FSHD Advocate
2026 • ISSUE 2

SEIZE THE MOMENT

Turning *Progress* into *Access*








FSHD SOCIETY













SEIZE THE MOMENT

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FSHD Advocate

The FSHD Society is the world's largest research-centered patient advocacy organization focused on facioscapulohumeral muscular dystrophy (FSHD). This genetic condition affects one million people worldwide and causes lifelong, progressive muscle weakness that can result in significant pain and disability. We are accelerating the development of treatments, empowering and activating the FSHD community, and making sure no one has to face this disease alone. The Society does not endorse any of the drugs, procedures, treatments, or products discussed in its reporting. We urge you to consult your physician about any medical interventions.

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WHAT HAPPENS WHEN...?

What happens when people living with FSHD refuse to accept that "nothing can be done"?
What happens when families, volunteers, researchers, clinicians, industry leaders, advocates, and donors decide that the time for waiting is over?

Everything changes.

You can see the power and the possibilities throughout this issue of the *FSHD Advocate*.

You'll see it in the thousands of people who sign up and show up for Walk & Rolls. Patients, families, caregivers, friends, and supporters turning miles into momentum and community into action. You'll see it in the volunteers who give their time, energy, and hearts because they know what they do matters. You'll see it in the people running races, climbing hills, organizing DIY fundraisers, and doing whatever they can to move us closer to treatments and a cure.

You'll see it in the voices of the youngest in our community helping to shape the future of research and care by joining a global pediatric study providing much-needed data to be considered for treatments when they become available. And you'll see it in the global FSHD community coming together at the International Research Congress, the FSHD Connect Conference, and World FSHD Day to share knowledge, strengthen connections, and accelerate progress.

But perhaps most importantly, you'll see what happens when the FSHD community prepares not only for a treatment, but for what comes after treatment approval.

We are getting closer to a moment we have dreamed about for generations: The possibility of the first treatment to stop FSHD. And when that happens, our work will not be finished. The FSHD Society is building a catalytic collaboration focused on three critical priorities: Helping achieve FDA approval, preparing patients and families to access and benefit from treatment, and ensuring providers and payors are ready (see p. 6 for details).

Because approval is only the beginning. We must make sure people know what treatment means for them. We must help healthcare providers recognize FSHD and understand emerging therapies. We must work with payors and policymakers so that access is not determined by geography, circumstance, or ability to navigate a complicated system.

What happens when the world comes together around FSHD? Hope becomes action. Research becomes opportunity. Opportunity becomes treatment. And treatment becomes access.

That is the path we are building—together. And every story in this magazine is a reminder that you are not simply watching this moment unfold. You are helping to make it happen.

What you do matters. What we do together matters even more.

Forward Together!

Mark



Mark A. Stone

Look for us online at *fshdsociety.org*. We thank the FSHD Society staff for their editorial assistance.

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HELP THE FSHD SOCIETY SEIZE THIS MOMENT

BY CHELSEA MOELLER, FSHD SOCIETY

Fifteen years ago, there were no serious treatment programs for FSHD. Ten years ago, one drug was being explored. Today, four therapies are in advanced clinical trials, six more are set to launch in the coming months, and more than 25 biotechnology companies are working toward a treatment. What was once a dream now feels inevitable. When this dream is realized and reaches everyone depends on what we do now.

None of this momentum happened by chance—it took a decade of deliberate work, made possible by partners like you.

Building momentum and converting it to meaningful change are two different challenges. Approval of an effective therapy is a crucial first step—a beautiful, long-sought, hard-won milestone. And in many ways, it will be the beginning. Access is the next "Everest." Ensuring everyone, regardless of age or mobility, benefits from this breakthrough is the ultimate end goal.

Without validated biomarkers and stronger data on pediatric and non-ambulatory patients, trials take longer, labels stay narrow, and the people who need a treatment most are the ones most likely to be excluded from it. That's why we're focused on research that addresses those realities while preparing clinics and insurers, and readying patients for treatment, so we don't lose a single moment or muscle once a treatment makes it to market.

Every day we are driven in this work by the lives lived and dreams dreamed by those in our FSHD community. By Coco, Grace, Katie, and Marjorie—three sisters and a mother who, together, represent two generations and a spectrum of this disease. Like so many in our community, they've all made hard decisions and had heart-wrenching realizations at inconvenient times. And, like so many, they all hold steadfastly to the hope of a better tomorrow.



Grace, Colette, Katie, and Marjorie



Kate working on a drawing



Evan with his wife Kiana and son Hal

We are driven by those like Kate who, at 15, has already lost more than many of us will in a lifetime. Kate is an artist, an adrenaline junkie, an advocate—a teenager pining for typical teenage concerns. Kate, who cries on the hardest of hard days and persists on all the others.

Those like Evan, a tech professional, husband, and father who wants nothing more than to teach his young son to play catch someday. Evan is a full-time powerchair user who, until recently, resisted the temptation to hope that something will change in time for him.

It won't—not for Evan, not for Kate, Coco, Grace, Katie, or Marjorie—not for anyone unless we all do what we can as a community to seize this moment and the future we deserve.

As you plan your year-end giving, please consider supporting our efforts and our priorities of approval and access for all. We are here at this pivotal place because you believed things could change. Now is the time to believe as big as we can and change the future for good.

See page 30 for more giving information.



POWERING THE PATH FORWARD: THE FSHD SOCIETY'S STRATEGIC PLAN FOR 2026–2029

How we're preparing our community, our clinicians, and our health system for the first FSHD treatment

BY MARK STONE, FSHD SOCIETY



For the first time in the history of facioscapulohumeral muscular dystrophy, the question is no longer whether a treatment will reach patients, but when, and *whether* our community will be ready *when* it does. Phase 3 clinical trials are underway, and current industry timelines suggest a first regulatory submission to the FDA could come soon.

That prospect shaped a months-long strategic planning process at the FSHD Society. Over the first half of 2026, our leadership team gathered input from outside experts, studied the experience of other rare disease communities that have seen a first approval, and worked with our Board of Directors to set priorities for the next three years. This article outlines where we're headed and why.

Our guiding principle: Approval is not the finish line

Other rare disease communities have taught us a hard lesson: When the first treatment is approved, the phones start ringing. Thousands of patients and families who have never contacted an advocacy organization suddenly want information. Physicians who have seen only a handful of FSHD patients need guidance. Insurers begin deciding who qualifies for coverage. A treatment that exists on paper but can't be diagnosed, prescribed, or paid for doesn't help anyone.

That is why our plan rests on four connected areas of work: Regulatory advocacy backed by strong data, patient readiness, provider preparedness, and payor readiness. Each one addresses a different link in the chain between a promising drug and a person living with FSHD who actually receives it.

1. Data-informed FDA advocacy through the Industry Collaborative

Supporting approval of the first disease-modifying treatment remains our number one priority. The Board was clear on this point, and it anchors everything else in the plan.

Regulators make decisions based on evidence, and their current standard is functional stability or improvement. One of the biggest challenges in FSHD research has been measurement itself: While this disease is relentless in its progression, the functional measures currently used to measure progression in trials vary widely from person to person, which makes it difficult to show in a trial whether a treatment is working. The FSHD Society's Industry Collaborative brings drug developers together to tackle that problem through shared MRI and biomarker research. Better tools for measuring disease reduce uncertainty for every company in the field and for the FDA reviewers evaluating their data.

