

Be Heard & Share Your Story with FDA

The U.S. FDA's Office of Patient Affairs, in collaboration with [National Organization for Rare Disorders \(NORD\)](#), is organizing a virtual [Patient Listening Session](#) on Proteus Syndrome. The FDA would like to better understand how this disorder and its symptoms impact people living with proteus syndrome, how they manage their symptoms, and their perspectives on clinical trials.

WHAT:	A virtual meeting on Proteus Syndrome with FDA
WHO:	People diagnosed with Proteus Syndrome and family who care for them. <i>FDA is particularly interested in hearing from patients who have a cerebriform connective tissue nevus (CCTN).</i>
WHEN:	December 1, 2022, from 12 – 1:30 PM ET
WHY:	Help the FDA staff better understand Proteus Syndrome.
HOW:	Interested? Tell us about yourself! Complete the survey by Oct 24 (link and QR code, below).



surveymonkey.com/r/FDAProteus

If you have questions about this Patient Listening Session or are interested in other ways to get involved, please contact the FDA's Patient Affairs at PatientAffairs@fda.gov.



NORD[®]
National Organization
for Rare Disorders



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