

## NPTR VIDEO CATALOG ENTRY

Disease	Pompe disease. Glycogen storage disease (GSD) type II. Carbohydrate disorders.
Title	Late-onset Pompe Disease - Patient's Story.
Link	<a href="https://www.youtube.com/watch?v=hGWvs9dY1k">https://www.youtube.com/watch?v=hGWvs9dY1k</a>
Key words	Pompe disease. Glycogen storage disease type II. Carbohydrate disorder. Patient/family experience. Symptoms. Diet/Treatment. Prognosis.
Description	The patient outlines his diagnostic journey and how he overlooked the early symptoms of the disease. He also describes the treatment he receives for Pompe disease and its impact on his functioning.
Length (min:sec)	2:59
Speaker(s) Background	Patient.
Objectives	<ol style="list-style-type: none"> <li>1. List some symptoms of late-onset Pompe disease and the course of the (untreated) disease.</li> <li>2. Identify reasons why these symptoms might be overlooked.</li> <li>3. Describe the potential benefits from enzyme replacement therapy.</li> </ol>
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 good 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 discusses the benefit of Myozyme as a treatment for Pompe disease.
Source	Rare Disease Report.

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