We're also looking ahead to who will qualify for the first treatment. Early approvals in rare diseases often come with narrow labels, limited to the populations studied in trials. We are generating evidence now to support future label expansion to children and to people who are non-ambulatory, so that no part of our community is left behind at the moment of approval.

Alongside this scientific work, we are amplifying the patient's voice. BetterLife FSHD, our patient registry, lets us publish research on the real experience and unmet needs of people living with FSHD. We plan to revisit the community's Patient-Focused Drug Development report, explore an annual "state of FSHD" report grounded in registry data, and maintain regular communication with regulatory partners, so decision makers hear directly and consistently what this disease means for the people who live with it.

2. Patient readiness

The second priority is ensuring that patients and families are informed, connected, and prepared, both to take part in research now and to access treatment later.

Today, the Society offers many strong programs: Our Navigator program, BetterLife FSHD, Care Connector, local Chapters, and a dedicated volunteer network. Over the next three years we will connect these into one integrated system, so that someone newly diagnosed can move smoothly from a first phone call to education, community, research participation, and support.

A centerpiece of this work will be the **Patient Readiness Passport**, a tool to help individuals understand and organize what they'll need to be ready for trials and treatment. As diagnosis is a critical piece of patient readiness, the Society is supporting the validation and rollout of a next-generation genetic test, and working toward relaunching TestFSHD, our industry-sponsored testing program, so that more people can receive a confirmed diagnosis, which will be the first requirement for treatment eligibility. Other initiatives, such as confirming that the proper ICD 10 code is on medical records, and implementing awareness and outreach initiatives to verify that everyone living with FSHD is ready when a treatment is approved, will be implemented.

We're also building capacity for growth. New "FSHD Impact Teams" will build volunteer communities around each chapter and region, and we're working to identify and reach areas of the US where chapter support does not yet exist. When the surge in interest comes, we want someone ready to help every family who reaches out.

3. Provider preparedness

A treatment can only be prescribed by a physician who knows how to diagnose FSHD, identify eligible patients, and manage their care. Today, much of that expertise is concentrated among a relatively small number of neuromuscular specialists.

Our plan addresses this gap on several fronts. Collaborating with our Clinical Trial Research Network (CTRN) and industry members, we are conducting a clinical readiness survey to understand where the healthcare system is prepared and where it isn't. We will lead the development of consensus treatment guidelines, giving clinicians a trusted, shared reference

for FSHD care. Additionally, we are expanding education efforts to reach physicians beyond the neuromuscular specialty as well as working on innovative systems for our families to access treatments more efficiently.

4. Payor readiness

Even with approval and an informed physician, patients face one more hurdle: Coverage. Insurers and health systems will decide who can receive a new therapy and under what conditions. Communities that engage with payors early are better positioned to advocate for fair, evidence-based access.

We are laying that groundwork now. Through a formal request for information, we are gathering guidance from leading market access experts on how patient organizations can best prepare for the path from approval to coverage. A review committee will translate those insights into recommendations for our staff and Board.

We've been deliberate about timing. Our Board asked us to keep today's resources focused on research and regulatory work while approval is still ahead. But our plan is built so that the moment a company files for FDA approval, we can move immediately to scale up payor engagement, clinician education, and healthcare system readiness, with the groundwork already in place.

Building the foundation to deliver

None of this is possible without a strong, sustainable organization. Our plan includes growing our community and our donor base, pursuing grant funding, expanding grassroots events like our Walk & Rolls, as well as a small group of thoughtful, committed individuals pledging support over the next three years, ensuring we have the resources necessary to deliver on our goal of a treatment for everyone who needs it.

A plan that adapts

Drug development rarely follows a straight line. Trials can be extended, timelines can shift, and regulatory decisions can bring surprises. Our plan is designed to adjust, with clear triggers for when to accelerate investment and contingency plans for the scenarios we hope never happen. Whatever comes, we are committed to keeping you informed with honest, regular updates.

How you can help

The most powerful asset in this effort is our community. You can join BetterLife FSHD and share your experience to strengthen the evidence regulators see. You can connect with a local chapter or become a volunteer leader. You can take part in a Walk & Roll or join the small group of committed individuals pledging support over the next three years. And you can make sure your own care team knows about the FSHD Society and its resources.

Together, we are powering the path forward, toward the day when a treatment for FSHD is not only approved but within reach for everyone who needs it.





CLINICAL TRIALS: REFLECTIONS AND HIGHLIGHTS

BY GRAY MURANAGA & AMANDA HILL, FSHD SOCIETY

Year after year, we have seen the FSHD clinical trial landscape grow. In decades past, progress was undeniably slow and uncertain—but today, we are watching seven different therapies progress through clinical trials simultaneously. And even more are on the horizon.

Here, we've consolidated all major clinical trial updates from the past six months, since our the last issue of the *FSHD Advocate*. This information is current as of September 2026.

Novartis del-brax (Avidity AOC 1020)

How it works: Silences DUX4 by degrading DUX4 mRNA

May 2026: Completed enrollment at study sites in the United States of the Phase 3 FORTITUDE clinical trial, designed to confirm Phase 1/2 findings and support regulatory approvals globally.

June 2026: Announced that del-brax met the primary and key secondary endpoints in the biomarker cohort of the Phase 1/2 FORTITUDE clinical trial; participants receiving del-brax showed reductions in KHDC1L, a biomarker linked to *DUX4* activity, as well as reductions in creatine kinase, a marker of muscle damage. Also announced that Novartis is engaging global regulatory bodies on the Phase 1/2 data.

Del-brax is the first therapy in clinical trials to directly target *DUX4*, and it appears to have the potential to slow or even halt disease progression. Looking ahead, we're eager to see the full Phase 1/2 data and whether Novartis will pursue accelerated approval in the US or wait until Phase 3 data are available.

Sarepta SRP-1001 (Arrowhead ARO-DUX4)

How it works: Silences DUX4 by degrading DUX4 mRNA

March 2026: Shared preliminary Phase 1/2 trial data showing a favorable safety profile and that a single dose of SRP-1001 reduced *DUX4*-regulated genes by at least 90% and reduced creatine kinase levels by 33%.

Sarepta's SRP-1001 is an exciting development: The second therapy to enter clinical trials specifically targeting *DUX4*, its Phase 1/2 trial began in 2024. We look forward to seeing the full Phase 1/2 data.

Epicrispr EPI-321

How it works: Silences DUX4 by methylating the D4Z4 DNA repeat region

June 2026: Presented preliminary Phase 1/2 clinical trial data showing early signs of disease improvements, such as increased muscle volume, improvements in strength and function, and novel biomarker ($DUX4_z$) decreases in 3 to 5 participants.

Epicrispr's gene therapy approach and clinical trial launch represent a major milestone in FSHD drug development. Looking ahead, we are excited to see additional data from this trial.

Scholar Rock apitegromab (SRK-015)

How it works: Supports muscle growth by blocking myostatin

August 2026: Announced the start of enrollment and dosing in their Phase 2 FORGE clinical trial at the first study site.

Apitegromab has been studied for more than four years in patients living with spinal muscular atrophy (SMA) and was recently approved as an add-on therapy for SMA patients receiving a targeted therapy. We are interested in learning its results in FSHD patients, and we are excited for this trial to complete enrollment and to see the first data.

