

## NPTR VIDEO CATALOG ENTRY

Disease	Maple syrup urine disease (MSUD). Amino acid disorders.
Title	Two video clips of a patient with maple syrup urine disease.
Link	1. <a href="https://www.youtube.com/watch?v=si0FyU7IqJw">https://www.youtube.com/watch?v=si0FyU7IqJw</a> 2. <a href="https://www.youtube.com/watch?v=CVE-cokQle0">https://www.youtube.com/watch?v=CVE-cokQle0</a>
Key words	Maple syrup urine disease (MSUD). Amino acid disorders. Patient/family experience. General disease overview. Symptoms. Newborn screening. Diet/treatment. Prognosis.
Description	<ol style="list-style-type: none"> <li>1. Living with MSUD – Diagnosis and early life - <a href="https://www.youtube.com/watch?v=si0FyU7IqJw">https://www.youtube.com/watch?v=si0FyU7IqJw</a></li> <li>2. MSUD - Baby Habul's first birthday - <a href="https://www.youtube.com/watch?v=CVE-cokQle0">https://www.youtube.com/watch?v=CVE-cokQle0</a></li> </ol> <p>These informative videos offer a peak into the early life of Habul, a baby with maple syrup urine disease, at two different times – in early infancy and again a year later. The mother, along with a number of Habul's providers, describe the disease severity and complexity, and portray the multi-dimensional approach needed to manage a child with a genetic metabolic disease.</p>
Length (min:sec)	1. 6:27 2. 4:01
Speaker(s) Background	Mother. Metabolic providers (including physicians, nurse specialist, dietitian).
Objectives	<ol style="list-style-type: none"> <li>1. List the symptoms and complications associated with MSUD.</li> <li>2. Review the clinical course and management of a patient with a severe case of MSUD.</li> <li>3. Describe and account for the multidisciplinary nature of the care needed for a disorder like MSUD.</li> </ol>
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	NIHRtv - CLAHRC South Yorkshire.
Author Date	MK. 07/16/2020