



# Huntington's Disease Society of America

## 2026 Request for Proposals

Human Biology Project | Human Experience Project

<b>Letter of Intent</b> May 22, 2026	<b>Full Proposal (by invitation)</b> July 24, 2026	<b>Award Notification</b> October 2026
<b>Project Start Date:</b> No later than December 1, 2026		

### About This RFP

HDSA's 2026 RFP introduces two complementary funding streams, grounded in the organization's strategic commitment to understanding Huntington's disease as it is lived by people. Both programs leverage HDSA's unique network of Centers of Excellence. Applicants select their program stream when submitting their Letter of Intent through ProposalCentral..

<b>Human Biology Project</b>	<b>Human Experience Project</b>
<ul style="list-style-type: none"><li>• Uses clinical samples or patient data to advance understanding of HD biology in humans</li><li>• Connects laboratory discoveries to clinical and translational relevance</li><li>• Emphasizes biomarkers, mechanistic insights, and endpoints that will support therapy development</li></ul>	<ul style="list-style-type: none"><li>• Uses active human participants to study the lived experience of HD: cognition, behavior, function, quality of life, and care</li><li>• Aligned with HDSA's strategic priority of supporting people living with HD as therapies emerge</li><li>• Encompasses rehabilitation, digital health for reach/adherence, and patient-centered outcomes</li></ul>

# Stream 1: Human Biology Project

## Program Goal

---

Support innovative, investigator-initiated research aimed at understanding the biology of Huntington's disease in humans. Projects should prioritize the use of clinical samples or data from HD patients and aim to generate findings that inform therapeutic development or improve patient care.

## Statement of Need

---

HDSA is committed to funding impactful human-focused HD research. As the field approaches an era of disease-modifying therapies, there is an urgent need to build the evidentiary foundation that will support clinical development, regulatory decisions, and the translation of biological discoveries into patient benefit. This year's Human Biology Project RFP emphasizes:

- Use of HD patient-derived samples (e.g., biofluids, CSF, PBMCs, postmortem brain tissue) rather than exclusively relying on cell lines or animal-derived material
- Translational approaches that connect laboratory findings to clinical relevance, including proof-of-response studies that demonstrate whether a therapy is measurably affecting its biological target in patients
- Development of a richer panel of biomarkers and measurable endpoints that can support clinical trial design and regulatory arguments, including the capacity to distinguish treatment responders from non-responders
- Connections between imaging, fluid biomarkers, molecular readouts, and clinical or functional assessments that payers and regulators can ultimately rely on
- Pilot-scale experimental medicine studies, even with limited statistical power, that establish feasibility and generate hypotheses at scale
- Recruitment of new investigators to the HD field through collaborative, mentored research

We especially encourage applications that:

- Translate findings from HD models to patient-derived samples
- Develop or validate clinically meaningful biomarkers, including those informative of treatment response and progression across HD-ISS stages
- Leverage emerging technologies (e.g., single-cell sequencing, AI-enhanced imaging, wearables used as biological measurement tools) applied to HD patient data
- Integrate data across COE sites to identify the most robust and reproducible measures
- Use or establish substantive collaborations with HD clinics or HDSA Centers of Excellence

## Project Requirements

---

- Projects must involve clinical samples or patient-derived data. iPSC-based studies must be clearly linked to human clinical relevance and framed in the context of findings from patient samples.
- Applicants must have, or establish, a meaningful collaboration with an HDSA Center of Excellence or equivalent HD clinical site.
- Applicants are encouraged to describe how their project complements or extends existing HD datasets, biorepositories, or COE infrastructure.

## Review Criteria

---

Proposals will be reviewed by the HDSA Scientific Advisory Board and scored based on:

- **Impact and Relevance:** Does the research address an important problem in HD biology and offer potential to advance understanding or enable treatment?
- **Scientific Approach:** Are the design, methods, and analyses well-developed, rigorous, and appropriate to the aims?
- **Feasibility:** Can the project be completed within the timeline and with the available resources?
- **Investigator and Environment:** Is the applicant well-suited to carry out the work, and is the institutional environment appropriate?
- **Clinical Collaboration:** Is there a strong and genuine relationship between the laboratory and clinic? Will sample procurement and data access be supported and feasible?