Additional highlights:

- **Soufflé Therapeutics** announced plans to launch a Phase 1/2 clinical trial in 2026 for SFL-0821, an infusion therapy designed to silence *DUX4* by degrading DUX4 mRNA. Soufflé is already working on an injectable form of the therapy.
- **Altay Therapeutics** announced plans to launch a Phase 1 clinical trial in 2026 for DX5057, an oral therapy designed to block *DUX4* by degrading the DUX4 protein.
- **Satellos Bioscience** announced its plans to launch a Phase 1 clinical trial in 2026 for SAT-3247, an oral therapy designed to support muscle repair and regeneration by stimulating stem cell division.
- **Dyne Therapeutics** announced plans to launch a Phase 1 clinical trial for DYNE-302, an infusion therapy designed to silence *DUX4* by degrading DUX4 mRNA.

Metrics:

16+ therapies in early stages of research and development

6 therapies in Phase 1 and 2 clinical trials

1 therapy in Phase 3 clinical trials

3 therapies in clinical trials that were developed specifically to silence *DUX4*

Learn all you need to know about clinical trials at *fshdsociety.org/research-and-clinical-care/research-and-clinical-trials/clinical-trial-education/.*

Check out our current drug development pipeline at *fshdsociety.org/research-and-clinical-care/research-and-clinical-trials/drug-development-pipeline/.*

CLINICAL TRIAL SNAPSHOT

FORTITUDE Phase 3 trial sponsored by Avidity Biosciences



To learn about clinical trial phases, visit *fshdsociety.org/clinical-trials/*.

For easy-to-understand details about each trial, visit *fshdsociety.org/research-and-clinical-care/current-trials-and-studies/*.

The information shared here is accurate as of October 2026. For status updates on specific locations, search on trial keywords at *clinicaltrials.gov*.

An open-label extension (OLE) is a study in which participants of a placebo-controlled trial are offered the option to continue to be studied after the trial has been completed. All participants in the OLE receive the active drug, so the study is no longer blinded or placebo controlled.

Quick Facts

Drug	Del-brax (AOC 1020)
How Is It Given?	Intravenous infusion
Phase	3
Participants	200
Placebo	Yes, 1:1
Genetic Testing	Required, provided by study
Rx Schedule	13 doses
Study Visits	~20, some may be virtual
Notable Activities	Strength & functional testing
Open-Label Extension	Yes

Eligibility

- Age 16–70; 18–70 only in EU countries
- FSHD1 or FSHD2
- Able to walk independently (without using a cane/walker) for approximately 10 meters
- Has sufficient total body muscle strength

Status

- Currently enrolling
- Locations: US, UK, Canada, the EU, & Japan
- Data expected in Q3 of 2028
- Trial ID: NCT07038200
  Fortitude-Study.com

FORTITUDE-3™

What you can do to be trial-ready

These steps will reduce delays and improve your chances of enrolling in a trial. You will also need to meet the eligibility criteria for the specific trial. There's no guarantee, as many factors must be considered in selecting people for a trial, but these measures can help.

- Make sure you have been diagnosed by a doctor.
- Get a genetic test confirming FSHD.
- Become a patient at an FSHD Clinical Trial Research Network location.
- Enroll in the MOVE or MOVE+ study.
- See your neurologist every year.
- Follow exercise recommendations and be as healthy as possible.
- Sign up to get FSHD Society email alerts.

Learn more:

CLINICAL TRIAL SNAPSHOT

Apitegromab (SRK-015) Phase 2 trial sponsored by Scholar Rock

Quick Facts

Drug	Apitegromab (SRK-015)
How Is It Given?	Intravenous infusion
Phase	2
Participants	60
Placebo	Yes, 1:1
Genetic Testing	Required
Rx Schedule	Every 4 weeks for 52 weeks
Study Visits	13 in-person
Notable Activities	MRI, strength & functional testing
Open-Label Extension	Yes

Eligibility

- Age 18-60
- FSHD1 or FSHD2
- Ricci score 1.5-3
- Able to walk 10 meters within 5 seconds

Status

- Currently enrolling
- Locations: US
- Data expected: N/A
- Trial ID: NCT07435129

Scholar Rock

SRP-1001 trial sponsored by Sarepta Therapeutics and Arrowhead Pharmaceuticals

Quick Facts

Drug	SRP-1001 (formerly ARO-DUX4)
How Is It Given?	Intravenous injection
Phase	1/2a
Participants	72
Placebo	Yes, 3:1
Genetic Testing	Required, provided if needed
Rx Schedule	Part 1: duration 3 months Part 2: 4 doses over 1 year Part 2 (C7): 5 doses over 1 year
Study Visits	~20
Notable Activities	MRI, leg muscle biopsy
Open-Label Extension	Yes, if warranted by study results

Eligibility

- Age 16-70
- FSHD1
- Clinical Severity Scale 3-8
- Must have leg muscle suitable for biopsy & be able to do MRI

Status

- Currently enrolling
- Locations: New Zealand, Australia, Canada, Europe, Thailand
- Data expected: TBD
- Trial ID: NCT06131983

SAREPTA THERAPEUTICS

arrowhead pharmaceuticals

CLINICAL TRIAL SNAPSHOT

EPI-321 trial sponsored by Epicrispr Biotechnologies

Quick Facts

Drug	EPI-321
How Is It Given?	One-time Intravenous (IV) dose
Phase	1/2
Participants	12
Placebo	No
Genetic Testing	Required, provided by study
Rx Schedule	One-time dose
Study Visits	Regular tests & checkups for ~5 years after receiving dose
Notable Activities	MRI, skeletal muscle biopsies, strength & functional testing
Open-Label Extension	N/A

Eligibility

- 18 to 75 years of age
- FSHD1
- FSHD Ricci clinical severity score 2 to 4 (on 5-point scale)
- Adequate vital organ function
- Must be able to do MRI and skeletal muscle biopsies

Status

- Enrollment is complete. Study is active.
- Locations: US, New Zealand, Australia
- Data expected: October 2026
- Trial ID: NCT06907875

epicrispr™ biotechnologies

FORTITUDE Phase 1/2 trial sponsored by Avidity Biosciences

Quick Facts

Drug	Del-brax (AOC 1020)
How Is It Given?	Intravenous infusion
Phase	1/2
Participants	90
Placebo	Yes, 2:1
Genetic Testing	Required, provided by study
Rx Schedule	8 doses
Study Visits	~15, some may be virtual
Notable Activities	MRI, leg muscle biopsy
Open-Label Extension	Yes

Eligibility

- Age 16–70
- FSHD1 or FSHD2
- FSHD clinical score of 2–14
- Able to walk 10 meters without assistance
- Reachable Workspace score
- Must have leg muscle suitable for biopsy & be able to do MRI

Status

- Enrollment complete. Study is active.
- Locations: US, UK, Canada
- Data expected in Q2 of 2026
- Trial ID: NCT05747924

AVIDITY BIOSCIENCES
A Novartis Company

CLINICAL TRIAL SNAPSHOT

Clenbuterol by University of Kansas

Quick Facts

Drug	Clenbuterol
How Is It Given?	Orally
Phase	1
Participants	30
Placebo	No
Genetic Testing	Required (for participant or first-degree relative)
Rx Schedule	Twice daily for 6 months
Study Visits	5 in-person and 1 follow-up call
Notable Activities	MRI, leg muscle biopsy
Open-Label Extension	No

Eligibility

- Age 18–75
- FSHD1 or FSHD2
- Clinical severity score 1 to 4
- Must be able to walk 30ft unassisted
- Must be able to do MRI

Status

- Currently enrolling
- Locations: US (Kansas, New York, Washington)
- Data expected in 2028
- Trial ID: NCT06721299

