

As part of our commitment to improving the lives of people living with rare diseases Alexion, AstraZeneca's Rare Disease supports quality, independent Continuing Medical Education (CME) designed to enhance patient care and health outcomes.

This call for grant applications provides public notice of availability of funds to provide education to community providers focused on importance of early recognition of NF1 and the need for lifelong patient monitoring.

Deadline for Submission	May 31, 2024
Decision Notification	July 1, 2024
Primary Area of Focus	Rare Disease
Therapeutic Area	Neurofibromatosis Type 1 (NF1)
Geographic Focus	United States
CGA Code	AX013
Intended Audience	Community adult/pediatric oncologists and neurologists
Budget	Up to \$300,000
Educational Need	<p>Neurofibromatosis type 1 (NF1) is a rare multisystem disorder that predisposes patients to tumor formation due to a deficiency in the neurofibromin protein.¹ Approximately 50% of cases are inherited.² NF1 is typically diagnosed in childhood but can be diagnosed throughout the lifespan. Approximately 30-50% of patients with NF1 develop plexiform neurofibromas (PN) during their lifetime, which are tumors originating along peripheral nerves.^{1,3} PNs often grow quickly during childhood and can cause disfigurement, pain, obstruction of vital structures, visual impairment, and bladder/bowel dysfunction.³⁻⁵ PNs carry the risk of transformation into malignant peripheral nerve sheath tumors in 8-13% of patients, often in adulthood, leading to severe pain and a poor prognosis.⁶ Patients with NF1 are also at higher risk of developing other malignancies, including gliomas, breast cancer and melanomas, with an earlier age of onset and worse prognosis than the general population.⁷</p> <p>Due to the heterogeneity and complex disease burden of NF1, treatment journeys differ greatly from patient to patient.⁸ Many patients with NF1 first present to community providers (community oncologists, neurologists, etc.) for management of presenting symptoms. It is essential for community providers to identify and diagnose NF1 efficiently, understand disease monitoring guidelines across the lifespan, and appreciate the importance of management by specialized NF multi-disciplinary teams to improve patient outcomes.⁹</p> <p>Alexion, AstraZeneca Rare Disease seeks to support independent medical education designed to develop community providers' understanding of:</p> <ul style="list-style-type: none"> • NF1 diagnosis and natural history of the disease across the lifespan

	<ul style="list-style-type: none"> • Importance of lifelong disease monitoring, including potential disease impacts on patient/caregiver quality of life and increased risk for development of other malignancies • The importance of early referral to a specialized multi-disciplinary team where possible; how to identify and connect with local NF specialists • Available treatment options for NF1 PN
<p>Educational Design and Focus</p>	<p>Series of live, local events in a Grand Rounds format or at local chapter meetings of relevant professional societies is preferred, allowing for local peer-to-peer discussion. An enduring web component will be considered to reach geographic areas that may not be targeted by live events.</p>
<p>Application Requirements</p>	<p>Proposal must be independently developed and include the following:</p> <ul style="list-style-type: none"> • Needs Assessment/Gaps/Barriers: Include a comprehensive, well-referenced needs assessment that provides a detailed description of the educational / practice gaps and barriers of the target audiences. The needs assessment must be independently developed and validated by the educational provider. • Audience Generation: Describe methods for reaching the target audience(s) and any unique recruitment methods that will be utilized. • Educational Strategy: Provide clearly defined and measurable learning objectives that are clearly designed to address the identified gaps and barriers. The proposal should demonstrate an understanding of instructional design issues as they relate to the gaps in the knowledge, competence, or performance of the targeted audience. • Program Evaluation and Outcomes: Provide a description of the outcomes methodology that will be employed to measure the impact of the educational program and how these results will be presented, published, or disseminated. Additionally, describe the methods that will be used to determine the extent to which activity has served to close the identified healthcare gap. Programs should include an outcomes plan of at least Moore's level 4. • Budget: Include a detailed budget with rationale, including breakdown of costs for content per activity, out-of-pocket cost per activity and management cost per activity. • Accreditation: Programs must be accredited and fully compliant with all ACCME Criteria and Standards for Commercial SupportSM.

References:

1. Blakeley JO et al. *Neuro Oncol.* 2016;18(5):624-638.

2. Pacot L, et al. *Genes*. 2019;10(9):633
3. Nguyen R, et al. *J Pediatr* 2011;159:652–655.e2
4. Dogra B, et al. *Indian Dermatol Online J*. 2013;4:195-198
5. Boyd K, et al. *J Am Acad Dermatol*. 2009;6:1-16
6. Evans DGR, et al. *J Med Genet*. 2002;39:311-314
7. Landry JP, et al. *JAMA Netw Open*. 2021;4(3):e210945.
8. Armstrong A, et al. *BMC Cancer*. 2023;23:553
9. Debs P, et al. *Skeletal Radiology*. 2024;53:909-916

Program Requirements: The Program must be planned and executed as an accredited activity and fully compliant with the criteria and/or standards of commercial support for ACCME, AAFP, AOA, ACPE, ANCC, AANP, or NCCPA. Furthermore, the program will be educational and nonpromotional in nature and will be planned, designed and implemented in accordance with the U.S. Food and Drug Administration’s Guidance on Industry-Supported Scientific and Educational Activities ("Policy Statement").

The Policy Statement and the ACCME Standards require, among other things, that (i) Institution conduct the Program independently and without control or influence by AstraZeneca over the Program's planning, content (including the selection of speakers or moderators), or execution; (ii) the Program be free of commercial bias for or against any product; (iii) Institution make meaningful disclosure of AstraZeneca support of the Program and any prior relationship between Institution and AstraZeneca, and the relationship, if any, between AstraZeneca and the speakers selected by Institution; and (iv) AstraZeneca not engage in, and Institution not permit any other sponsor to engage in, promotional activities in or near the Program room or advertise its products in any materials disseminated as part of the Program.

In addition, Institution is required by the Policy Statement and, if applicable, accreditation standards to ensure that any product discussions at the Program be accurate, objective, balanced and scientifically rigorous. This includes a balanced discussion of each product and of treatment alternatives, that limitations on data be disclosed, that unapproved uses be identified as such, and that for live presentations there be opportunities for questioning or debate.