2025 Uplifting Athletes Young Investigator Draft Grant Request For Applications

Application Deadline: Monday, September 23, 2024, 11:59 pm EST

Contact Information: Uplifting Athletes, 8 Atkinson Drive, PO Box 574, Doylestown, PA 18901

For any questions or concerns, please contact grants@upliftingathletes.org



Abstract

Uplifting Athletes (UAI) is seeking rare disease patient advocacy organizations who A) have identified a promising young investigator to be nominated for the 2025 Young Investigator Draft and B) are willing and able to provide a match of \$10,000, or greater, so that the selected researcher will receive an unrestricted grant of at least \$20,000.

Project Overview

The Young Investigator Draft is the result of Uplifting Athletes' ongoing commitment to cultivating resources that accelerate scientific advancements for rare disease treatments and potential cures while celebrating the next generation of rare disease researchers. The Young Investigator grants fund research that is collaborative and translational. The Young Investigator Draft stage provides a platform to recognize these scientists, spread awareness of their efforts, and highlight the importance of their research, along with its future impact on the rare community.

Project Goals & Target Audience

The goal of the Young Investigator Draft is to provide funding that will support the pursuit of new FDA-approved treatments and potential cures for the rare disease community. These seed grants are intended to support early-career investigators, who are still being mentored, and patient advocacy organizations that have an emphasis in supporting research within their disease state.

Organizations that apply should meet the following criteria:

Nonprofit 501(c)(3) with a specific focus on rare disease(s) and an emphasis on research within that
disease state.
Located in the US or Canada.
Patient advocacy organization that is willing and able to match Uplifting Athletes \$10,000 grant to the
nominated and selected researcher.
Has an established Medical and/or Scientific Advisory Board with advanced knowledge of the
disease(s) that are the focus of the advocacy organization.



The Goals of the Young Investigator Draft

- 1. To fund current and aspiring young investigative rare disease researchers.
- 2. To share the unique platform we have developed with patient advocacy organizations and researchers. Furthermore, the Young Investigator Draft hopes to engage with patient-focused advocacy organizations emphasizing research within their disease state. Uplifting Athletes works with advocacy organizations that prioritize research and support researchers who understand the needs of the patient community and are working to resolve those unmet and underserved needs. Uplifting Athletes will provide the Young Investigator Draft stage as a platform to celebrate and elevate these investigative rare disease researchers.

Underrepresented Researchers in Medicine

This year, we will continue the Underrepresented Researchers in Medicine (URM) Initiative. Uplifting Athletes recognizes and celebrates our responsibility to play a role in inclusion, diversity, equity, and accessibility in medicine. The URM Initiative guarantees that at least one (1) underrepresented researcher, <u>as defined by the NIH</u>, will be selected through the Young Investigator Draft. The URM initiative includes broadened outreach through partnerships with organizations that work with underrepresented researchers to expand the pool of nominated researchers.

Key Dates

Application Open Date	July 29, 2024, 12:00 pm EST	
Application Close Date	September 23, 2024, 11:59 pm EST	
Award Notice	November 2024	
Award Execution	January 2025	
Project Start/End Dates (estimated)	February 2025 - February 2026	



The Uplifting Athletes Young Investigator Grant

The Young Investigator Grant is a one (1) year award designed to support scientists in the early stages of a rare disease research career, such as postdoctoral or clinical fellows. Outstanding mentorship and demonstration of a career plan that shows commitment to rare disease investigation are critical components of a successful applicant.

The grant will be for a minimum of \$20,000 USD (\$10,000 USD from UAI and a matching \$10,000 USD from the nominating advocacy organization). It will be issued to the institution of the young investigative researcher with the caveat that the funds will be used at the sole discretion of the identified young investigator to move their research forward.

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	Funds from UAI may not be used for indirect costs (including tuition remission).
	The grant may not be renewed.
	No-cost extensions are strongly encouraged.
	Funds must be granted to nonprofit institutions/organizations or federal government labs operating in
	the US or Canada. However, US citizenship is not required.
	Institutional Review Board (IRB) approval is expected to be sought when studies in humans are
	planned. Animal Care Committee approval is required for animal studies.

