



## Request for Educational Support (RFE)

Reference # *RFE-22-IME-100*

### Independent Medical Education

Ultragenyx Pharmaceutical Inc. and its Affiliates "Ultragenyx" Grants & Medical Education program is committed to supporting global healthcare improvement for patients with rare and ultra-rare genetic disorders through educational initiatives, patient advocacy, research, and access to information about relevant disease states.

Ultragenyx's competitive grant program involves a publicly posted general Request for Education (RFE) that provides detail regarding a general area of interest, sets timelines for review and approval, and uses an internal Ultragenyx review process to make final grant decisions. Decisions are not based on, or influenced by, commercial interests. Organizations are invited to submit an application addressing the knowledge gaps as outlined in the specific RFE.

For all independent medical education grants, the grant requester is responsible for the design, implementation, and conduct of the independent initiative supported by the grant. Ultragenyx will not be involved in any aspect of the project, development, faculty selection, nor the conduct of the educational program. Each request will be evaluated independently and on its own merits, and Ultragenyx will not provide any guidance on whether a request will be granted or not, or otherwise evaluated favorably or not.

<b>Deadline for Submission:</b>	August 31, 2022
<b>Therapeutic Area:</b>	X-linked Hypophosphatemia (XLH)
<b>Area of Interest/Unmet need</b>	It is our intent to support a comprehensive, innovative, educational initiative that: <ul style="list-style-type: none"><li>• Reviews recommendations and effective management and practices related to the <b>transition of care</b> needed for adolescent and young adult (AYA) patients moving into adulthood.</li></ul>
<b>Geographical Scope:</b>	United States & Canada
<b>Intended Audience:</b>	<b>Primary:</b> Rheumatologists, Endocrinologists (Pediatric and Adult), Pediatricians, Nephrologists, Family Practice, Primary Care Physicians, Nurse Practitioners, and Nurses. <b>Secondary:</b> Fellows
<b>Applicant Eligibility Criteria:</b>	Ultragenyx is interested in supporting a comprehensive and innovative web-based, enduring, educational initiative that includes the following:

	<ul style="list-style-type: none"> <li>• The activity(ies) should measure improvement of learners’ knowledge, confidence, competence, and performance and should achieve at least a Moore’s Level 4 impact.</li> <li>• Applicants will be from medical, nursing, allied health, and/or pharmacy professional schools; healthcare institutions (both large and small); professional associations and medical societies; medical education companies; and other entities with a mission related to healthcare professional education and/or healthcare improvement.</li> <li>• Ultragenyx believes that every person deserves to be seen and heard, and we work to further this goal by encouraging grant requestors with different backgrounds, perspectives, and experiences to apply.</li> <li>• For projects offering continuing education credit, the requesting organization must be accredited. Accreditation from AACME, or others as deemed appropriate, should also be specifically noted for components where continuing education credit will be offered to learners.</li> </ul>
<b>Available Budget:</b>	<ul style="list-style-type: none"> <li>• The maximum amount of funding available for this RFE is <b>\$180,000 USD</b>.</li> <li>• Single or multi-support initiatives will be considered.</li> </ul>

**Healthcare Gap and Background**

Ultragenyx recognizes that a transition of care healthcare gap exists in X-linked Hypophosphatemia (XLH). X-linked hypophosphatemia (XLH) is an inherited skeletal disorder that may lead to lifelong complications and consequences, particularly when treatment and coordinated care is not urgently addressed. XLH is often thought of as a childhood condition, but the progressive and lifelong nature of the disease implies negative effects of XLH extend to both young adults and adults. Adolescents and young adults (AYAs) benefit from effective health care transition (HCT) preparation to support the transition from pediatric to adult care. This prevents loss to follow-up and creates opportunities to improve health outcomes of this progressive disease.

Ultragenyx has identified, through insights from educational needs assessments, literature searches, educational outcomes, and other methods, the need to address the following professional practice gaps:

- Need to educate on the characteristics of XLH and variation among patients.
- Need to disseminate the most recent recommendations on the diagnosis and treatment of XLH, with particular focus on avoidance of delayed care.
- Need to better understand the implications of undiagnosed, underdiagnosed, or delayed treatment of XLH, especially for AYAs who often fall out of a coordinated care plan.

