

NPTR VIDEO CATALOG ENTRY

Disease	Homocystinuria (HCU). Amino acid disorders.
Title	Homocystinuria Parent Testimony - Sarah.
Link	https://www.youtube.com/watch?v=OIJXMvGLqQo&list=PLvz3MWdu8TP3wTE9wYNxq3WOxQxMbx4XV&index=3
Key words	Homocystinuria (HCU). Amino acid disorders. Patient/family experience. General disease overview. Symptoms. Diagnosis. Newborn screening. Biochemistry. Diet/treatment.
Description	In this video, Sarah (a nurse) describes her children's diagnostic journey to find out their diagnosis. She reviews the complexity of therapy for homocystinuria, and discusses some of her hopes and fears about their future.
Length (min:sec)	5:56
Speaker Background	Parent.
Objectives	<ol style="list-style-type: none"> 1. Educate viewers on the day to day challenges/experiences of patients diagnosed with Homocystinuria 2. Describe the dietary restrictions and challenges experienced by patients with Homocystinuria
Key words	Patient/family experience. General disease overview. Biochemistry. Diagnosis. Newborn screening. Diet/treatment.
Stand-alone Nature	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	Excellent 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.
Source	HCU Network America.

Author	JA. 08/07/20
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