KU THE UNIVERSITY OF KANSAS

Restem-L trial sponsored by RESTEM

Quick Facts

Drug	Restem-L
How Is It Given?	Intravenous infusion
Phase	1
Participants	16
Placebo	Yes, all participants receive 2 doses of Restem-L and 2 doses of placebo
Genetic Testing	Required
Rx Schedule	4 doses over 9 months
Study Visits	11 in-person and 5 virtual
Notable Activities	Blood tests, MRI, heart and lung tests, functional tests, physical exam, and questionnaires about symptoms, daily activities, pain, and overall well-being
Open-Label Extension	No

Eligibility

- Age 15 and older
- FSHD1 or FSHD2
- Ricci score: ≥ 1.5 on the Ricci Clinical Severity Scale (range 0–5)
- Able to walk without support
- Must be able to do MRI
- Reduced upper arm strength

Status

- Currently enrolling
- Locations: US (California)
- Trial ID: NCT07086521

RESTEM

GOVERNMENT FUNDING IS KEY TO ADVANCING DRUG DEVELOPMENT

BY KEVIN BRENNAN, BLUEBIRD STRATEGIES, & ANNA SYLVESTER, FSHD SOCIETY



Over the past decade, National Institutes of Health (NIH) research funding for many chronic and common diseases doubled and even tripled, while rare diseases like FSHD experienced flat funding. A 2023 study by researchers at Bentley University, US, reported a strong correlation between federal biomedical research funding on higher-risk, basic science and an increase in later-stage private sector investment in drug development, clinical trials, and drug commercialization. Put simply, when the government invests in medical research, drug companies follow suit, and everyone wins. While the FSHD Society continues to urge Congress to increase NIH funding for FSHD research, in 2025 we launched an exciting new advocacy campaign to increase FSHD research funding as part of a unique Defense Department program, the Peer Reviewed Medical Research Program (PRMRP).

In our first year of advocacy, we succeeded in securing a provision in the fiscal year 2026 Defense budget that makes FSHD research eligible for funding as part of the $370 million PRMRP budget. Following passage of the budget, the FSHD Society has worked closely with PRMRP program staff to prepare for this exciting opportunity, and has recommended consumer reviewers who now serve on PRMRP peer review panels. We already know of several grant applications that have been submitted for FSHD-related projects. PRMRP is finalizing this grant cycle, and grant awards will be announced soon, likely in January.

Our success is the direct result of citizen advocates from across the United States building awareness and urging Congress to increase support for FSHD research. Congress has not yet completed work on this year's budget funding the NIH and determining disease eligibility under PRMRP. We anticipate that Congress will pass a full-year budget sometime in December. It is important that the FSHD community continue to pressure their elected officials to make medical research funding a top priority. Keep an eye out this fall for advocacy calls to action! When we speak with one voice, we can create lasting change. Thank you for all of your efforts!

WE CANNOT WAIT

Early-onset FSHD families bring their voices to the FDA

BY ALLY ROETS & SARA VASQUEZ

On July 1, 2026, the FSHD community made history with a powerful message to the U.S. Food and Drug Administration (FDA): Those living with early-onset FSHD cannot afford to wait. For the first time, an FDA listening session focused specifically on early-onset FSHD, bringing the voices of those living with the most severe forms of the disease directly to regulators.

The session marked the fourth formal interaction between the FSHD community and the FDA, but the first dedicated to early-onset FSHD. The panel included three teenagers, two young adults, and two caregivers of children living with childhood- or early-onset FSHD, and the session was attended by 35 representatives from all four divisions of the FDA.



Justin (panelist)

Why it matters

An FDA listening session is an opportunity for patients and families to share what it is really like to live with a rare disease.

For families affected by FSHD, this is especially important, as these patients are routinely excluded from clinical trials because of their age, disease stage, or level of disability. Their voices can help the FDA understand what those exclusions mean in real life: Lost time, fewer options, and disease progression while waiting for access to a potential treatment.

The session

For families living with early-onset FSHD, time is measured in muscle. Every day without treatment can mean losing strength, mobility, independence, and the ability to do things most people take for granted. Yet there is still no FDA-approved therapy that slows muscle loss or stops disease progression.

One panelist described the reality bluntly: “Nothing we can do.... No meaningful treatment options. No roadmap. No relief. Only progression.”

All seven panelists said they would participate in an FSHD clinical trial. Still, participation is often blocked, not by lack of interest but by the rules of the trials themselves. Sam captured the impossible cycle: “We’re excluded when we’re younger because of age. Then, when we’re older, because of disease severity. We’re caught in a system that never gives us a chance.”

Maggie knows that frustration firsthand. Hoping to preserve her remaining strength, she pursued a clinical trial but was told she did not qualify because she “moved too fast” during a functional

test. “My arms barely move. My muscles hurt. I push through fatigue and nap often…. And somehow … I was not affected enough.”

What do patients actually want from a treatment? Not perfection. They want to keep what they have. “I hope to receive a treatment soon so I can keep the function I still have,” Maggie said. Kate expressed the urgency felt by so many: “I don’t have time to wait for a perfect future. I need a world—and treatments—that can keep up with me today.”

The consequences of progression can be severe. Justin described scoliosis that compromised his lung capacity and required spinal surgery, followed by respiratory failure that nearly took his life. For parents, the fear is profound. Vera spoke of the unimaginable question, “Who will care for my daughters if something happens to us?” Angela shared the devastating experience of watching her daughter Alyssa suffer respiratory distress, go into cardiac arrest, and ultimately making the decision to remove her from life support one week later.

These are not abstract measures of disease progression. They are lived realities that underscore the urgency of intervening before irreversible muscle and respiratory function are lost.



Sara (panelist)



Kate (panelist)

Sara’s journey

I’m Sara and I was diagnosed with FSHD when I was about seven years old. The most recent challenge I’ve encountered because of muscular dystrophy started five years ago when I got spinal fusion surgery. All of my vertebrae except the bottom three were fused together with titanium screws and rods to correct what was a painful case of scoliosis, and to prevent the collapse of my right lung. I’m quite grateful for this surgery; it’s allowed me to move throughout the world with much less pain, but there are always tradeoffs. I spent nearly two weeks in the hospital recovering, when the norm is a five-day stay. Being sedentary, I lost a lot of muscle function. After the surgery I could no longer get up from the floor unassisted, and because of weakness in my hips I was left with a gait akin to a waddle.

It was an excruciating five months until I was fully recovered. I spent a lot of time waiting. Waiting for confidence. Waiting to feel comfortable enough

