

# Alagille Syndrome Accelerator Award

## Application Instructions

Website: <https://hria.org/tmf/alagille/>

### Online Application Links:

Begin a new application:

[https://www.GrantRequest.com/SID\\_738?SA=SNA&FID=35130](https://www.GrantRequest.com/SID_738?SA=SNA&FID=35130)

Return to a saved application:

[https://www.GrantRequest.com/SID\\_738?SA=AM](https://www.GrantRequest.com/SID_738?SA=AM)

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**DEADLINE:** Tuesday, July 23, 2019 at 2:00 PM

**FUNDING START/END DATE:** September 15, 2019 – September 14, 2020

**AWARD:** One Year \$25,000 Award to support investigators working in non-profit academic, medical and research institutions in North America

### APPLICATION SECTIONS

- A. **Application Face Sheet:** The Face Sheet is the first page of the application. The Face Sheet must be completed and signed by the Applicant as well as signed by the Institutional Officer administratively responsible for the conduct of the project prior to submission. The signature of the Institutional or Executive Officer on the Face Sheet will indicate that the proposal has been reviewed and has been approved for submission to the Alagille Syndrome Accelerator Award.
- B. **Table of Contents:** Follow the Table of Contents and number pages sequentially beginning with the Application Face Sheet as page number one. Note that the name of the Principal Investigator should appear at the top right-hand corner of each page.
- C. **Research Project Summary** (*maximum of 300 words*): The Research Project Summary is a scientific abstract stating the project's objectives and specific aims.
- D. **Non-Technical Project Summary** (*maximum of 200 words*): Describe your project in non-technical language and its potential either 1) research findings will contribute to finding effective therapies or cures for Alagille Syndrome 2) eligible research projects in the discovery and testing of potential drugs directed at relevant pathways in animal models or support of exploratory small clinical studies in human volunteers
- E. **Biosketch (maximum of 5 pages):** Submit the biosketch of the Applicant. The latest revision of the NIH Biographical Sketch form must be used. The categories include Personal Statement, Positions and Honors, Selected Peer-reviewed Publications and Research Support. In the publication section, Applicant's name should be in caps or bolded in the list of authors. Manuscripts in submission may also be listed. In the Research Support section, begin with the projects that are most relevant to the research proposed in this application. Briefly indicate the overall goals of these projects and the Applicant's responsibilities. Do not include person months or direct costs.

- F. **Research Proposal (maximum of 4 pages, not including references cited):** The four pages must include Specific Aims, Background and Significance, Potential Impact, Research Design and Methods, Project Timeline. The Impact section should address how funding from this Award will contribute to finding effective therapies or cures for Alagille Syndrome, or the discovery and testing of potential drugs directed at relevant pathways in animal models or support of exploratory small clinical studies in human volunteers.

Format this section with **Arial 11** as the font and size. Use single line spacing within paragraphs, double line spacing between paragraphs, and one inch or larger margins on all four sides. Bibliography, figures, legends and tables may use a smaller font size. The Applicant's full name should appear at the top of each page.

- G. **Budget Forms and Budget Justification:** Complete the budget forms and budget justification. Indirect costs (institutional overhead) are not allowed for this Award.
- H. **Current and Pending Support Form:** Complete this form and list all current (active) or pending (not yet activated) support available to the Applicant for projects related or unrelated to this proposal. Clearly describe any scientific or budgetary overlap with the proposed project.
- I. **Department Chair Letter of Recommendation:** This letter must address the applicant's qualifications to conduct the proposed research as well as note the space and equipment available for the completion of the project. The letter should also speak to the Chair's assessment of the candidate's prior research accomplishments as well as his/her contributions to the Department's scientific and training activities. Recognizing that position titles vary among institutions, the level of experience and independence of the applicant, as detailed in the Department or Division Chair's Letter will be given serious consideration. If the candidate is a junior investigator, then the Chair should describe the candidate's potential for a productive research career. If the applicant is Chair of his/her department, a letter of recommendation from the Dean should be submitted.

### **Notification to Applicants**

The online application system will notify applicants once the upload is received. Final notification of application status will occur in September, 2019. Critiques of the grants are not provided to successful or unsuccessful applicants.

**PLEASE NOTE:** If the Applicant is unable to accept the Award, the Award will not be transferred to another investigator involved in the research project.

### **Direct any questions to:**

Kim Lezak, Ph.D.

