

NPTR VIDEO CATALOG ENTRY

Disease	Tyrosinemia type I. Hepatorenal tyrosinemia. Amino acid disorders.
Title	Living with Tyrosinaemia.
Link	https://youtu.be/PaHzdYJVbM
Key words	Tyrosinemia type I. Hepatorenal tyrosinemia. Amino acid disorders. Patient/family experience. General disease overview. Symptoms. Pathophysiology. Biochemistry. Diet/treatment. Prognosis.
Description	This video showcases the history of several young patients with hepatorenal tyrosinemia and the impact of the disease on their families. The patients' mothers talk about their early symptoms and struggles prior to starting therapy; a treating liver specialist provides a medical perspective on the children's condition.
Length (min:sec)	10:46
Speaker(s) Background	Several mothers of patients. Treating hepatologist.
Objectives	<ol style="list-style-type: none"> 1. Detail the symptoms and disease progression of tyrosinemia type I. 2. Explain the pathogenesis of the disease. 3. Identify an overview of disease management. 4. Describe how parents cope with the challenges of having a child with a potentially lethal chronic disease.
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 video quality but the audio quality is variable; there may be sections during which it is difficult to hear what is being said.
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	Birmingham Children's Hospital.

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