Who Qualifies as a Young Investigator?

Applicants must meet the following criteria to qualify for the Uplifting Athletes Young Investigator Draft:

Note: Please contact Uplifting Athletes before applying if eligibility questions remain after reviewing these guidelines.

_	Training of basis researcher (mb, be, ring) and maintained equivalency menting in the second called
	who is currently in a mentored academic position, i.e. postdoctoral training at an academic medical
	institution, AND either
	A) within ten years of obtaining their doctoral degree at the time of grant submission OR
	B) within five (5) years of initiating rare disease research.
	Mentors must be in the proposed research field from the sponsoring institution, assume
	responsibility, and guide the research.
	Be planning, or actively engaged in, an investigative career in rare disease research. An institutional
	commitment for a faculty appointment is not required at the time of grant submission. Still, the applicant
	should work in a rare disease laboratory or clinical research setting.
	Eligible applicants may hold only one grant from Uplifting Athletes at a time.

☐ A clinical or basic researcher (MD, DO, PhD, or international equivalent) working in the US or Canada



How To Apply

Please follow the "Application" section of the RFA and submit one PDF file containing the requested information to <u>grants@upliftingathletes.org</u> before the application deadline of Monday, September 23, 2024, at 11:59 pm EST.

Review Process

The Uplifting Athletes Scientific Advisory Council (SAC) will review all proposals submitted to grants@upliftingathletes.org. Once proposals are submitted, the committee will determine the number of grants that meet or exceed the minimum criteria for funding. If the number of qualifying grants exceeds ten (10), the committee will determine a minimum of ten (10) young investigators to be awarded and honored at the 2025 Young Investigator Draft. The grant awardees will be notified ahead of the 2025 Young Investigator Draft.

Reporting Requirements

We ask that a report be issued to Uplifting Athletes one year after the grant has been received by the investigator to detail progress made with the research and how the grant impacted the researcher and their work.

About Uplifting Athletes

Uplifting Athletes is a nonprofit organization founded in 2007 that harnesses the power of athletics to build a community that invests in the lives of the more than 30 million people impacted by rare diseases in America. Since its inception, Uplifting Athletes has raised more than \$9 million by engaging athletes in order to positively impact the rare disease community through driving action, awareness, and funding research. To learn more about Uplifting Athletes visit <u>upliftingathletes.org.</u>



Frequently Asked Questions (FAQ)

What is the purpose of this grant?

The purpose of this grant is to generate preliminary data and prepare for an F (fellowship), K (career development award) or R (research) grant from the NIH, or larger funding source.

How does the grant matching work? What will qualify as a match?

For the 2025 Young Investigator Draft, we require that all advocacy organizations selected provide the funds to Uplifting Athletes for the matching gift amount, and Uplifting Athletes will process the grant at no cost. We are doing this to streamline the grant award process and ensure that the entire grant award is received and utilized at the sole discretion of the nominated researcher.

What happens if your organization and researcher are selected?

If your organization and young investigator are selected, you will be notified by phone or email in November 2024. You will be asked to verify all information provided in the application.

What expectations do we have of the advocacy organization concerning the promotion leading up to and on the day of the event?

We ask that you share the information about the Uplifting Athletes Young Investigator Draft with your network. We will provide social media graphics and content to distribute.

Who will review the grant application?

The grant submissions will be reviewed by the Uplifting Athletes' Scientific Advisory Council (SAC) and they will use an established rubric to assess each application. The rubric will be released alongside the RFA so that patient advocacy organizations and researchers will know what the SAC is looking for.

Where does the money go?

Each Uplifting Athletes Young Investigator Draft recipient will receive access to the full \$20,000 grant award through their research institution. At this time, we do not pay indirect expenses on the grants given to researchers, and the money is earmarked to be used at the sole discretion of the grant recipient to move their rare disease research forward.

Can an advocacy organization submit more than one application?

Yes. We ask that you submit one (1) application per researcher nomination. All applications will be reviewed independently. **Organizations may submit a total of two (2) applications.**

Does my organization need a Scientific or Medical Advisory Board?

