

NPTR VIDEO CATALOG ENTRY

Disease	Maple syrup urine disease (MSUD). Amino acid disorders.
Title	Grayson: A Story about Hope, Inspiration, and Courage – Living with Maple Syrup Urine Disease (MSUD).
Link	https://www.youtube.com/watch?v=pxLe6Z8Q5wE
Key words	Maple syrup urine disease. Amino acid disorders. Patient/family experience. Symptoms. Diet/treatment.
Description	Grayson's parents describe well the feelings and challenges around raising a child with a rare disease, like maple syrup urine disease. A medical professional describes the basic pathophysiology of the disease, while Grayson's parents discuss the challenges of managing his diet. Grayson was also born with a heart defect that needed surgical repair (unrelated to the MSUD); a few comments in this video refer to the heart defect (e.g., regarding the prenatal ultrasound) and not the metabolic condition.
Length (min:sec)	5:00
Speaker(s) Background	Parents. Physician. Advocacy organization leader.
Objectives	<ol style="list-style-type: none"> 1. Identify the brain impact of untreated MSUD. 2. Describe the basic dietary approach of an individual with MSUD. 3. Characterize the feelings that caregivers may have in managing children with a rare and acute disease like MSUD.
Educational utility	Provides a personal narrative about living with the disease but would be more effective if accompanied by some medical teaching.
Technical aspects	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.

Promotional aspects	This video does not promote a commercial product, treatment, and/or medical device.
Source	Produced by Michael Daingerfield and Jef Gibbons.
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