Interim Director

Alagille Syndrome Accelerator Award

The Medical Foundation, *at HRiA*

2 Boylston Street, Boston, MA 02116

[klezak@hria.org](mailto:klezak@hria.org)

## Terms of the Award

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**Overview:** Awards are made to non-profit academic, non-governmental or research institutions on behalf of the Award Recipients. The Award Recipient Institution is responsible for the administrative and financial management of the project, including any subcontracts, and maintaining adequate supporting records and receipts of expenditures.

**Award Amount and Funding Period:** The Award will be in the amount of up to \$25,000 for a one-year grant. The Award funding start date of September 15, 2019 may not be postponed by the Award Recipient without a formal request and approval by The Medical Foundation, *at Health Resources in Action* (Boston, MA), administrator of the Alagille Syndrome Accelerator Award.

**Institutional Assurances:** If applicable, Award Recipients are expected to adhere to all national, state and local regulations regarding the use of animals, radioactive or hazardous materials, recombinant DNA in their research projects and human tissue.

It is the responsibility of the Award Recipient Institution to make sure that all approvals (IRB, IACUC, other) are in place prior to releasing any Award funds. The signature of the Authorized Institutional Representative on the Application Face Sheet confirms this oversight.

**Liability:** The Administrator and Trustee, do not assume any liability or responsibility for activities supported by this Award including, without limitation, incidents or accidents involving the Award Recipient (whether on travel, in the laboratory or classroom, or otherwise).

**Scientific Misconduct:** The appropriate federal, state, and local guidelines with regard to scientific misconduct must also be in place and enforced at the Award Recipient Institution. In the unlikely event that an Award Recipient is involved in an investigation of scientific and/or financial misconduct, he or she will be subject to the procedures in place at the Institution. The Institution must notify the Administrator of both the investigation and the procedures that the Institution will follow. According to the NIH/U.S. Department of Health and Human Services, research misconduct is defined as the “fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or in reporting research results.” A finding of scientific and/or financial misconduct must be reported to the Administrator and may affect the Award Recipient’s continued eligibility for support under this Program.

**Use of the Award Funds:** The laws of the United States place certain restrictions on the manner in which funds awarded to organizations by charitable trusts and foundations may be expended. This Award may be used to support the Award Recipient’s salary and fringe benefits; salaries and fringe benefits of personnel essential to the project; publication of scientific data; travel to scientific meetings; laboratory and data processing supplies; and other direct expenses such as equipment essential to the project. A proportion of the Award must be allotted towards funding undergraduate student research through stipend support. Salaries must be in proportion to the percent effort on the research project. However, percent effort may exceed the percent of total remuneration requested.

Funds may not be used for new construction, the renovation of existing facilities, general operating costs, fundraising projects or endowments. Funds may not be used for any political activity or for any other purpose prohibited by the Internal Revenue Service Code.

**Indirect Costs** (institutional overhead): The Award monies may not be used to cover any Indirect Costs at either the Award Recipient Institution or any contracting institution.

The grant monies which have been awarded, including any interest earned therein, may only be used for the purposes stated in this agreement. Funds may not be expended for any other purpose without the prior written approval of the Trustee.

**Re-Budgeting:** Expenditures are expected to be within reasonable range of the Budget that was submitted in the Award Recipient's original application. All requests for re-budgeting or reallocation of grant funds over \$5,000 must be conveyed by email to the Administrator. The request must include the current allocation of resources along with specific detail and justification for the reallocation.

**Financial Responsibilities of the Award Recipient Institution:** The Award Recipient Institution will keep systematic records of all expenditures relating to this Award. Vouchers consisting of bills, invoices, cancelled checks, receipts, etc. will be retained by the Institution for three (3) years after the close of the Award period and will be available for inspection by representatives of the Trust, during normal business hours and upon reasonable notice throughout this period. The Trustee may, at their expense, examine, audit, or have audited the records of the Institution insofar as they relate to activities supported by this Award.

**No-Cost Extension:** Following the Award period, a no-cost extension for up to nine months may be granted upon receipt and approval for a no-cost extension. The request will contain a section for justifying the extension, the unexpended balance, and a timeline for expenditure of the remaining funds. A Final Scientific report is due at the completion of the extension period. Any portion of the Award not expended at the conclusion of the extended project period must be made returned to the Administrator within thirty (30) days.

