

# Conquer Chiari & Column of Hope Research Grant Guidelines

## INTRODUCTION

These guidelines are intended to detail the Conquer Chiari/Column Of Hope Research Grant process. Both Conquer Chiari and Column of Hope are committed to having a major positive impact on the lives of people suffering from Chiari, syringomyelia, and the neuropathic pain and disability caused by these conditions. In support of this goal, the organizations are issuing a joint call for research proposals to advance the state of clinical care and/or fundamental understanding in these areas.

## RESEARCH PRIORITIES

In general, the organizations are open to any and all ideas in the areas of Chiari, syringomyelia, and associated neuropathic pain and disability; including, but not limited to:

- Improvements in diagnosis, such as the development of an objective definition of symptomatic Chiari, which will result in quicker, more accurate diagnoses
- Development of novel treatments, both surgical and non-surgical; or research which advances a recognized standard of care
- Research which advances the understanding of the pathophysiology and/or natural history of Chiari/syringomyelia; such as the genetic basis of Chiari; investigating possible underlying causes, such as posterior fossa volume, tethered cord, and intracranial hypertension; identifying which patients will develop syringomyelia; and research into when and why asymptomatic patients become symptomatic
- The application of novel techniques and technologies to mitigate the nerve damage and pain associated with these conditions, including the potential commercialization of such technologies
- Research which will mitigate the burden of living with Chiari/syringomyelia, such as the neuropsychological effects of Chiari, the use of rehabilitation techniques to improve quality of life, and the development of an objective, comprehensive measure – from a patient’s point of view – of the impact of the disease(s) on quality of life

### *Special Focus Area*

- Conquer Chiari has research funds specifically designated for pediatric research. Recognizing that many research topics apply to both children and adults, we are especially interested in research which directly addresses pediatric issues and needs

Priority will be given to proposals which demonstrate a clear path to clinical impact and/or a fundamental improvement in the current state of scientific understanding. Priority will also be given to proposals which can demonstrate the potential to generate future funding outside this grant process, such as from Federal or private foundation grants.

If there is a question as to the relevance of a project idea, applicants are encouraged to discuss their project ideas with the organizations prior to submitting a full application.

To discuss project ideas, please contact Rick Labuda via email at [director@conquerchiari.org](mailto:director@conquerchiari.org) or by phone at 724-940-0116.

## **GRANT DESCRIPTION**

### **Structure**

In order to address the needs of the research community, starting with the 2009 grant cycle, two different types of grant awards will be made available, a traditional research grant and a smaller clinical research grant.

#### *Traditional Research Grant*

The Traditional Research Grant is similar to the grants awarded previously, and is intended for a broad range of research, which requires significant funding. Grant awards will be for a maximum of \$75,000 per grant (although \$50,000 is preferred) with a duration of one year. Multi-year proposals will not be considered.

#### *Clinical Research Grant*

The Clinical Research Grant is intended for research based in a clinical setting where the majority of costs are born by the standard of care being provided. Grant awards will be for a maximum of \$5,000 per grant with a duration of one year. Funds are intended to cover costs required to produce high-level, quality research from the clinical setting, such as data collection, IRB approval, etc. Multi-year proposals will be considered, but single year proposals are preferred.

#### *Eligibility*

Applications are invited from any researcher with a Ph.D., M.D., or other equivalent professional degree, who is an employee in good standing at a recognized research institution.

It is hoped that this grant process will:

1. Encourage new researchers to focus on Chiari and syringomyelia
2. Encourage established researchers to transfer their knowledge, skills, and techniques to this area
3. Provide seed funding for researchers with novel ideas to generate the preliminary results and pilot data necessary to pursue NIH funding awards

#### *Deadlines*

Currently, the grant process entails a single grant cycle. The deadlines and award dates for 2009 are:

Call For Proposals:	January 15 <sup>th</sup> , 2009
Applications Due:	March 31 <sup>st</sup> , 2009
Award Notification:	May 15 <sup>th</sup> , 2009
Funding:	June 1 <sup>st</sup> , 2009

### *Proposal Review*

Conquer Chiari and Column of Hope will review submitted proposals independently. Each organization has established a committee of qualified experts who will assess the proposals and make funding recommendations to the Boards of Directors. Final funding decisions will be made by the individual Boards of Directors. Conquer Chiari and Column of Hope may fund separate projects or co-fund projects, depending on the specific proposals submitted.

Once the Boards of Directors have made their final funding decisions, applicants will be notified. An attempt will be made to provide feedback to unsuccessful applicants, but this is not guaranteed. Upon award notification, the final terms of the grant award will be decided between the organization(s), the principal investigator, and the host institutions.

The proposals will be reviewed based on the following criteria:

1. Sound theoretical basis for work, including prior research
2. Sound experimental design and methods
3. Qualifications of PI and co-investigators
4. Access to patient subjects if required
5. Quality of available research facilities and equipment
6. Originality of research idea
7. Alignment with the missions and goals of Conquer Chiari and/or Column of Hope
8. Clear path to clinical significance (including commercialization if necessary) and/or a fundamental advancement in understanding
9. Potential of research team and line of research to generate follow-on funding outside of this grant process

### *Human/Animal Subjects Approval*

Proper approval for the use of human/animal subjects from the host institution must be demonstrated prior to any monetary awards. In addition, a copy of the patient informed consent must be submitted prior to award.