Yes. We ask that all organizations have their Scientific or Medical Advisory Board review the research project details and sign off on the project before submitting the application.



Step-by-Step Instructions

Overview on how to submit an application:

A complete application consists of one (1) PDF document that is filled out by the nominating patient advocacy organization and the nominated researcher. The mentor statement may be added to the same PDF document, or be sent as a separate PDF attachment. Applications must be submitted to grants@upliftingathletes.org before the application deadline of Monday, September 23, 2024, at 11:59 pm EST.

Formatting Requirements:

- Times New Roman or Arial 11-point font size (unless noted otherwise), single spaced, and .5 inch margins on all sides. Smaller font sizes are acceptable for use in tables, figure legends, biographical sketches, and cited literature.
- Please number the pages, label each section with the question pertaining to it, and limit each question response to one page.

Summary of Application Components:

Patient	Advocacy Organization Section (Page 8):
	Organization Overview (Page 8)
	Nomination (Instructions on page 6)
	Additional Information (Instructions on page 6)
Resear	cher Section (Pages 9-10):
	Researcher Overview (Page 9)
	Personal Statement (Instructions on page 6)
	Patient Community Interaction (Instructions on page 6)
	Abstract (Instructions on page 6)
	Background and Significance (Instructions on page 6)
	Specific Aims (Instructions on page 6)
	Preliminary Data (Instructions on page 7)
	Approach (Instructions on page 7)
	References (Instructions on page 7)
	Funding (Instructions on page 7)
	Timeline (Instructions on page 7)
	Biographical Sketch (Instructions on page 7)
	Mentor Statement (Instructions on page 7)



Patient Advocacy Organization Section:

Nomination:

From the perspective of a leader of the nominating patient advocacy organization, please describe why you have chosen to nominate your selected researcher. Please describe what his/her research means for your community. It is also a chance for you to describe the personal commitment and relationships the researcher has with your community and what kind of person the nominee is.

Additional Information:

You may use this section to provide additional information about your organization, disease state, or patient community. You may also decide to provide additional information about why you nominated your selected researcher, their accomplishments, or other pertinent information.

Researcher Section:

Personal Statement:

In this section you should describe your reasons for choosing rare disease research, your specific disease state, and your future plans in the field and the rare disease community.

Patient Community Interaction:

In this section the applicant should describe how they have connected with the rare disease community. Applicants should discuss if they have met with the patient community in person, plans to collaborate with the patient community, and what engagement activities have occurred.

Abstract:

In this section the applicant should outline their proposed research project. Applicants should address the timeline for the project, anticipated pitfalls, and alternate strategies.

Background and Significance:

In this section the applicant should address the following:

What is the research question being addressed?

Why is your proposal important and original?

What are prior or concurrent studies being conducted?

What preliminary work has already been completed on this subject?

Specific Aims:

Describe a gap in the literature.

Detail your hypothesis to address the gap in the literature.

Specify one or more specific aims (with subaims if necessary) to test your hypothesis.



Preliminary Data:

Please describe any existing data done by the principal investigator to address the hypothesis.

Approach:

Describe the procedures and methodology that will be used to accomplish the specific aims of the proposed project. Be sure to specify the number of patients, experiments, or observations to be evaluated to prove or disprove the hypothesis. *Applications submitted without this information are not eligible for review.*

References:

Provide scientific references

Funding:

Provide a budget justification for the proposed expenses. In addition, if this project will cost more than the \$20,000 allotted funding, please describe your plan to secure additional funding.

Timeline:

Detail the timeline of your proposed project. If your project is a subset of a larger project, then justify how your portion can be completed within one year.

Biographical Sketch

A biographical sketch must be provided for the researcher, and should be in the current NIH format.

Mentor Statement:

The mentor statement can be attached to the application or be submitted as a separate attachment. Only one (1) mentor statement is required.



Application

Uplifting Athletes intends that this application is completed by a representative of a Patient Advocacy Organization in collaboration with the researcher being nominated for the grant award.