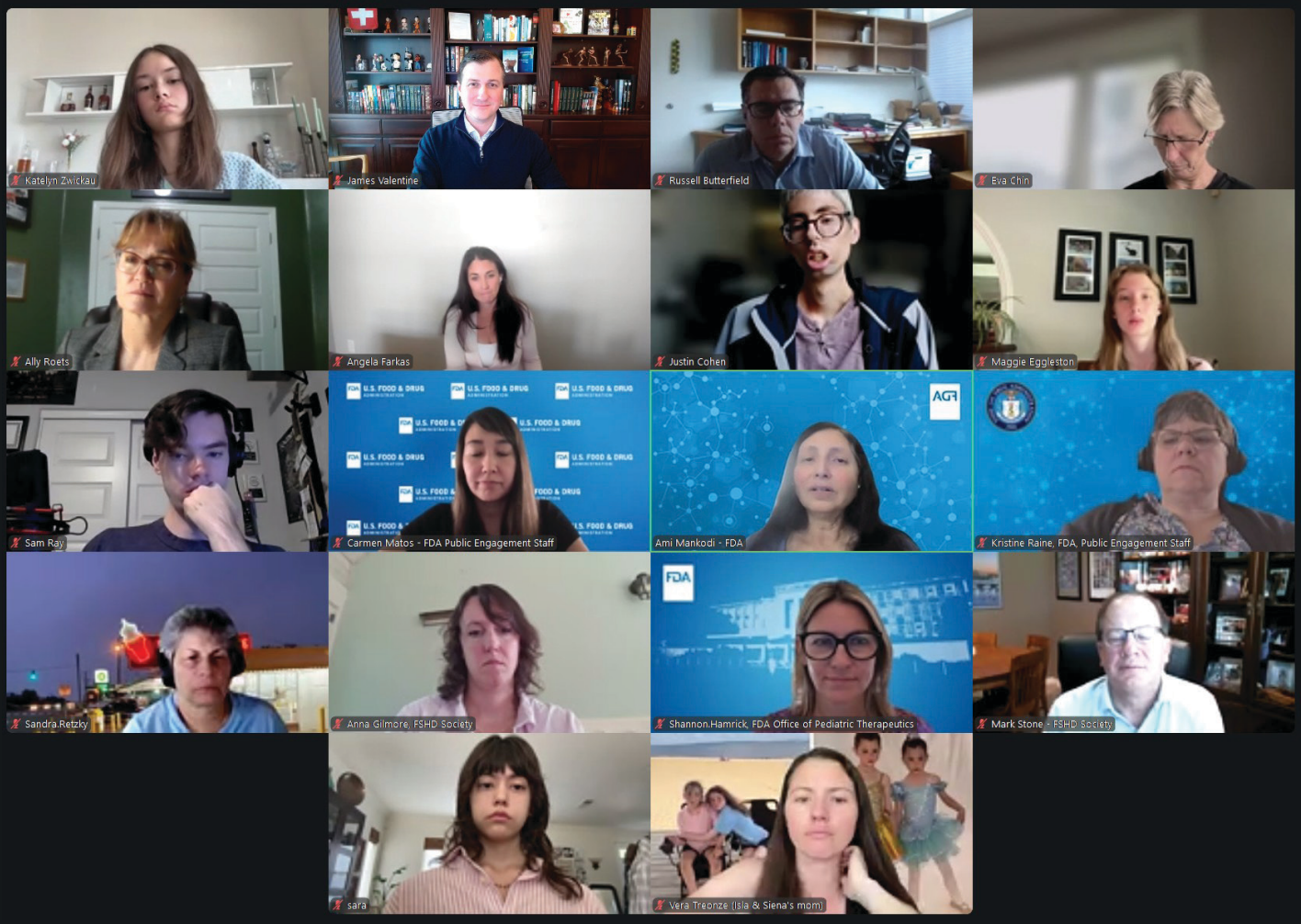
to use my new mobility scooter. Waiting for the stares to decrease. Being comfortable in my new body wasn't something I could wait for. The stares will never stop.

So slowly my philosophy shifted, and into it I wove three unbreakable threads. One, the lordosis is better than the burning pain of scoliosis. Two, confidence is a practice to be built, not some passive emotion. And three, give them something to stare at! So slowly I became fond of the scar down my back. I started addressing myself with high esteem, and I dressed myself exactly how I wanted, but this new approach to life doesn't change the fact that I don't want my muscles to keep dying.

For those who attended the listening session and will read the summary report, I want to make sure they understand I don't want to be praised for how strong I am. I don't want my only choice for my lifestyle to be dependence. What I truly want, for me and my community, is a cure.

Being heard isn't enough

The listening session and the patients' and caregivers' stories are an important first step, but listening is only the beginning. The hope of the families who spoke that day is that their stories will help turn awareness into action and ensure that when the next FSHD treatment reaches the clinical-trial stage, early-onset individuals will have a place at the table.



10 TIPS FOR LIVING WELL WITH FSHD FROM THE 2026 INTERNATIONAL RESEARCH CONGRESS

BY ASHLEY FERREIRA

Currently, there are no approved medication-based treatments for FSHD, but that doesn't mean there aren't other ways to manage symptoms. At the 2026 International Research Congress on FSHD (IRC) in Chicago, Dr. Enza Leone, a research physiotherapist from University College London Hospitals, shared her "10 Top Tips" for managing FSHD without drugs, which provide practical ways for individuals to manage their symptoms, stay active, and feel their best. Her tips were built from real research, clinical experience, and, most importantly, input from people living with FSHD and their caregivers.

Here are the tips that Dr. Leone shared.

1. **"Use it or lose it":** Staying active every day and keeping your body moving are two of the most important things you can do. Even small amounts of daily activity can help you maintain strength and flexibility over time.
2. **Exercise regularly and mix it up:** Strength training, aerobic exercise, stretching, water-based exercise, yoga, and Pilates can all be helpful. One person with FSHD shared that aqua fitness was a favorite because it's gentle and safe, even when balance is a concern.
3. **Make exercise personal:** There is no one-size-fits-all approach. The right exercise plan for you depends on your goals, your current abilities, your energy level, and your lifestyle. Work with a healthcare provider to build a practice that fits you.
4. **Listen to your body:** Pay attention to how your body responds to activity. Muscle soreness should go away within 24 hours. Don't exercise through pain. If fatigue is affecting your daily life, that's a sign to ease up. Watching for these signals helps you stay safe.
5. **Manage pain with gentle therapies:** Massage, heat therapy, stretching, hydrotherapy, yoga, and Pilates can all help reduce pain and muscle tension. Orthotic devices and adjusting how you sleep may also help.
6. **Fight fatigue with smart strategies:** Instead of pushing through exhaustion, try "exercise snacking"—short bursts of movement spread throughout the day. Rest, good sleep, pacing yourself, and planning your tasks wisely can all make a big difference in your energy levels.
7. **Take care of your mental health:** Living with FSHD affects more than the body—it can take an emotional toll, too. Approaches like mindfulness, cognitive-behavioral therapy, and acceptance and commitment therapy can be helpful. FSHD-specific psychological support is recognized as an important part of quality care.
8. **Stay connected with your care team:** Don't wait until things get really hard to reach out. Having a go-to contact (someone you can call when something changes) can prevent small problems from becoming big ones. Good communication with your care team matters.

9. **Know your resources:** At diagnosis and beyond, it's important to know where to turn. Patient registries, peer support groups, patient advocacy organizations like the FSHD Society, and educational resources are all there to help you and your caregivers navigate life with FSHD.
10. **Talk to your doctor early about shoulder surgery:** If you experience scapular winging (shoulder blade sticking out), don't wait too long to have a conversation about surgical options. According to specialists, the window for shoulder stabilization surgery can close if you wait until function is severely limited. Early conversations with your care team are key.

Why this matters

These tips weren't developed in a lab—they came from a large research effort that included observations at five UK neuromuscular centers, surveys of nearly 200 adults with FSHD, and focus groups with patients, caregivers, and healthcare professionals. That means they reflect the real-world experiences of people like you.

Dr. Leone's goal is to make these tips available as educational tools for both clinicians and the FSHD community so that more people have access to practical, evidence-based guidance.

Want to learn more?

Join us for an upcoming FSHD University webinar on Thursday, November 19, at 1:00 p.m. ET, where Dr. Leone will discuss these tips in detail and answer your questions. You can also discover resources on our website to help you navigate your FSHD journey.



