

NPTR VIDEO CATALOG ENTRY

Disease	Homocystinuria (HCU). Amino acid disorders.
Title	Homocystinuria Patient Testimony - Bartke.
Link	https://www.youtube.com/watch?list=PLvz3MWdu8TP3wTE9wYNxq3WOxQxMbx4XV&v=1heSeXfwbJg&feature=emb_title
Key words	Homocystinuria (HCU). Amino acid disorders. Patient/family experience. Symptoms. Diet/treatment.
Description	Danae is executive director of HCU Network America. She describes how she was diagnosed with homocystinuria, and the daily routine she follows to manage her diet and disease. She also talks about her hopes and what makes her anxious about the disease.
Length (min:sec)	4:34
Speaker Background	Patient.
Objectives	<ol style="list-style-type: none"> 1. Discuss some of the day-to-day challenges/experiences of a patient living with homocystinuria. 2. Review the complexity of homocystinuria treatment.
Educational utility	Provides a personal narrative about living with the disease but should be accompanied by significant medical teaching to increase understanding about the disorder.
Technical features	Great audio and video quality.
Relevant/ Target Audience	Health professionals and specialists. Trainees and students in the health professions. Other stakeholders who have an interest in the inborn errors.
Promotional aspects	The patient mentions her formula and medication. This video does not otherwise promote a commercial product, treatment, and/or medical device.
Source	HCU Network America.

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