

YouTube Video Index

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National
FABRY DISEASE
Foundation

#	Title (w/ link embedded)	Topic (Year)	Description
1	Fabry Disease (FD) Symptoms - Recognize And Rescue Everyone	Overview (2011)	Jerry Walter, president of the National Fabry Disease Foundation and Fabry patient, presents an illustrated overview of Fabry disease symptoms to increase recognition and diagnoses.
2	Fabry Disease (FD) Update	Overview (2020)	Dr. Robert Hopkin provides an overview of Fabry disease, this is a great video to start with. Dr. Rob reviews signs and symptoms experienced over the lifetime of individuals with Fabry disease with a focus on minimizing serious complications with treatment to increase lifespan and quality of life.
3	Fabry Disease (FD) and the Heart	Cardiology (2023)	Dr. Jefferies provides an overview of cardiac symptoms in Fabry disease, focusing on monitoring and treatment.
4	Testing for Cardiac Involvement	Cardiology (2021)	Dr. Jefferies provides an overview of cardiac symptoms in Fabry disease, with a focus on the tests suggested for symptomatic and asymptomatic individuals.
5	Heart Failure in Fabry Disease	Cardiology (2021)	Dr. Jefferies reviews the late stages of heart disease, called heart failure, that can be seen in advanced Fabry disease.
6	FD Cardiology and Electrophysiology	Cardiology (2020)	Dr. Al-Khatib provides an overview of the physical and electrical heart problems seen in individuals with Fabry disease.
7	Fabry Disease and the Kidney	Nephrology (2024)	Dr. Wallace provides information about kidney manifestations in Fabry disease, with a focus on monitoring and treatment.
8	Renal Involvement in Fabry Disease	Nephrology (2021)	Dr. Wallace reviews kidney involvement experienced over the lifetime of individuals with Fabry disease and possible management options.
9	Adjunct Therapies for Kidney Health	Nephrology (2021)	Dr. Wallace reviews kidney involvement in Fabry disease and discusses kidney-directed therapies often used in addition to primary Fabry therapy.
10	Kidney and U	Nephrology (2020)	Dr. Rastogi provides an overview about kidney function and health in Fabry disease.
11	FD Overview: Focus on Neurology	Neurology (2023)	Dr. Hopkin provides an in depth overview of Fabry disease, with a focus on the nervous system.
12	Understanding Fabry Pain	Neurology (2021)	Dr. Lawson provides an overview of how small fiber neuropathy in Fabry disease causes symptoms of pain across the lifetime.

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13	Cerebrovascular Involvement in FD	Neurology (2021)	Dr. Lau reviews how Fabry disease affects the blood flow and blood vessels in the brain, leading to a risk of TIA and stroke.
14	Effects of FD on the Nervous System	Neurology (2020)	Dr. Lau reviews how Fabry disease affects the nervous system and provides management recommendations to manage the risk of neurological symptoms.
15	Gastrointestinal Upset in FD	Gastro (2021)	Dr. Zar-Kessler reviews gastrointestinal symptoms experienced over the lifetime of individuals with Fabry disease and possible management options.
16	Nutritional Interventions in FD	Gastro (2021)	Dr. Zar-Kessler reviews what is known about dietary considerations and nutritional interventions for GI symptoms in Fabry Disease.
17	Gastroenterology Involvement in FD	Gastro (2020)	Dr. Zar-Kessler provides an overview of digestive system involvement in Fabry disease.
18	Females with Fabry Disease	Women (2021)	Learn about how females with Fabry disease experience symptoms over their lifetime with a review of data from peer-reviewed publications.
19	FD in Women - MythBusters	Women (2023)	Learn about common misconceptions regarding females and Fabry disease, presented in the fun "Mythbusters" format.
20	Pulmonary Involvement in FD	Lungs (2021)	Dr. Skloot reviews what is known about pulmonary (lung) function in Fabry disease.
21	Eye Involvement in Fabry Disease	Eyes (2021)	Dr. Michaud provides information about eye involvement in Fabry disease.
22	Lymphedema in Fabry Disease	Edema (2021)	Dr. Hopkin provides an in-depth overview of lymphedema, commonly seen in the lower legs, ankles, and feet.
23	Anxiety, and Depression with FD	Psychology (2021)	Dr. Ali reviews what is known about stress, anxiety and depression with Fabry disease.
24	Fabry Disease (FD) Inheritance	Genetics (2012)	Jerry Walter, president of the National Fabry Disease Foundation and Fabry patient, presents an illustrated overview of Fabry disease inheritance.
25	GB3 and Lyso-GB3 in FD	Biomarkers (2023)	Dr. Albinia Nowak presents via Zoom to provide an overview of important biomarkers to monitor in individuals with Fabry disease.
26	Fabry Disease Infusion Reactions	Treatment (2021)	Dr. Hopkin reviews treatment with enzyme replacement therapy and the incidence and management of infusion-related reactions.
27	Chaperone Therapy for Fabry Disease	Treatment (2021)	Dr. Ganesh provides information about oral chaperone therapy available to treat some individuals with Fabry disease.