Dr. Enza Leone

WHAT HAPPENS AFTER A TREATMENT GETS FDA APPROVED?

BY ASHLEY FERREIRA

If you or someone you love has FSHD, you've probably heard this question a lot: "When will there be a treatment?" It's a fair question, but there's a piece of the story that often gets left out. Getting a treatment approved by the FDA will be a huge milestone, and one that we look forward to celebrating as a community. But this milestone will actually be the start of a new set of steps before someone can hold that treatment in their hands.

We don't know exactly when a treatment for FSHD will be approved, and no one can promise a date. But we do know what usually happens after approval, based on how other new treatments have rolled out for different diseases. Understanding these steps now can help you and your family feel less caught off guard later—and there are things you can do today to make the process smoother when the time comes.

Approval doesn't mean "available tomorrow"

When the FDA approves a new treatment, it means the treatment has been tested and shown to be safe and effective enough to be sold. But before a treatment reaches a pharmacy shelf or an infusion center, a few more things typically need to happen.

1. Getting to market: After approval, a company usually needs some time to actually start manufacturing and distributing the treatment. This step can take anywhere from a couple of months to closer to a year, depending on the treatment.
2. Insurance coverage decisions: Insurance companies—including Medicare and Medicaid—have to decide how they'll cover a new treatment and what the rules will be. This can take several months.



3. Prior authorization: After insurance agrees to cover a treatment, your doctor usually has to submit paperwork proving you meet the requirements before insurance will pay. This step alone can take a month or more.
4. Appeals, if needed: Sometimes prior authorization gets denied the first time. If that happens, appealing the decision can add more months to the process. Missing paperwork is one of the most common reasons for delays here—which is exactly why getting your records in order now matters.
5. Filling the prescription: Many new treatments are handled through specialty pharmacies rather than a regular drugstore, which can add more time.
6. Scheduling: Depending on how the treatment is given—a pill, an infusion, an injection—there may be a wait to schedule your first dose depending on patient capacity.

Put together, these steps can add up to many months after approval before someone receives treatment. That's not a reason to lose hope—it's simply how the system works for most new treatments, and it's important to know so you're not blindsided.

What you can control right now

Here's the encouraging part: A lot of what causes delays is avoidable, and you have real power to get ahead of it. While there are steps that are out of your control, such as market approval and insurance coverage decisions, there are tasks that you do have control over.

Getting genetically confirmed, finding a neuromuscular specialist, and keeping your medical records current won't speed up the FDA or insurance companies. But it can keep you from losing extra months to missing paperwork or not having a doctor in place yet.

Wait times to see a neuromuscular specialist can already run 6 to 18 months or longer, and they're expected to get even longer once a treatment is approved and demand goes up. Getting on a specialist's schedule now, rather than waiting for an approval announcement, is one of the most concrete things you can do today.

Nobody can currently tell you exactly when a treatment will be approved, or exactly how long each step after approval will take—every treatment is a little different. What we do know is that preparation now shortens the distance between "approved" and "in your hands." That's something you have real control over, starting today.



MILES THAT ADD UP

Our community turned personal passions into fundraisers this summer, and the mission went along for the ride.

BY SAMANTHA SCHNEIDER, FSHD SOCIETY



Not every fundraiser starts with a route and a registration table. Some start with a race entry. Some start with a recipe, a tee time, or a fire pit.

This summer, our supporters raised money for FSHD research however they knew best: A chili cook-off, a golf tournament, an annual music festival, a sip and s'more gathering, a golf scramble hosted by a local firefighters' association, among many others. Each one gathered a crowd that showed up for the fun first and left knowing what FSHD is (if they didn't already).

There was endurance, too. At August's Falmouth Road Race, our team of five took on seven hilly miles along the Cape Cod coast and raised nearly $15,000.

Movement matters for muscle, and research in FSHD suggests moderate activity is safe and beneficial for many people. For a growing number of our supporters, staying active and supporting the search for a treatment have become the same effort.

That's the quiet power of a Do-It-Yourself fundraiser: It fits almost any idea and is an opportunity for any age to get involved with the FSHD community and our mission. A race, a ride, a cook-off, a concert, a birthday, or a challenge of your own design can make a big impact.

Thank you to everyone who cooked, played, drummed, ran, and pushed their limits this summer!

Ready to turn your next idea into a fundraiser that helps to power the path forward? Visit *fshdsociety.org/get-involved/how-to-help/ways-to-give/fundraise-your-way/.*





VOLUNTEER SPOTLIGHT

Meet Holly Duckworth—Leader, Colorado Walk & Roll to Cure FSHD

Tell us about yourself—your interests, your passions, and your relationship to FSHD.

I'm passionate about philanthropy, volunteering, and giving back wherever I can. When I'm not volunteering, you'll often find me enjoying music and dancing, riding my e-bike, exploring the beautiful Colorado Rocky Mountains, or traveling and experiencing new places. My relationship with FSHD is deeply personal. I was diagnosed in 2005, but FSHD has been part of my family for generations. My mother and her brother both had FSHD, and we believe my grandmother and great-great-grandfather were also affected. That family history has made supporting the FSHD community and the search for treatments and a cure especially meaningful to me.

What is your first memory of volunteering with the FSHD Society?

My first memory of volunteering with the FSHD Society was during COVID, when so much of our connection happened through Zoom. I had the opportunity to guide participants through a discussion on stress management. It was a meaningful experience to connect with others in the FSHD community during such an uncertain and isolating time.

How have you evolved as a volunteer?

My volunteer journey has grown into a leadership role. This year, I stepped into the role of Colorado Walk & Roll Coordinator, bringing with me many years of leadership, event planning, and fundraising experience from other philanthropic organizations. It has been incredibly rewarding to put those skills to work for a cause that is so deeply personal to me, and to help bring our FSHD community together.

How do you feel volunteering has changed your perspective?

Volunteering has empowered me and given me a sense of control over a disease that can otherwise leave you feeling powerless. FSHD can take things from you at any given time, but volunteering gives me a way to fight back. It makes me feel like I'm helping move the needle forward—raising awareness, funding research, and holding onto hope that there will be a treatment in my lifetime.

Tell us about your recent volunteer role involving The CO Walk & Roll to Cure FSHD, and how it came to be.

In February of this year, Beth Johnston and Amanda Hill approached me about becoming the Colorado Walk & Roll Coordinator. I had to give it some thought because living with FSHD means always asking, "Will my body do what my mind wants to do?" I have to be realistic about what I commit to, no matter how much my heart wants to say yes. Fortunately, after 11 years, the Colorado Walk & Roll is a well-oiled machine. My focus was largely on engaging volunteers, empowering them in their roles, and making a few thoughtful improvements. I learned so much this year and already see opportunities to make the Walk & Roll even stronger in 2027.



What would you tell someone thinking about getting more involved?

I would say absolutely give it a try. Whether you participate in person or through a Zoom meeting, connecting with others who truly understand FSHD is incredibly powerful. You gain knowledge about the disease that you may never find online or even get from your doctor, while feeling less isolated and becoming part of a community. We learn so much from one another, and I believe that shared knowledge and connection are where real growth—and ultimately breakthroughs—can happen.

ONE COMMUNITY, 30 STARTING LINES

BY SAMANTHA SCHNEIDER

Nearly 30 events. About 60 volunteer leaders. Over 2,000 people moving together for a cure.

Some Walk & Roll events draw 15 people to a park on a Saturday morning. Others fill a local park with 250 participants. The same thing happens at each one: For the first time someone meets another family living with FSHD, a team captain hugs a donor she's only ever emailed, and people who spent the year feeling like the only ones on this journey are no longer alone.