## Stream 2: Human Experience Project

### Program Goal

---

Support investigator-initiated research that advances understanding of how HD is experienced and managed by people living with the disease. Projects must engage active human participants (not only samples or de-identified records) and should generate findings that improve cognition, function, quality of life, or care for people with HD across disease stages.

### Statement of Need

---

HDSA's 2026 strategic plan identifies a clear gap: while the HD field has made substantial investments in biology and therapeutic development, the experience of living with HD has been underserved by research. The Human Experience Project is HDSA's response to that gap. It is grounded in two complementary sources of evidence.

First, HDSA's Voice of the Patient Report (2025), which captured the perspectives of over 1,000 people living with HD across disease stages, documented that the cognitive, psychiatric, and behavioral dimensions of HD (anxiety, depression, difficulty concentrating, memory lapses, anger and irritability, obsessions and compulsions) rank among the most impactful aspects of daily life, often above motor symptoms. Over two-thirds of respondents across all stages cited worry about the future as a top concern; nearly half of early- and mid-stage respondents reported depression; and more than 70% of early-stage respondents reported difficulty concentrating as a current symptom. Yet these domains have historically received less research attention than motor features, and evidence-based guidance on how to address them is limited.

Second, HDSA's strategic planning process identified the following as organizational priorities that research funding can help advance:

- Supporting people living with HD as disease-modifying therapies emerge, including understanding how function, cognition, and quality of life evolve in the context of treatment
- Expanding and strengthening the HDSA Center of Excellence network as a platform for research that reaches people where they receive care
- Building the evidence base for patient-centered outcome measures that matter to people with HD and can be used in clinical trials and regulatory submissions
- Addressing equity in access to care and research participation, including for people in rural or underserved communities

We encourage applications that address, but are not limited to:

- Cognitive, psychiatric, and behavioral features of HD (e.g., anxiety, depression, apathy, obsessions/compulsions, emotional dysregulation, executive dysfunction) and interventions to address them
- Rehabilitation approaches (physical, occupational, speech-language, and cognitive therapies) and their impact on function and quality of life
- Pre-symptomatic and early-stage HD: the burden of living with genetic knowledge, evidence-based guidance on lifestyle approaches, and interventions to support wellbeing before motor onset
- Caregiver burden and support interventions
- Patient-reported and caregiver-reported outcome measures, including those relevant to clinical trial design and regulatory submissions
- Comparative effectiveness of HD care practices across COE sites
- Digital health tools, remote monitoring, or telehealth approaches where the research question concerns reach, adherence, accessibility, or lived experience (rather than biological measurement)
- Studies that engage people with lived experience in the design or conduct of the research

## Project Requirements

---

- Projects must involve active human research participants. The participant's experience, response, or perspective must be central to the research question, not merely incidental to sample collection.
- Projects focused primarily on molecular or cellular biology, or on biomarker development without a direct quality-of-life or functional relevance, should be directed to the Human Biology Project stream.
- Applicants must have, or establish, a meaningful collaboration with an HDSA Center of Excellence or equivalent HD clinical site. The clinical partnership must be substantive; nominal arrangements will not be considered sufficient.
- Survey-based or lifestyle studies must demonstrate methodological rigor, a well-defined study population, and sufficient statistical power, or must justify a pilot design with a clear and feasible plan for scale-up.

