



Nationwide Children's Hospital ATTN: Community Education 700 Children's Drive Columbus, OH 43205-2696



# FSHD Lab Day July 8, 2023

FSHD SOCIETY LIGHTING THE WAY TO A CURE



## **FSHD** Lab Day

#### **Program Description**

Join Nationwide Children's Hospital and the FSHD Society in a day of educational sessions and lab blood draw to promote research efforts.

### Summary of Biomarker Clinical Study:

Facioscapulohumeral dystrophy (FSHD) is a rare genetic muscle disease that affects approximately 1 in 8,000 individuals worldwide. FSHD causes progressive muscle weakness and wasting, particularly in the face, shoulders, and upper arms. Currently, there are no effective treatments for FSHD, and diagnostic methods are limited to clinical examination and genetic testing. This creates a significant burden for FSHD patients and their families, who often experience delays in diagnosis and a lack of treatment options.

The Saad lab is conducting a clinical study to identify molecular blood biomarkers for FSHD using a novel approach that focuses on analyzing the content of exosomes, which are tiny particles found in the blood that contain proteins and genetic material. By decoding the exosome content, Dr. Saad's team hopes to identify non-invasive blood biomarkers that can be used to diagnose and predict FSHD onset, severity, and progression, as well as assess the efficacy of FSHD therapeutics in future clinical trials.

Your blood donation will play a crucial role in supporting this research and accelerating the validation of therapies in clinical trials. Identifying blood biomarkers for FSHD could significantly improve the diagnosis and management of the disease. Furthermore, this research could pave the way for the development of new treatments and improve the quality of life for individuals affected by FSHD.

#### Who Should Attend

People with FSHD and their families. Both people with FSHD and their family and friends can give blood.

## Date and Time

July 8, 2023 10 a.m. - 2 p.m.

## Location

Nationwide Children's Hospital Education Center 575 South 18th Street, Columbus, OH 43205

#### Agenda

9:30 a.m.	Check in Opens
10 a.m.	Welcome: What This Day is For
	Sue Aumiller, Columbus Chapter Director, FSHD Society, and Brittany Connor
10:10 a.m.	The Bigger Picture: The Road to Treatments for FSHD and Why Blood
	Biomarkers are Important
	Kevin Flanigan, MD, Scott Harper, PhD
10:35 a.m.	The Biomarker Study and Why We Need
	<b>Blood Samples</b> Nizar Saad, PhD
10:50 a.m.	Q and A
10:30 a.m.	C
11 a.m.	Red Scooter Diaries Film and Discussion
12:35 p.m.	Lunch
2 p.m.	Adjourn

Blood draws will be done throughout the day. If you choose to donate, you will receive a call to schedule your donation.

## Cost

No charge, this program is free.

#### **Program includes:**

Education, light breakfast, box lunch and free parking. Research blood draw participation for those 18 and older.

## Parking

Is located in the Orange Garage near the Education Center at 543 South 18th St.

We will give you a parking sticker to validate your parking when you check in at the program.

## Confirmation

You will receive a confirmation email with driving directions both when you register and one week before the program.

#### Can't Attend?

If you can't attend but want to participate in the blood draw, contact Brittany at (614) 355-2727

Program Questions? Call (614) 355-0662

#### REGISTRATION FORM: FSHD DAY

□ I have FSHD	☐ I am a relati someone wi		□ None of the abov
I am 18 or over and want to be part of the blood draw Yes			No
Name			
□ I have FSHD	I am a relati someone wi		□ None of the abov
I am 18 or over an to be part of the bl		Yes	No
Name			
☐ I have FSHD	I am a relati someone wi		□ None of the abov
I am 18 or over an to be part of the bl		Yes	No
Address			
City	State	Zip	
County			
Daytime phone			
Fax			

Register online at NationwideChildrens.cloud-cme.com/FSHD

Or mail this form to: Community Education Nationwide Children's Hospital 700 Children's Drive, Columbus, OH 43205