This season, the Walk & Roll to Cure FSHD brought our community to nearly 30 locations across the United States and Canada. Together, more than 2,000 participants raised $1.27 million to fund research, accelerate treatments, and support families living with FSHD.

Each Walk & Roll brings people together around a shared purpose. For some families, it is a chance to meet others who understand the realities of living with FSHD. For others, it is an opportunity to reconnect with friends they have made through the community, share experiences and practical advice, and introduce coworkers, neighbors, and extended family to a disease they may know little about. Along the way, participants also raise critical funds to advance FSHD research and support programs and resources for the community.



The name Walk & Roll reflects the community itself. People participate using wheelchairs, walkers, scooters, canes, strollers, sneakers, and whatever works for them. There is no single way to take part. What matters is coming together, showing up for one another, and moving the FSHD community forward.



That momentum comes from the people who make Walk & Roll possible: Passionate volunteer leaders, team captains who continue to reach out to their networks, and thousands of community members who give what they can. Their time, energy, generosity, and commitment bring these events to life in communities across the United States and Canada. The Walk & Roll simply wouldn't be possible without them.

Thank you for making this Walk & Roll season one to remember!

Want to help plan a Walk & Roll or get even more involved? Visit *fshdsociety.org/walkroll*.



WHAT HAPPENS WHEN THE WORLD COMES TOGETHER?

Introduction

In June, the FSHD community came together to raise awareness; share research updates, announcements, and new findings; and celebrate the resilience of people living with FSHD. Just as importantly, it was a chance to learn, reconnect, laugh, and create lasting memories.

World FSHD Day

On June 20, 2026, the FSHD community around the world flooded the Internet, and plenty of streets, in orange. This year marked the 10th anniversary of World FSHD Day—here's to 10 years of advocacy and resilience!

World FSHD Day in the US and Canada

In Canada, buildings, monuments, and landmarks in each province were lit up in orange, including Niagara Falls, the Sails of Light, the Ottawa sign, and multiple city halls. Our chapters in British Columbia and Alberta hosted community gatherings, and the Ontario Chapter led a popular social media awareness campaign.

In the United States, community members gathered together in St. Louis, Colorado, Atlanta, North Carolina, Philadelphia, the Pacific Northwest, and Chicago. Additionally, the governors of Michigan and New Jersey signed proclamations recognizing June 20 as World FSHD Day. And more than 20 buildings were lit up in orange, including various office buildings and the Catlow Theater in Barrington, Illinois; the King and Queen Towers in Atlanta; and the James S. McDonnell Planetarium in St. Louis.

International Awareness and Celebration

Around the world, our international community gathered to celebrate and raise awareness.

- FSHD Finland—Rami Jokinen and the Beat FSHD Combo released *Feel Free to Beat FSHD*, a rock anthem and a call to action
- ABRAFEU—Christ the Redeemer, one of the new Seven Wonders of the World, and the Brazilian Parliament Building were lit up in orange
- FSHD Japan—the Marine Tower was lit up in orange

- FSHD Spain—more than 215 sites were lit up in orange and a number of city buses used their marquees to inform riders about World FSHD Day

International Research Congress

Researchers from across the globe gathered in Rosemont, Illinois, on June 25-26 for the 33rd annual International Research Congress (IRC) on FSHD. The two days focused on three pressing topics—biomarkers of disease activity and progression, clinical care progress, and disease mechanisms—and included:

- 250 in-person and virtual attendees
- 28 pharmaceutical companies
- 36 presenters
- 91 posters

The message we brought home is that FSHD research is advancing rapidly, filled with hope and new discoveries that keep us moving forward.

One of the valuable presentations was on data from Roche's emugrobart clinical trial. This was the FSHD research community's first opportunity to view the completed trial data, which showed that blocking myostatin might be beneficial, but the results were not strong or consistent enough to meet the trial's endpoints. Nevertheless, the research community can still learn from this trial data; for one, the discussion among the researchers in the room suggested that myostatin inhibitors may be most helpful as a secondary therapy after stopping disease progression.

IRC attendees also received preliminary data from ongoing clinical trials, leaving us eager to see data from the completed studies to determine whether these early findings are sustained in more participants and over longer periods of time:



2026 Young Investigator Award Winners Dr. Nizar Saad (left) and Dr. Elvira Ragozzino (center) with Dr. Lucienne Ronco (right)



2026 Community Hero Award Winner, Ranae Beeker



- Sarepta's SRP-1001 trial showed early evidence of a strong reduction in *DUX4*.
- Epicrispr's EPI-321 trial presented early signs of increased muscle volume and improvements in strength and function.

We were also privy to several exciting announcements:

- Soufflé, Altay, and Satellos shared encouraging preclinical data and stated their intentions to launch new clinical trials by the end of 2026.
- With the help of participants at our FSHD Patient Connect Conference in 2024, Dr. Sujatha Jagannathan of the University of Colorado identified a potential new biomarker, ZBTB17 (which they call "$DUX4_z$").

Every precious moment that we spent knowledge-sharing, absorbing, and connecting reminded us how far FSHD research has come, how much there is still to learn, and how



Emma Weatherley of FSHD Global (left) and Ray Jordan



Dr. Russell Butterfield, University of Utah

continued collaboration among researchers, clinicians, industry, and the patient community will be essential to turning today's promising research into meaningful treatments for people living with FSHD.

FSHD Connect

The Future in Motion: A Reflection on the 2026 FSHD Connect Conference

From June 26 to 28, the FSHD community came together at the Hyatt Regency O'Hare in Rosemont, Illinois, for the 2026 FSHD Connect Conference, and the energy in the room said it all. More than 220 patients, caregivers, researchers, clinicians, and advocates gathered under the theme *The Future in Motion: Empowerment, Connection, and Care for Life with FSHD*.

The conference opened Friday evening with a joint reception alongside the International Research Congress on FSHD, bringing together two communities united by a shared mission. From there, the weekend unfolded across three full days of programming. Saturday's breakout sessions offered three distinct tracks, giving participants the flexibility to personalize their experience and explore topics most relevant to their lives. Sunday's plenary sessions turned toward the future, with highlights including an industry panel on the path to treatments that generated much engagement. One attendee noted, "The industry panel could have been two hours [instead of one]—the number of questions and interest were amazing!"

This year's conference also featured dedicated programming for the early-onset community, including a youth program with art activities, a careers panel, an escape room, and a trip to the Shedd Aquarium, creating meaningful space for children, teens, and their families to connect with peers who truly understand their experience.

For the Chicagoland Chapter, hosting Connect in their own backyard was a moment they won't soon forget. Co-directors Mary Mauch and Suzy Kosten reflected warmly, "The FSHD Society gave each of us something we didn't know we needed until we found it: A place to belong. A place where

you don't have to explain yourself, where someone across the room just gets it."

That sentiment echoed throughout the weekend. Attendees shared that the experience was transformative, not just for the knowledge gained, but for the connections made. "I had a wonderful time. It was great talking and sharing information with people from all over—it was just nice to feel comfortable and not like the odd man out," one participant shared. Another added, "My family and I really look forward to this event. Seeing others who live with this disease is motivational and provides a real sense of community."

The 2026 FSHD Connect Conference reminded us that progress in FSHD isn't driven by science alone—it is powered by every person who shows up, shares their story, and carries this community forward. The future is still in motion, and so are all of us.