- Need to understand current practices in coordinated care during patient(s) transition from pediatric to adult care teams and improve upon those current standards of practice.
- Need to treat, follow-up and/or refer diagnosed patients with improved cross disciplinary communications.
- Need to enhance collaborations among healthcare providers to improve patient care and educate patients on the importance of treatment adherence, as well as the benefits of routine visits with care team.

References:

1. Lecoq AL, Brandi ML, Linglart A, Kamenický P. Management of X-linked hypophosphatemia in adults. *Metabolism*. 2020; PubMed
2. Hughes M, Macica C, Meriano C, Doyle M. Giving credence to the experience of X-linked hypophosphatemia in adulthood: an interprofessional mixed-methods study. *J Patient Cent Res Rev*. 2020; PMC - PubMed
3. Haffner D, Emma F, Eastwood DM, et al. . Clinical practice recommendations for the diagnosis and management of X-linked hypophosphatemia. *Nat Rev Nephrol*. 2019; PMC - PubMed
4. Dahir K, Roberts MS, Kroleczyk S, Simmons JH. X-linked hypophosphatemia: a new era in management. *J Endocr Soc*. 2020; PMC - PubMed
5. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy Of Family Physicians; American College of Physicians . Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018; - PubMed
6. Dahir K, Dhaliwal R, Simmons J, Imel E, Gottesman G, Mahan J, Prakasam G, Hoch A, Ramesan P, Díaz-González de Ferris M. Health Care Transition From Pediatric- to Adult-Focused Care in X-linked Hypophosphatemia: Expert Consensus, *The Journal of Clinical Endocrinology & Metabolism*, 2022; JCEM - PubMed

**Proposal Requirements Summary**

Please also refer to [www.grants-rms.ultragenyx.com](http://www.grants-rms.ultragenyx.com) for detailed guidance on request submissions.

<b>Needs Assessment:</b>	Include an independent comprehensive needs assessment, which demonstrates an understanding of the specific healthcare gap and the needs of the appropriate healthcare or patient community.
<b>Audience Generation:</b>	Describe the methods and rationale by which specific target audience(s) for education will be identified, reached and how participation will be maximized. Include any relevant partnerships with professional associations, medical societies, patient advocacy groups or other entities who may be leveraged in disseminating the activity.

<b>Objectives:</b>	Provide clear, well-defined, measurable objectives that address the identified healthcare gap(s).
<b>Methods:</b>	Provide the format and methods by which this program will address gaps as they relate to the overall needs assessment.
<b>Faculty Recruitment:</b>	Include methods that will be used to identify and recruit multidisciplinary clinicians who are qualified and knowledgeable within this area of interest. Please provide conflict of interest resolution policy for any suggested faculty or advisors.
<b>Program Outcomes:</b>	Describe the assessments that will be used to measure the impact of your program and provide rationale for how these assessments will address the identified healthcare gaps.
<b>Budget:</b>	Provide a detailed line-item budget with a clear breakdown of costs and rationale for expenses.
<b>Timeline:</b>	Provide an estimated timeline of development, availability of each activity, and schedule for interim and final outcomes data.
<b>Publication Plan (Optional):</b>	Provide a description of how the outcomes of this program may be presented, published, or widely disseminated.

### **Submission Instructions**

Complete proposal applications should be formally submitted through the Request Management System (RMS) at <https://www.ultragenyx.com/our-purpose/corporate-sustainability/grants-and-charitable-contributions/>.

Please select the application page: **Medical Education** and include Reference ***RFE-22-IME-100*** in request title.

All complete proposal applications and must be received by **5pm PST on 31 August 2022**  
**Please note: Late submissions will not be accepted for review and incomplete submissions may not be reviewed.**

Applicants may be asked to provide additional information or clarification during the proposal review period. All applicants will be notified of a decision via RMS system email by 20 September 2022.

If accepted, applicant must attest to the terms, conditions, and purposes of grant as described in the Letter of Agreement. Grant award funds will be distributed within 30-days following the execution of a fully signed Letter of Agreement.

**Questions** regarding this RFE should be directed in writing to [grants@ultragenyx.com](mailto:grants@ultragenyx.com) with the subject line “RFE XLH Reference # RFE-22-IME-100”