

PTR VIDEO CATALOG ENTRY

Disease	Isovaleric Acidemia (IVA) – Organic Acidemia
Title	Living with a rare disease: A story of two siblings
Link	https://www.youtube.com/watch?v=XeuBZf0nrM&t=1s&ab_channel=Children%27sNationalHospital
Key words	Patient/Family Experience, Newborn Screening, Prognosis.
Description	This video highlights the stories of Stephen and Caroline, two siblings with IVA with dramatically different health outcomes. Their mother and a director at Children’s National describe how the drastic difference in their disease progression is largely due to diagnosis of the disease at birth, compared to just a few years later. The video is a promotion for The Rare Disease Institute at Children’s National Hospital.
Length (min:sec)	3:39
Speaker(s) Background	Mother, Director at Children’s National.
Objectives	1. Describe the potential benefits of identifying a metabolic disease at newborn screening.
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 aspects	Excellent audio and excellent 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	This video is highly promotional of The Rare Disease Institute at Children's National Hospital. This video does not promote a commercial product, treatment, and/or medical device.

Source	Children's National Hospital.
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