## Review Criteria

---

Proposals will be reviewed by the HDSA Scientific Advisory Board, with input from reviewers with relevant expertise in clinical, behavioral, and patient-centered research, and scored based on:

- **Impact and Relevance:** Does the research address a meaningful gap in the lived experience of HD, and will findings have practical implications for people with HD, their families, or their care?
- **Scientific Approach:** Are the design, methods, and outcome measures rigorous, appropriate, and patient-centered?
- **Feasibility:** Can the project be completed within the timeline, including participant recruitment?
- **Investigator and Environment:** Does the team have the relevant expertise, and is the environment suited to this type of research?
- **Clinical Collaboration and Patient Engagement:** Is the COE partnership substantive? Are people with lived experience engaged in meaningful ways?

# General Information (Applicable to Both Streams)

## Online Application Portal

---

Applications must be submitted through ProposalCentral.

If you have previously used ProposalCentral, sign in at [proposalcentral.com](https://proposalcentral.com) and click Create New Proposal, search for Huntington's Disease Society of America, and select either the Human Biology Project or Human Experience Project program. If you have not used ProposalCentral before, you can create an account at the same link.

To continue editing an existing application, log in to ProposalCentral and click the "Home" or "Proposals" tab to access your submission in progress.

## Eligibility

---

### Who Can Apply

- Researchers from academic, clinical, nonprofit, and for-profit institutions worldwide
- Investigators from all disciplines, including neuroscience, genetics, data science, rehabilitation, engineering, psychology, occupational therapy, palliative care, and social work
- Early-career investigators and HD newcomers are especially encouraged to apply

### Requirements Applicable to Both Streams

- Applicants must have, or establish, a meaningful collaboration with an HDSA Center of Excellence (COE) or equivalent HD clinical site. Purely in silico or data-only projects must include active consultation with COE clinical experts.
- Mentored applications (e.g., from trainees or fellows) must include a letter of support from a mentor who holds a PhD and/or MD/DO and has a primary appointment at an academic, public, or private research institution

## Awards and Budget

---

The following budget structure applies to both program streams:

### **Up to \$90,000 per year for 1 or 2 years**

Up to \$72,000 may be used for salary and fringe benefits

Up to \$30,000 may be used for research-related costs, including supplies and travel

Annual travel costs may not exceed \$5,000

No funds may be used for the purchase of laboratory equipment or personal computing devices

No indirect or overhead costs are permitted

Minimum 50% effort from the applicant is required

For-profit institutions must submit a letter confirming that publication will not be restricted due to proprietary concerns

## Reporting and Terms

---

- Proposals can be submitted as one or two-year projects
- Awards will be paid in installments and are contingent upon submission and approval of progress and financial reports
- A progress report is due 8 months after project start; continued funding is conditional on satisfactory progress
- A final scientific report and financial reconciliation are due within 30 days of the project end date
- A no-cost extension (up to 6 months) may be requested once if justified
- Award transfers to another institution require prior written approval from HDSA

## IRB and Human Subjects Requirements

---

- IRB/IACUC (or international equivalent) approvals are not required to submit the application but are mandatory prior to fund disbursement
- Projects involving the recruitment of study participants must complete the HD Trialfinder Listing Request Form (available at [hdsa.org/hd-research/hd-trial-finder](https://hdsa.org/hd-research/hd-trial-finder)). Studies will be listed in HDSA's HD Trialfinder to support participant recruitment across North America

- Projects using postmortem tissue must include documentation confirming sample availability
- Applicants must ensure compliance with all applicable ethical standards for research involving human participants

## Data Sharing and Publication Policy

---

- Funded researchers must acknowledge HDSA support in all publications and presentations
- Awardees agree to submit manuscripts to PubMed Central within 12 months of publication
- HDSA may share raw data with third parties 24 months after the project ends; prior to that, sharing may occur under confidentiality agreements
- Data may be included in public repositories in accordance with HDSA's open science policies

## Contact

---

For questions about either program stream, please contact:

**Tamara Maiuri, PhD**

Associate Director, Research & Patient Engagement

[TMaiuri@hdsa.org](mailto:TMaiuri@hdsa.org)

**Howlatu Sowe**

Mission Program Coordinator

[HSowe@hdsa.org](mailto:HSowe@hdsa.org)