

Request for Applications:

Pilot Studies and Pre-doctoral Fellowships for the study of Profound Autism and/or Severe, Intense and Dangerous Behaviors

RFA Released: November 10, 2025
Applications Due: March 2, 2026, 5:00PM Eastern
Anticipated earliest project start date: August 1, 2026

I. INTRODUCTION

The Lancet Commission on the Future of Care and Clinical Research in Autism introduced the term "profound autism" and encouraged its use to describe autistic people who are at least 8 years old, minimally verbal or nonverbal, have IQ below 50, are not able to advocate for themselves, and will likely require 24-hour access to an adult who can care for them for the rest of their lives.

Past research has established that individuals with autism exhibit a wide range of abilities and disabilities and that those with challenging or problematic behavior, minimal verbal ability, and/or intellectual disability are demonstrably underrepresented in research. Their exclusion prevents the generalizability of research discoveries and impedes understanding of the supports and interventions they require to live fulfilling lives. There is an immediate need for research to identify the specific and unique needs of individuals with profound autism.

While the *Lancet* definition does not specify the presence of severe, intense and dangerous behaviors, this RFA also includes research on severe and challenging behaviors which may cause distress or harm including but not limited to

self-injury, aggression, pica, wandering and irritability, which are prevalent in those with profound autism.

Applicants should use the following criteria to define profound autism (non inclusive of severe, intense and dangerous behaviors):

- 1. Age 8 or older, although research on younger children are encouraged with sufficient follow up outside this funding opportunity;
- 2. Meets the diagnostic criteria for autism spectrum disorder;
- Requires adult supervision to ensure physical and mental health, safety and well-being;
- 4. Inability to independently perform most activities of daily living;
- 5. Has severely impaired cognitive abilities (IQ<50) OR does not verbally communicate other than single words or fixed phrases and communicates predominantly to have their basic needs met;
- 6. These criteria are neither intermittent nor transient.

ASF has published a <u>Strategic Plan for Profound Autism Research</u>, which should serve as a guide in prioritizing research questions to be addressed by profound autism study.

II. PURPOSE OF THIS RFA

The Autism Science Foundation invites applications for two related award mechanisms under this RFA:

- Pilot Grants To support one-year research projects focused on profound autism conducted by established investigators
- Pre-doctoral Fellowships To support one-year, mentored training awards for graduate students focused on profound autism

III. RESEARCH PRIORITIES

This RFA specifically calls for:

- Pilot studies to identify or characterize the underlying biological mechanisms of profound autism (including model systems);
- Examination of the preliminary efficacy of behavioral and/or pharmacological treatment or genetic medicines for core or co-morbid symptoms of profound autism or severe, intense and dangerous behaviors;
- Projects which address challenges in recruitment, retention or data collection in individuals with profound autism.
- Research examining co-morbid conditions documented to be common in those with profound autism.

Individuals with profound autism may or may not exhibit severe and dangerous behaviors. Research on severe and dangerous behaviors does not need to be exclusive to those with profound autism.

Preference will be given to those studies that include a control arm, or a group of those with non-profound autism.

IV. ELIGIBILITY

Both US citizens and non-US citizens are eligible for these awards, and either may be affiliated with US-based institutions or institutions outside of the US.

Pilot Grant:

Applicants for the pilot award must hold an M.D., Ph.D., Ed.D., or Sc.D. and currently hold a position at a university or institution, or an organization with 501c3 status.

Pre-doctoral Fellowship:

Applicants for the Pre-doctoral Fellowship must be enrolled students in good standing in a program leading to a research doctorate, such as a Ph.D. or Sc.D., or a dual degree, such as an M.D./Ph.D., in an academic department at an

accredited university or health/medical institution. Medical school students are also eligible. They may apply at any time during their training. Pre-doctoral applicants must have a mentor and may also choose an additional advisor (optional) if needed.