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28	An Update on Gene Therapy	Treatment (2021)	Dr. Hopkin provides an overview about gene therapy and reviews ongoing clinical trials.
29	Fabry Disease and Covid-19	COVID (2021)	Dr. Lau provides an update regarding what is known about COVID and Fabry disease.
30	Fabry Disease and the Pandemic	COVID (2020)	Dawn Laney, CGC provides an overview about what is known thus far about COVID and Fabry disease.
31	FD Psychology Update: Pandemic	COVID (2020)	Dr. Ali provides guidance for taking care of ourselves during the global pandemic.
32	NFDF Family Assistance (KGA)	Support (2023)	NFDF Family Assistance Program in partnership with KGA provides valuable psychosocial resources available free of charge for individuals with Fabry disease and their family members.
33	TAF Financial Assistance	Support (2023)	Learn about The Assistance Fund program that supports financial needs of individuals with Fabry disease.
34	PAN Foundation Financial Assistance	Support (2023)	Learn about the PAN Foundation program that supports financial needs of individuals with Fabry disease.
35	Accessia Health Financial Assistance	Support (2023)	Learn about the Accessia Health program that supports financial needs of individuals with Fabry disease.
36	AKF Financial Assistance	Support (2023)	Learn about the American Kidney Fund program that supports financial needs of individuals with Fabry disease who are on dialysis or post kidney transplant.
37	Psychosocial Aspects of FD	Support (2024)	Stacey Feuer, PsyD reviews what is known about the psychosocial aspects of living with lysosomal storage disorders including common concerns and provides strategies to increase quality of life.
38	Mindfully Rare Resources for Mental Health Support	Support (2024)	Mindfully Rare is a resource developed by with Chiesi and the National Alliance of Mental Illness (NAMI) to support the mental health of individuals with Fabry disease and their caregivers.
39	NFDF Family Assistance Program	Support (2024)	Learn about the NFDF Family Assistance Program with KGA. This free program provides valuable psychosocial support and referrals as well as assistance with financial, legal, work, and family life.
43	10 Things about Clinical Trials	Support (2024)	Learn about what it's like to participate in a clinical trial, as presented by Sangamo.
44	Is Home Infusion Right for You?	Support (2020)	Learn about the home infusion process, as presented by Diplomat Specialty Infusion Group.
45	Data Registry Services	Support (2020)	Learn about the Fabry Registry hosted by Data Registry Services, LLC.

#	Title (w/ link embedded)	Topic (Year)	Description
46	What do participants say about NFDF's annual conference & camp?	Community (2023)	Listen to what some of our attendees have to say about the NFDF's annual conference and camp.
47	October 2022 Fabry Family Camp at Victory Junction hosted by the NFDF	Community (2024)	See behind the scenes of Fabry Family Camp at Victory Junction in 2022.
48	Rare Disease Update from Sanofi	Community (2023)	Duane Clarke, General Manager of US Rare Disease at Sanofi reflects on the state of rare disease treatment.
49	Fabry Disease from the NFDF	Community (2015)	Watch the short awareness video created by Jerry Walter, president of the National Fabry Disease Foundation and Fabry patient.
50	The Faces of Fabry Disease	Community (2015)	Individuals with Fabry disease list it many symptoms and share their personal/family stories.
51	Fabry - Please Take Us Seriously	Community (2015)	Teenagers with Fabry disease share what they want you to know about this rare genetic disorder.
52	NFDF Awareness Video	Community (2014)	Interview of multiple individuals with Fabry disease who share stories about their diagnosis, treatment, and ongoing symptoms.