**Transfer or Termination of Award:** Awards are made to the Institution on behalf of the grant's designated Award Recipient. If the Award Recipient moves to another nonprofit research institution during the Award period, the funds may be transferable to the Award Recipient's new institution at the discretion of The Administrator. If the Award Recipient is not continuing his/her research in another nonprofit research setting, the Award will be cancelled and unused funds must be returned within sixty (60) days. Disposition of any equipment purchased by the Award Recipient with Award funds will be evaluated on a case by case basis.

It is the responsibility of the Award Recipient as well as the Institution to notify the Administrator of any change in employment status of the Award Recipient in a timely manner and usually not less than thirty (30) days prior to such change.

**Unused Funds and Reversion:** Should any of the following events occur, the Administrator, on behalf of Trustee, may demand repayment of all unexpended portions of the Award; moreover, all unpaid installments may be cancelled. The Award Recipient Institution is also required to give written notice if there is a change in the Institution's status as noted below.

- A determination, preliminary or otherwise, is made by the United States Internal Revenue Service that the Award does not constitute a qualifying distribution.
- The Award Recipient Institution fails to perform any of its duties, in the judgment of the Trustee the Administrator, or the Scientific Review Committee, required by the Terms of the Award. In such cases, the Administrator shall provide no less than thirty (30) days termination notice in writing to

the Institution, upon which the Institution shall have an additional thirty (30) days following receipt of such notice within which to cure any deemed failures.

- The Award Recipient Institution ceases to be exempt from income taxes under the Internal Revenue Service Code or becomes a private foundation.
- There is a material change in the purpose, character, or method of operation of the Award Recipient Institution such as to jeopardize its tax status.

**Family and Medical Leave:** The Award Recipient may continue to expend any Award funds allocated to salary during medical or parental leave consistent with the Institutional level of paid leave for such purposes. Medical leave may be taken for a serious health condition of the employee or to care for the employee's spouse, child, or parent who has a serious health condition. Family leave may be taken by either parent for the adoption or the birth of a child.

**Reporting Requirements:** Final Scientific and Financial Reports are due sixty (60) days following conclusion of the Award Period or at the start of a no-cost extension period. The Award Recipient will receive Report forms by email approximately three weeks prior to their due dates. It is the responsibility of the Award Recipient to email the Fiscal Report Form to the Fiscal Officer and ensure that the Administrator receives this completed form. The Trustee and the Administrator reserve the right to place a hold on funds where the Award Recipient is non-compliant with these Reporting Requirements.

**Patents, Copyright and Intellectual Property:** The Award Recipient should follow the Institution's policies regarding discoveries or any other intellectual property that results from research conducted under this Award. Neither the Trustee nor the Administrator will retain any rights to published results or patents that result from the research.

**Confidentiality and Third Party Release:** Application materials as well as Scientific Progress and Final Reports are considered confidential. The Administrator engages third parties who have the necessary expertise to review the submitted materials and evaluate each project. Although the Administrator endeavors to protect the confidentiality of the reports by requiring reviewers to sign confidentiality agreements, confidentiality cannot be guaranteed. The administrator and Trustee are not responsible for any consequences resulting from the disclosure of the content of these materials to such third parties. The Administrator and the Trustee, reserves the right to public acknowledgement of Award information (Award Recipient Name, Institution, Project Title, and Research Project Summary). This information will be made available through the website of the Administrator and may be posted on other affiliated organization websites, publicly accessible databases of privately funded awards, or published in print form or other media. Noted in the online application form, it alerts the applicant that the project summary will be posted on the Administrator's website if the project is funded.

**Scientific Poster Sessions and Events:** Award recipients are expected to share research findings in a timely manner through professional meetings and/or publications.

**Additional Information:** The donor may wish to meet with the Award Recipient at the Award Recipient place of employment. During this meeting, the Award Recipient will be asked to present their research project to the donor in non-technical language.

**Acknowledgements:** The Award Recipient is expected to share research findings in a timely manner through professional meetings and/or publications. Publications or presentations resulting from research work supported by the Award must acknowledge support from the **Alagille Syndrome Accelerator Award**.

**Post Award:** Award Recipients agree to update the Administrator about any new position, affiliation, or contact information (especially email address) and provide his/her current Biosketch as requested. The Recipient understands that this obligation survives the Award period and that he/she has an ongoing obligation to provide this information.