- Mentor: The proposed mentor must hold a tenured or tenure-track faculty
 appointment (or equivalent) at an accredited institution of higher education
 or health/medical/research institution, and must be an established and
 active investigator in some aspect of autism research. Each mentor may
 sponsor only one applicant, and each applicant may only name one mentor.
- Advisor: This mechanism allows for an advisor that would work on a day-to-day basis with training and oversight. This could include a post-doctoral fellow or other research staff. This is not mandatory, but if the mentor is unable to provide day-to-day support to the fellow, it is highly suggested. The advisor may also provide expertise or opportunities outside the mentor's specific field, and should also work directly with the mentor. We recommend that a faculty member with more autism experience serve as the mentor while those who provide day-to-day support and guidance serve as the advisor. If the mentor is able to take on this responsibility, an advisor is not needed.

V. AWARDS

The Autism Science Foundation will fund a number of awards determined by available financial resources. The term of the award will be one year. This award cannot be used to cover tuition payments. No portion of these funds shall be used to cover indirect university costs.

Pilot Grant:

The award **is up to \$35,000 and** may be used to cover supplies or salary support and fringe for staff, including post-doctoral fellows, tenured or tenure-track faculty or other percent effort. It also may be used to cover small amounts of consulting costs.

Pre-doctoral Fellowship:

The award is \$35,000 to support salary and fringe benefits.

VI. REQUIREMENTS

- **A.** Applicants must prepare and submit proposals as instructed below. Most formatting and content instructions apply to both Pilot and Pre-doctoral applications. When requirements differ, those differences are clearly indicated in the Proposal Preparation section. Please review them carefully.
- All applicants must include a letter of support from an advocacy В. organization involved in profound autism. The advocacy organization is expected to act in an advisory capacity on the design of the study, outcomes of interest to families with profound autism, applicability of the study to those with profound autism, as well as help with recruitment, and support dissemination. Examples of organizations that have written strong letters in the past include the National Council on Severe Autism and the Profound Autism Alliance and the Patient Advocacy Groups (PAGs) that represent families with idiopathic autism or with rare genetic syndromes that result in a high prevalence of neurodevelopmental disorders, including autism, are also good choices. Many of these groups are represented in the Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism (AGENDA). Collaborations and partnerships with local organizations or other autism service organizations are also very welcome. Examples include the Bancroft School and The Center for Discovery. These are examples; this is not an exhaustive list. It is the responsibility of the applicant to inform the advocacy organization of the outcome of the grant review.
- C. In addition to the above, applications for Pre-doctoral Fellowships must also include an additional letter of recommendation

provided directly to ASF from someone other than the mentor named on the application.

VII. PROPOSAL PREPARATION

Proposals must be written using 12-point Arial font with margins of 0.5 inches or greater with line spacing at 1.5. The applicant's last name must appear in the header on every page of the proposal.

All of the sections below (with the exception of the additional letter of recommendation required for predoctoral applications) should be assembled into a single .pdf document in this order:

A. Title Page

The title page should include the applicant's name and full contact information (including a permanent, non-university affiliated email address), ORCID ID, race and ethnicity, project title, and name of the sponsoring institution. There may be multiple PIs on the project, but there needs to be one lead PI to whom the funding will be directed and who takes administrative responsibility for the project.

Pre-doctoral applicants must additionally indicate that it is a pre-doctoral fellowship application and include the name, affiliation and email addresses of the mentor and (if applicable) advisor.

B. Proposal Abstract (*Max. 500 words*) and **Lay Abstract** (*Max. 250 words*) The proposal abstract should indicate the goals and objectives of the project and clearly state the value of the work toward improving the lives of people with profound autism or people with severe and challenging behaviors.

The lay abstract must be intelligible to a knowledgeable layperson or non-expert. It should not include jargon and should clearly and succinctly state the goals of the project and the expected impact on people with autism and their families. It should not regurgitate the scientific abstract. Basic science projects should focus on the discovery value of the work if there is no immediate benefit.

C. Research and Analytic Plan (Max. 7 pages)

The top of this section should state "Research and Analytic Plan" in bold underline.

