-profit enterprises.

Research Proposals

The Cystinosis Research Foundation is pleased to announce its Autumn 2014 call for research proposals and fellowships. The Cystinosis Research Foundation is prepared to fund proposals to improve the immediate care of children and adults with cystinosis and to develop a new understanding and treatment of cystinosis in an effort to help these patients in the future.

Postdoctoral Fellowships

The Cystinosis Research Foundation has launched a postdoctoral research fellowship program to attract qualified, promising investigators to establish careers in cystinosis research. The fellow's stipend should be the usual amount for such a trainee at that institution. The total award cannot exceed \$75,000 per year including overhead. Awards will generally be for a period of 1-3 years.

First priority will be given to "named" postdoctoral trainees. However, investigators who are already studying cystinosis can apply for a fellowship position with the expectation of attracting a suitable postdoctoral fellow within a year. Predoctoral students, who are already studying cystinosis, will be considered if funding is available.

REVIEW PROCESS

Proposals are evaluated by the Cystinosis Research Foundation Scientific Review Board (SRB) comprised of leading experts on cystinosis who determine the scientific validity and merit of the proposed research based on the NIH scale of standards. The SRB then advises the Cystinosis Research Foundation on the scientific merit of each proposal. The Foundation will balance the eventual funding to support bench, translational and clinical research and fellowships. Applicants will be notified in writing via email regarding the final status of their application.

PROPOSAL GUIDELINES AND FELLOWSHIP GUIDELINES

We encourage concise proposals. The research proposals and fellowship applications should describe the rationale and importance of the project and should include the specific aims and research design and methodology. Include sufficient detail in a concise manner to facilitate evaluation of the proposed work.

Research Grant Proposals: Maximum length is **nine** one-sided pages, single-spaced, using a standard 12-point font with 1 inch margins (2.54 cm) on all sides including figures, diagrams and drawings. Cover sheet, documentation, budget and budget justification and curriculum vitae (CV's) are not included in the 9-page limit. **Longer applications will not be evaluated.**

Fellowship Grant Applications: Maximum length is **six** one-sided pages, single-spaced, using a standard 12-point font with 1 inch margins (2.54 cm) on all sides including figures, diagrams and drawings. Cover sheet, documentation, budget and budget justification and curriculum vitae (CV's) are not included in the 6-page limit. **Longer applications will not be evaluated.**

Cover Sheet Information: Names and Affiliations of Principal and Co-Principal Investigators and/or Research Fellow – **It is mandatory that you complete and attach the Cystinosis Research Foundation cover sheet as part of your application.** Please download and attach the applicable cover sheet – either the Research Grant Proposal Cover Sheet or Fellowship Grant Proposal Cover Sheet.

Please format Grant and Fellowship Applications as follows:

1. Abstract/Summary of project – Explain the relevance to cystinosis. What problem does the project or fellowship address? Why is the work important to children and young adults with cystinosis? How will the project be accomplished?
2. Specific Aims – List the study or fellowship objectives and describe the specific goals of the research, including any hypotheses to be tested.
3. Preliminary Studies/Progress reports.
4. Research Design and Methods – Describe the research design and methodology that will be used to accomplish the study or fellowship aims.

Additional Information NOT part of the maximum length requirement for the Research Grant and Fellowship Grant Applications:

1. Detailed Budget – The Cystinosis Research Foundation will generally provide up to 10% of indirect costs. Requests for higher amounts must be carefully justified. Funding requests must be submitted in U.S. dollars.
2. Currency exchange rates will be established at the time the grant contract is issued.
3. The Cystinosis Research Foundation will not cover travel expenses as part of a grant or fellowship budget.
4. Budget Justification – Please explain items that might be confusing or unusual to the review committee.
5. Key Personnel - Please include a current CV and indicate the percent effort that each person is expected to devote to the project.
6. Statement detailing all other available resources including other grant support available – Indicate the amount and granting organization for any other sources (current or pending) of funding for the study.
7. IRB (human subject) approval and consent forms or plan to obtain such approval, if applicable. Animal subject approval if applicable. If the proposal involves human gene therapy, NIH Recombinant DNA Advisory Committee (RAC) review or equivalent. Funds for awards will not be released until all necessary approvals for human and/or animal studies are received.
8. A statement as to why funding from the Cystinosis Research Foundation is essential for the execution of this project. Please also include other funding support for this study if applicable.

ADDITIONAL REQUIREMENTS FOR FELLOWSHIP APPLICANTS

In addition to the above, fellowship applications must provide a complete CV of the proposed candidate and a statement outlining his/her career goals. Please discuss why this fellowship is important to the applicant. It should be clear who the fellow's mentor(s) will be. The mentor must provide a complete CV as well as a statement of the plan for training the fellow.