Patient Advocacy Organization Section

- 1. Name:
- 2. Website:
- 3. Tax Identification Number (also known as the Employer Identification Number or EIN):
- 4. Point of Contact Name:
- 5. Point of Contact Email:
- 6. Point of Contact Phone Number:
- 7. Disease(s) represented:
- 8. Has the applying advocacy organization provided research funding to this Young Investigator in the past 12 months?
- 9. Has your Scientific Advisory Board or Medical Advisory Board reviewed the research project details specified? If requested, please be prepared to verify your review process.
- 10. Medical/Scientific Advisory Board Members (Please Attach List):
- 11. From an advocacy organization perspective, why should Uplifting Athletes select this Young Investigator?
- 12. Please provide any additional information that you feel may be relevant to the review committee.



Young Investigator Researcher Section:

- 1. Project Title:
- 2. Young Investigator Name:
- 3. Current Institution:
- 4. Phone Number:
- 5. Email address:
- **6. Personal Statement:** Why did you come into rare disease research? What are your future plans in the field?
- **7. Patient Community Interaction:** Describe your engagement activities with the patient community and patient advocacy organization for your disease state.
- **8. Abstract:** Outline the planned research. Please include anticipated timelines for the project, as well as anticipated pitfalls and alternate strategies.
- **9. Background and Significance:** Include the problem, its significance, prior or concurrent studies conducted, and any preliminary work the investigator has completed on this subject.
- **10. Specific Aims:** A statement outlining the gap in literature and how your hypothesis will address this gap.
- **11. Preliminary Data:** Please describe any existing data done by the principal investigator to address the hypothesis.
- **12. Approach (two pages maximum):** Include a precise description of the methods of data collection, analysis, and research model to be used. Specify the planned number of patients or experiments or observations to be evaluated to prove or disprove the hypothesis with power analysis. Methods should be described in detail to allow peer reviewers to appraise their scientific merit critically. *Note: A grant submitted without this information will not be eligible for review.*
- 13. References: Please list scientific references.
- **14. Funding:** How do you plan to utilize the funding from this grant? If your project will cost more than the \$20,000 in funding allotted from this grant please address where you will secure additional funds.



- **15. Project Timeframe:** Is your project a subset of a larger project? How confident are you that it can be completed within the one-year timeframe?
- **16. Biographical Sketch:** Please use the <u>NIH biosketch form</u> to list your experience and qualifications.
- 17. Mentor Statement/Letter of Support stating mentor's research experience and how the mentor will support the mentee during the project and in the future:

18. Which	disease category/categories would this research impact? Please check ALL that apply.
	Rare Muscular and Neurological Diseases
	Rare Autoimmune Diseases
	Rare Cancers
	Rare Blood Disorders
	Rare Genetic Disorders

- 19. The National Institute of Health (NIH) recognizes that there are underrepresented groups in medicine and includes the following groups as underrepresented in biomedical research:
 - Individuals from racial and ethnic groups such as Blacks or African Americans, Hispanics or Latinos, American Indians or Alaska Natives, Native Hawaiians, and other Pacific Islanders
 - Individuals with disabilities

Other____

- Individuals from disadvantaged backgrounds (as defined in the <u>November 22, 2019 Guide</u> notice)
- Women from the above backgrounds at the graduate level and beyond in scientific fields

Do	you identify	with one or m	ore of these un	derrepresented	groups as def	fined by the l	NIH?
	□ Yes						
	□ No						

Criteria for Evaluation of the Proposals	Points Possible	Points Awarded
Researcher Evaluation Relevant Education & Training - 5 Points Possible Environment - 5 Points Possible Related Publications - 5 Points Possible	15	
Scientific Approach Feasibility & Assessment of Project Summary - 25 Points Possible	25	
Impact and Innovation Significance Of Proposed Project Within: Specific Disease State - 15 Points Possible Rare Disease Community - 5 Points Possible	20	
Purpose / Patient Engagement Purpose & Future of Pursuing Rare Disease Research - 10 Points Possible Patient & Family Engagement - 5 Points Possible Relationship to Patient Advocacy Organization - 10 Points Possible Personal Statement - 5 Points Possible	30	
Budget Justification Budget Explaniation - 10 Points Possible	10	
Total	100	