The plan should describe the specific project, including the rationale and background, relevance to understanding those with profound autism or severe and challenging behaviors, any preliminary data, specific aims, methodology, participant characterization and recruitment (if applicable), expected results and how they will be shared, and the timeline for completion. Please note that for animal studies, ASF strongly encourages applicants to follow this guidance.

We recommend that proposals include a statement of how the application is responsive to the RFA and needs of those with profound autism. Basic science projects should focus on the discovery value of the work if there is no immediate benefit to people. While there are various interpretations of the term "profound autism" we require use of the Lancet definition in these applications. Other groups can be included, but will be defined as non-profound autism.

D. Bibliography (Max. 2 pages)

The top of the section should state "References" or "Bibliography" in bold underline.

Include complete literature citations, including titles and all authors. We recommend numbered references to save space in the Research and Analytic Plan section.

E. Budget, Timeline and Budget Justification (Max. 1 page)

The top of the section should state "Budget, Timeline and Budget Justification" in bold underline.

Pilot Grant applicants:

The budget should include a breakdown of all the expenses, where the funding will go and to whom/what for the full funding amount. Each item should include a justification. A table listing the type of expense, the justification, and the amount is sufficient. For those holding positions at institutions (including post-doctoral fellowships) funding can be used to support salaries and fringe benefits, but should not exceed \$20,000 total.

Pre-doctoral applicants:

The entire budget should support salary and fringe benefits.

F. Biosketch (es): (5 pages maximum each)

Pilot Grant applicants must Include a biosketch for the PI and anyone receiving salary support, at all career levels.

Pre-doctoral applicants must include their own biosketch as well as biosketches for the mentor and any named advisor(s).

G. Support letter from Patient Advocacy Group

A letter from a Patient Advocacy Group, support group, or organization that works directly with families is required (see *requirements* section above). This letter should highlight the role that the organization will play in the project and the specific activities they will undertake to help support the research. They should also describe any unique expertise they have that will help ensure the project delivers results. Basic science projects have received outstanding letters from patient advocacy groups in the past so don't let this discourage application.

This letter should be included in the application packet, not sent directly to ASF.

H. Training plan (Max. 8 pages, predocs only) Only Pre-doctoral applicants should submit a training plan.

The Training Plan highly impacts the review and award decisions. It should be *prepared by the mentor in collaboration with the applicant*. The mentor should provide a thorough description of a training program that includes a clear logical plan of professional development for a future career in autism research specific to the applicant, as well as a comprehensive summary of the mentor's autism research and experience mentoring other students and postdocs. The training plan should include exposure to both clinical and basic sciences, and should take advantage of opportunities outside the university, including community based training.

If an advisor is included in the project, his/her expertise and role on the career development of the applicant in autism research should be described. Special attention should be given to the interaction between the advisor and the applicant if the advisor is at a different organization or research institution. The training plan should also utilize the relevant research and educational resources of the institution, including the research environment and the availability and quality of needed research resources. The training plan should be specific to autism, not just a training plan in science. It should also utilize the relevant research and educational resources of the institution, including the research environment and the availability and quality of needed research resources. In past grant cycles, highly qualified applicants have been rejected due to mentors submitting inadequate, overly generic training plans.

Mentors should also indicate current funding source(s), total award amounts, award durations (inclusive dates), project titles and clearly explain the extent to which currently funded research projects will overlap, complement and/or contribute to the training of the applicant. Mentors may also choose to list recent (last 3 years) as well as pending grant support relevant to autism research.

Pilot Grant applications do not require a training plan.

I. Letter of recommendation (pre-doctoral fellowships only)
Only Pre-doctoral applicants are required to submit a letter of recommendation.

This letter should be from someone other than the mentor named on the application and should be **submitted separately and sent directly to ASF** (not included in the application packet) by the recommender as a .pdf document on official letterhead. *Letters received as a word or google document will not be accepted.*

The letter should be submitted directly from the recommender to ASF by email to grants@autismsciencefoundation.org.