SUBMISSION INFORMATION

Applicants must submit the original of the completed application, **eleven** printed copies of each proposal and an electronic copy (PDF format if possible) to:

Cystinosis Research Foundation
Nancy Stack, President
18802 Bardeen Avenue
Irvine, California 92612-1521
(949) 223-7610
Email: nstack@cystinosisresearch.org

The electronic copy of the proposal must be submitted by midnight (PT), Wednesday, October 15, 2014 and the original application plus the eleven printed copies must be received by Friday, October 17, 2014 in order to be considered.

PARTIAL LIST OF GRANTEE OBLIGATIONS

Upon acceptance of research funding by the Cystinosis Research Foundation, the award recipient agrees to the following (among other requirements):

1. The recipient of any grant award from the CRF must use the funds for the specific purpose for which they were originally intended in the grant or fellowship application. The study must commence by the stated start date and end within the time frame given. If the study is delayed, the CRF must immediately be notified and a detail explanation of the reasons for the delay must be explained and sent to the CRF by email as well as a hard copy via regular mail. If an extension of time is required, the awardee must notify the CRF in writing 60 days before the scheduled end date of the study.
2. Progress reports are required at regular intervals for the duration of the study and a final report is required and due within sixty days after the completion of the date of the award. The final grant payment will be made to the award recipient(s) upon receipt of the final report. These progress reports should be an executive overview of the study's progress against key milestones and should include any personnel updates. The progress reports must also include a budget report which shall be a one page detailed accounting of budget receipts and expenditures. All progress reports should be sent electronically to Nancy Stack at nstack@cystinosisresearch.org. The progress and budget reports will be reviewed and if approved, the next scheduled grant payment will be issued.
3. Payment for all CRF awards will be made payable to an institution, university, company or equivalent organizational entity. CRF will not make checks payable to an individual, whether that person is the principal investigator or someone within the awardees' institution. The CRF will issue grant payments in U.S. dollars only.

4. When the Cystinosis Research Foundation awards a grant for a specific study, the award recipient agrees to not accept other sources of funding for the same study from other funding agencies or groups unless the Cystinosis Research Foundation is notified in writing via email to nstack@cystinosisresearch.org.
5. If the research proposal funded is clinical in nature and requires recruitment of volunteers for the study, the recruitment letter must acknowledge CRF as the source of funding and such recruitment letter must be sent to Nancy Stack, nstack@cystinosisresearch.org to be posted on the CRF web site.
6. When the results of CRF funded research are available to the public through appropriate scientific channels and publications including press releases, research publications, or other newsworthy articles that pertain to the funded research, it must clearly state in writing that the work was supported by the Cystinosis Research Foundation. If the study was supported by multiple sources but CRF was the major contributing source, language acknowledging that fact must be used. A copy of such publications should be mailed to the CRF at 18802 Bardeen Avenue, Irvine, CA 92612 Attn: Nancy Stack. The Cystinosis Research Foundation must be acknowledged as the source of funding, in whole or in part, in poster and/or oral presentations given at research symposiums or conferences.

SCIENTIFIC REVIEW BOARD

Chairperson

Corinne Antignac, M.D., PhD

Department of Genetics
Director of Inserm Research Unit U574
Hôpital Necker Enfants-Malades
Paris, France

Board Members

Stéphanie Cherqui, PhD

Assistant Professor
The Scripps Research Institute
La Jolla, California

Pierre J. Courtoy, MD, PhD

Board Certified Internist
Professor of Cell Biology and General Pathology
Louvain University Medical School
Head of Cell Biology Unit
De Duve Institute
Brussels, BELGIUM

Allison A. Eddy, MD, FRCP(C)

Head, Department of Pediatrics
University of British Columbia
Chief, Pediatric Medicine
BC Children's Hospital

Francesco Emma, MD

Head of Pediatric Nephrology
Director of Nephrology Laboratory
Bambino Gesù Children's Hospital
Rome, Italy

Julie R. Ingelfinger, MD

Deputy Editor of the New England Journal of Medicine
Professor of Pediatrics
Harvard Medical School
Boston, Massachusetts

Martin Konrad

Department of General Pediatrics
University Children's Hospital
Muenster, GERMANY

Elena Levtchenko, MD, PhD

Associate Professor
University Hospital Leuven
Leuven, Belgium

William E. Smoyer, MD, FASN

Clinical and Translational Research Director
Center for Clinical and Translational Research
Professor of Pediatrics
Ohio State University