Early-onset advocates Ally Roets, Kristin Zwickau, and Debbie Eggleston

In case you missed it...

There's always more to learn about FSHD. Check out these recent podcast episodes, webinars, and conversations on our YouTube channel:

- FSHD School Guide for Educators—Understanding & Supporting Students with FSHD
- Rethinking Fashion through FSHD with Vasiliki Charitonos on FSHD Straight Talk
- Navigating Women's Health with FSHD, FSHD University
- Tiny Desk Concert: Gracie Caggiano, FSHD Straight Talk
- Travel the World without Limits: Traveling with FSHD, FSHD University

YouTube

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YEAR-END GIVING REMINDERS—MAKE AN IMPACT TODAY!

Every donation helps us maintain momentum in the fight against FSHD. Give your way today!

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Please make checks payable to FSHD Society

- Scan the QR code or visit *fshdsociety.org/advocategiving26* to make a secure gift online.
- For gifts of stock, donor-advised funds, EFT, or IRA charitable distributions, please contact us at (781) 301-6058.

Become a Torchbearer

Join our monthly giving program and add reliable, year-round strength to our financial ability to keep all our FSHD initiatives on track. A uniquely impactful team of supporters, Torchbearers make an individual difference and, collectively, contribute more than $60,000 annually—an impact few of us can make alone. Visit *give.fshdsociety.org/campaign/torchbearer/c434372* to join today!

FSHD Torchbearer

Important year-end giving reminders

Here are a few friendly reminders as you consider year-end giving:

- Gifts mailed via USPS must be postmarked by December 31, 2026, to receive a 2026 tax receipt. Due to high-volume year-end mail, we recommend sending your gift a few days before December 31 rather than on the deadline itself, so it has time to be postmarked in the new year's rush.
- Gifts made online using a credit card may be made as late as December 31, 2026. You'll receive an immediate confirmation of your gift at the email address provided during checkout; this confirmation serves as your tax receipt.
- The gift date for stock or mutual funds transferred electronically is the date the shares arrive in the FSHD Society account. At year end, many brokerage firms are extremely busy. Please allow extra time for the transfer and call our office at (781) 301-6058 to ensure proper credit.

The Give & Get of Gift-Giving!

Giving to a cause we care about feels good—and has other benefits, too!

If you're 70½ or older, a Qualified Charitable Distribution from your IRA is a powerful way to make a tax-smart gift. These donations can count toward your required minimum distribution and are excluded from your taxable income. Contact your financial advisor to learn more.

New this year: Thanks to a 2026 change in federal tax law, you no longer need to itemize to get a tax benefit for your giving. Taxpayers who take the standard deduction can now deduct up to $1,000 (single filers) or $2,000 (married filing jointly) in cash gifts to charities like the FSHD Society, directly on their tax return. If you've given up on itemizing in recent years, this new deduction means your year-end gift can still lower your tax bill.

This is not professional tax or legal advice. Donors should consult their tax and legal advisors regarding their specific situation.

Upcoming Events

FSHD University
Your questions. Expert answers.

Nov 5—FSHD University: Autonomy in Driving: Maintaining & Expanding Independence

Join Don Burke, an experienced Tesla Full Self-Driving beta tester and road-trip adventurer, for an engaging discussion on how autonomous driving technology is transforming mobility and independence. Don will explore the opportunities and limitations of today's self-driving technology, discuss who may benefit most, and examine practical considerations, including electric vehicles, affordability, and why now is the right time for the FSHD community to become familiar with these rapidly evolving innovations.

Nov 19—FSHD University: Managing FSHD without Medication

Living well with FSHD involves much more than medication—it's about adopting practical strategies that help maintain function, independence, and quality of life. In this webinar, Dr. Enza Leone, research physiotherapist at the Queen Square Centre for Neuromuscular Diseases and University College London Hospitals, will share evidence-based recommendations developed in partnership with people living with FSHD, caregivers, and clinical experts. Participants will learn the "10 Top Tips" for non-pharmacological management, including staying active, exercising safely, managing pain and fatigue, and understanding considerations around shoulder surgery.

Local Chapter Meetings

FSHD SOCIETY
Chapter Program

Discover one of our 30+ FSHD Society chapters and connect with others who understand your journey. Whether you join in person, virtually, or through our seasonal and multi-chapter gatherings, there's a place for you to learn, share, and find support. Everyone is welcome.

The Gathering Place

The Gathering Place
Find Your Circle

The Gathering Place is your monthly virtual meetup to connect with others living with FSHD around the world. No matter where you are on your journey, you belong here. Join us at the next meeting and find your circle!

Women on Wellness
First Wednesday of every month
5 p.m. ET | 4 p.m. CT | 3 p.m. MT | 2 p.m. PT

Living Spiritually with FSHD
First Tuesday of every month
7 p.m. ET | 6 p.m. CT | 5 p.m. MT | 4 p.m. PT

Wellness Hour
Second Monday of every month
5 p.m. ET | 4 p.m. CT | 3 p.m. MT | 2 p.m. PT

Weekend Wellness Hour
Last Saturday of every month
1 p.m. ET | 12 p.m. CT | 11 a.m. MT | 10 a.m. PT

Feeling Fit with FSHD
Second Thursday of every month
12:00 p.m. ET | 11 a.m. CT | 10 a.m. MT | 9 a.m. PT | 6 p.m. CET| 5 p.m. GMT

Young Adults
Third Monday of every other month. Meets in February, April, June, August, October, December
8 p.m. ET | 7 p.m. CT | 6 p.m. MT | 5 p.m. PT

Parents' Roundtable
Now meeting quarterly on the third Thursday of the month. Meets in January, April, July, October
8 p.m. ET | 7 p.m. CT | 6 p.m. MT | 5 p.m. PT

CarePartner Hour
Last Tuesday of every month
8 p.m. ET | 7 p.m. CT | 6 p.m. MT | 5 p.m. PT

Chair Yoga with Donna
Third Monday of every month
7 p.m. ET | 6 p.m. CT | 5 p.m. MT | 4 p.m. PT

Podcast

FSHD Straight Talk

On the second and fourth Tuesday of every month, listen for a new episode of FSHD Straight Talk with Tim Hollenback. These episodes highlight members of our community who are living rich, full lives and diving into their experiences with FSHD. FSHD Straight Talk is available to stream on-demand on major streaming platforms.



FSHD 360 Regional Conferences

FSHD 360 Conference
The Latest in Health & Research

Central Florida FSHD 360
November 14, 2027, 10 a.m. to 3:30 p.m.
Location TBD

Bay Area FSHD 360
December 5, 2027, 10:00 a.m. to 3:30 p.m.
Chabot College, Event Center Room 722B,
25555 Hesperian Blvd,
Hayward, CA 94545

Visit our Events Calendar for updates and to register for events at *fshdsociety.org/fshd-events-calendar.*

FSHD Advocate

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Seize this moment with us—make a gift today!

It's a time of remarkable progress for those living with FSHD:

- *Ten years ago, there was one FSHD drug being explored.*
- *Today, more than 25 biotechnology companies are working toward treatments.*
- *There are four therapies now in advanced clinical trials.*
- *Six more trials are set to launch in the coming months.*



What was once a dream now feels inevitable. When this dream is realized and reaches everyone depends on what we do now.

Scan the QR code or visit *fshdsociety.org/advocategiving26* to make a secure gift online.

Give a gift today to help the FSHD Society make the most of the moment at hand as we fight for FSHD treatment approval and access for all (read more on page 4).