If animal subjects are to be used in the project it is expected that the research will adhere to the host institution's guidelines for such use and that these guidelines:

- Ensure the humane treatment of animals during the course of the proposed work
- Follow, at a minimum, the guidelines established by the NIH
- Comply with any and all laws and regulations covering the use of animals in research

All work funded in whole or in part through this grant process is expected to comply with current laws regarding the privacy and confidentiality of individuals' health information, as defined in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and any other relevant State and Federal regulations.

## *Funding Guidelines & Limitations*

Proposed project budgets should adhere to the following guidelines:

### *Traditional Research Grants*

- Funding for PI salary is limited to \$10,000. In addition, budgets for salaries shall follow the current NIH salary cap.
- Indirect costs are limited to 10% of the project's direct costs. The combined direct and indirect costs can not exceed \$75,000.
- Major equipment purchases must be justified, including an explanation of how the equipment will be used after the grant period
- Travel costs should be integral to the proposed experimental design and methods, necessary to achieve clinical impact and/or fundamental advancement in understanding, or be for the purpose of attending the Conquer Chiari Research Conference

### *Clinical Research Grants*

- Funding for PI salary is not allowed
- Indirect costs are limited to 10% of the project's direct costs. The combined direct and indirect costs can not exceed \$5,000.
- Major equipment purchases are not allowed
- Travel costs should be integral to the proposed experimental design and methods, necessary to achieve clinical impact and/or fundamental advancement in understanding, or be for the purpose of attending the Conquer Chiari Research Conference

### *Intellectual Property*

The Conquer Chiari/Column of Hope Research Grant Program is intended to advance the missions and goals of the grantmaking organizations and be of benefit to those affected by Chiari, syringomyelia, and related neuropathic pain and disability. The grantmaking organizations acknowledge that during the course of research supported, in whole or part, by the organizations, that inventions may occur which constitute intellectual property and can be protected through patents, copyrights, etc.

It is the grantmaking organizations' explicit wish that such inventions be administered in a way consistent with the purpose of this grant program, and in as timely a manner as possible. Therefore, unless otherwise requested by the host institution, title to such inventions shall reside with the host institution and/or the inventor(s), as per the host institution's intellectual property policy. If, however, the host institution does not have an established policy and procedure for administering such inventions, or chooses not to pursue the administration of an invention, the grantmaking organizations retain the right to determine the disposition of the invention rights in question.

The grantmaking organizations also recognize that securing and protecting the rights involved in an invention may delay the publication and dissemination of information about the invention. Such a delay is acceptable only if the purpose of the delay is to administer the invention in a manner consistent with the missions and goals of the grantmaking organizations and the purpose of this grant program. A delay in publication for this reason, however, shall at no time extend more than 6 months beyond the completion of the research grant without the express written

consent of the grantmaking organization(s). It is expected that at no time shall researchers or the host institution allow commercial interests to come before or interfere with the scientific, medical, and academic interests of this program and the advancement of the missions and goals of the grantmaking organizations.

Based upon the specifics of the proposed work, and in recognition of their support, the grantmaking organizations may elect to negotiate a royalty sharing agreement, with the host institution, as justified by the amount of the grant award relative to the total cost of research resulting in the invention in question.

## **RESPONSIBILITIES OF GRANT RECIPIENTS**

Conquer Chiari and Column of Hope are interested in finding researchers who are willing to work collaboratively with the organizations in pursuit of their goals. With this in mind, it is expected that grant recipients will:

1. Attend and present their work at a Conquer Chiari Research Conference. This is required and applicants are encouraged to allocate appropriate funds for this in their project budget.
2. Provide Conquer Chiari and/or Column of Hope end of year progress and financial reports within two months of the end of the funding cycle. Conquer Chiari and Column of Hope may specify the format and content of such reports.
3. If requested, provide a summary of research progress suitable for general, non-technical audiences. This summary may take a variety of forms, such as a Word document, PowerPoint presentation, or video of work being done in the research facility. The release of such summaries will be coordinated with any planned publications in a professional journal.
4. Disseminate the results of their research through commonly accepted methods, such as journal publications and conferences. The grantmaking organization(s) will be duly recognized as having provided funding in all such publications, conferences, etc.
5. Not issue any press releases or other statements intended for a general, non-scientific audience without giving advance notice, an opportunity to review, and the option to participate in such statements to the grantmaking organization(s).
6. Share and forward copies of all publications which result from the funded work, both during and after the grant period, to the grantmaking organization(s).
7. Make themselves available for a reasonable number of phone calls and discussions regarding the progress of the research, changes to the research project, and new ideas that may develop over the course of the project.
8. Notify the grantmaking organization(s) of the intent to pursue patent(s) or copyright(s) based on the funded work.

In order to minimize the potential burden on grant recipients, and to ensure clear communication between parties, the grantmaking organization(s) will appoint a single point of contact to communicate with the grant recipient for each award.

## **APPLICATION INSTRUCTIONS**

Applicants should complete the Research Grant Application, keeping in mind the above Grant Guidelines and following the specific instructions on the Grant Application.

The completed Grant Application, along with supplemental information, such as an NIH style biosketch and research papers (maximum of 3), may be submitted via email (preferred) to:

[director@conquerchiari.org](mailto:director@conquerchiari.org) with the Subject: Research Grant Application

or by regular mail to:

C&S Patient Education Foundation  
Attn: Rick Labuda  
320 Osprey Court  
Wexford, PA 15090

Questions regarding the grant process, guidelines, application, or relevance of proposed work should be directed to [director@conquerchiari.org](mailto:director@conquerchiari.org)