Request for Proposals:
Survey to Identify Gaps and Needs for Patients Living with Rare Disease
Patient and Caregivers Engagement Workgroup
Rare Disease Diversity Coalition (RDDC)

Release Date: April 20, 2022  |  Close Date: May 18, 2022  |  Selection Date: May 31, 2022
Contract Period: June 1, 2022 – Dec. 1, 2022
Funding Level: $70,000

Background: RDDC is an initiative launched by the Black Women’s Health Imperative (BWHI) to address the extraordinary challenges faced by rare disease patients of color. The RDDC brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to reduce racial disparities in the rare disease community. The Coalition is made up of five dedicated working groups including Patient and Caregiver Engagement. In August 2021, the RDDC working groups were granted a budget to address some of the most pressing problems identified by each group.

Purpose: The Patient and Caregiver Engagement Workgroup seeks to secure a vendor to lead the development and execution of a survey to identify needs and better understand specific gaps experienced by a diverse population of patients of color living with rare diseases and their caregivers. The proposed survey will help to identify gaps in areas such as healthcare access, patient/provider communications, engagement, and other critical areas of need. Survey findings will be used to inform additional workgroup activities and product development.

Eligibility Criteria: This request for proposals is open the following types of entities:
- 501(c)(3) Non-profit (must provide documentation)
- Academic Institutions, in partnership/collaboration with a minority project lead
- Minority, women, disabled, veteran owned and/or led business entity (project lead should represent one of the identified groups)
- Area Health Education Centers (AHEC)- national and state chapters
- Applicants with experience working with rare disease community; populations of color and/or other diverse populations groups (i.e., LGBTQA, rural, etc.)

Scope of Work:
- Develop a survey to gain a better understanding of the unmet needs of diverse rare disease patients and caregivers.
- Develop and implement a dissemination strategy to engage a diverse group of respondents, including those representing racial and ethnic minority populations, parents of children with rare disease and other diverse and under-represented populations.
- Incorporate input from workgroup members into survey design and dissemination strategy.
- Produce an analysis of the survey results that includes key themes and recommendations for potential follow-up work.
- In collaboration with workgroup co-leads and advisors, establish a process for regular progress updates and present key findings at workgroup and RDDC meetings.
Proposal Requirements:

- Brief background of your organization’s current capacity and infrastructure to implement the proposed scope of work, noting any expertise in rare disease, engagement with racial and ethnic minority populations, direct patient engagement and/or caregiver research. Please identify the project lead and document any experience in leading similar projects.
- Draft project plan that includes a proposed strategy for survey design, including engagement with members of the RDDC Patient and Caregiver Workgroup. The proposed work plan should identify all project timelines including design, dissemination, analysis, and reporting.
- Detailed six-month budget breakdown with supporting narrative justification that reflects all direct and indirect costs. The indirect rate should not exceed 10 percent of the total budget. The budget should include but is not limited to the following categories: personnel (including percentage of time devoted to project), fringe benefits, supplies, travel, and consultants.
- Description of prior experience engaging hard-to-reach or not actively engaged patients and caregivers in the rare disease community. (Note: Samples of previous work in the rare disease and/or minority health space are not required but encouraged.)
- References or letters of support are not required but strongly encouraged. (Note: The workgroup reserves the right to contact any references provided by the applicant.)

Selection Process: Proposals shall be evaluated based on the following criteria:

- Organization’s current capacity and infrastructure to implement and sustain the proposed scope of work.
- Organization’s demonstrated experience with developing, conducting and analyzing survey data.
- Organization’s experience in working with and engaging racially and ethnically minority populations.
- Demonstrated understanding of rare disease communities.
- Experience reaching “hard-to-reach” individuals and populations not actively connected to healthcare systems.

Submission Guidelines:

- Organization should include a cover letter on company letterhead that includes the following:
  A. Organization/Agency Name
  B. Name, address, telephone number, title/position, and email address of the primary contact
  C. A current w-9
- Each item of the proposal packet should be appropriately labeled
- Each section should use 1.5 line spacing with a one-inch margin and 12-point Calibri font
- All pages should be numbered, including any appendices
- The full proposal shall not exceed a total of 5 pages in length (excluding any attachments including but not limited to a detailed budget, references, and samples of past work)

Submission Instructions: All proposal components must be submitted in PDF format by 11:59 p.m. ET on Wed. May 18, 2022 to suzanne.joy@hklaw.com. Please indicate organization name and “RDDC Patient and Caregiver Survey RFP Response” in the subject line. Late proposals will not be considered.