Please ask your recommender to use the subject line:

Applicant Last Name/Institution/Letter

TypeExample: Martin/Tulane/Letter

Pilot Grant applications do not require a letter of recommendation.

VIII. REVISIONS

Proposals reviewed but unfunded during the last cycle may be resubmitted for reconsideration. (If submitted prior to our 2025 funding cycle, the proposal would be considered a new submission.) In addition to the proposal, the applicant should provide a one page, single-spaced letter addressing the changes made in response to the reviewers' comments. The one-page, single-spaced letter will not be included in the proposal page limit; it should only contain information relevant to the reviewers' previous comments and suggestions. The revised proposal should be submitted without track changes or other editing notation.

IX. SUBMISSION OF PROPOSALS

Proposals should be submitted by email as one .pdf document with the subject line: Last Name/Institution/ProfoundAutismGrant to grants@autismsciencefoundation.org.

Example: Martin/Tulane/ProfoundAutismGrant

Successful electronic submission will be confirmed by email notification to the sender.

Applications are due **March 2, 2026 by 5:00PM ET.** This deadline applies to both the proposal and all applicable letter(s). It is your responsibility to inform letter writers of this deadline. Any proposals or letters received after this deadline will not be reviewed.

It is the applicant's responsibility to ensure that the proposal complies with the conditions prescribed in the RFA. The Autism Science Foundation reserves the right to return without review any proposal found not to comply with the conditions prescribed in the RFA, or any proposal that is not responsive to its research goals or exceeds its funding limits or available resources, at any time during the application and review process.

The Autism Science Foundation reserves the right to make changes to this RFA at any time. Changes will be posted on the website. We advise applicants to check this link frequently:

https://autismsciencefoundation.org/apply-for-a-profound-autism-pilot-grant/

X. REVIEW PROCESS AND EVALUATION CRITERIA

Proposals will be reviewed by members of the Autism Science Foundation's Scientific Advisory Board, as well as by active and experienced investigators recruited from the scientific community for their expertise in the research areas of the proposals. Proposals may also be reviewed by a panel of experienced laypersons (parents, individuals with autism, other advocates) who will provide input to the Scientific Advisory Board.

XI. AWARD NOTIFICATION AND START DATES

Award notifications will be made in June/July 2026. We expect grants offices to sign off on contracts and projects to begin no later than August 1, 2026. We highly suggest determining if the approval of an IRB or IACUC amendment is possible between notification and August 1st. We will not extend the start date due to IRB delays. In addition, if the grants office has significant delays in signing off on the contract, we have the right to rescind the offer.

XII. PAYMENT OF AWARDS

Upon notification of award, we will require a copy of the underlying project's IRB approval letter. Upon receipt of the IRB letter by ASF, we will issue a contract to the investigator's sponsoring institution and make a partial payment on signature of the contract. Please note, sponsoring institutions must accept the contract as is, or with only minor revisions. A sample contract is available for your grants office to review in advance to ensure the institution will be able to agree to the terms. The sample contract can be found at:

https://autismsciencefoundation.org/wp-content/uploads/2025/10/Sample-Contract-Template.pdf

Awardees must submit brief written reports to the Autism Science Foundation at the midpoint and at the conclusion of the award, documenting the status of the research funded and detailing the use of funds. A template will be provided by ASF for this purpose. All forms and report templates may also be accessed on our website:

https://autismsciencefoundation.org/grantee-resources/

XIII. QUESTIONS?

A question-and-answer session will be held online over Zoom on **Monday, December 22nd at 1:00PM ET** to review the goals of this RFA. It will include tips on writing a strong application. Please register here:

https://us06web.zoom.us/meeting/register/fPqvJ5MCTAWQ89pMJ9 fYw

Questions about proposal submission, proposal content and review, or applicant eligibility should be addressed to Dr. Alycia Halladay, Chief Science Officer, Autism Science Foundation (ahalladay@autismsciencefoundation.org).