

The Future IN MOTION

Empowerment, Connection,
and Care for Life with FSHD



JUNE 26–28, 2026 | HYATT REGENCY O'HARE CHICAGO | ROSEMONT, ILLINOIS

For social sharing:
#FSHDCONNECT2026
#CureFSHD

Tag **@FSHDSociety**
in your posts

FSHD
SOCIETY
FACIOSCAPULOHUMERAL
MUSCULAR DYSTROPHY

Wi-Fi network:
Hyatt_Meeting

Passcode:
avidity



Welcome to the FSHD Connect Conference in Chicago!

It is truly an honor to gather together in this space with patients, families, caregivers, clinicians, researchers, advocates, and friends. Whether this is your first time attending or you've been part of this community for years, please know this: You belong here!

There is something powerful about being in a room filled with people who understand the challenges, the questions, the resilience, and the hope that come with living with FSHD. For many, this conference is more than a series of sessions or presentations. It is a place of recognition where experiences are validated and no one has to feel alone.

Over this weekend, you will participate in seminars, hear about promising therapies in development, and learn ways to "live better" with FSHD. And perhaps even more importantly, you will learn from one another through conversations in hallways, shared meals, and moments of connection.

Remember that every question asked here matters. Every story shared here matters. Every person here matters.

Progress in FSHD research is moving forward in ways that once felt out of reach. While there is still work to be done, there is real momentum, driven not only by science, but by your voices and advocacy. Through your willingness to participate in research, share your experiences, and keep pushing for answers, you are a vital part of progress.

At the same time, it is important to acknowledge that hope does not erase difficulty. Living with FSHD can be challenging. This conference is not about pretending everything is easy. It's about facing reality together while still holding onto possibility.

If you are someone living with FSHD, thank you for your courage and your presence. If you are a family member or caregiver, thank you for the care and support you give every day, often in ways that go unseen. If you are a researcher, clinician, or working with a biopharmaceutical company, thank you for your dedication to seeking treatments and improving lives.

Forward together!

Mark

Mark Stone
President & CEO

Scan the QR code to read
our speaker bio book.



FRIDAY
JUNE 26

Registration & Joint IRC Reception

The Future in Motion: Empowerment, Connection, and Care for Life with FSHD

Uniting patients, families, and experts to equip, connect, and prepare for what lies ahead.

6:00–8:00 p.m.
Registration Open
Rosemont Foyer

6:00–8:00 p.m.
IRC & Connect Joint Reception – Welcome to Chicago!
Entry Level Foyer

Kick off FSHD Connect with a warm and welcoming evening as we bring together attendees from both the International Research Congress (IRC) and Connect. This relaxed reception is a chance to reconnect with familiar faces,

meet new members of the FSHD community, and engage with researchers and clinicians over light refreshments and appetizers. Whether you're continuing conversations from IRC or just arriving for Connect, this is the perfect way to start building connections, sharing experiences, and celebrating the strength of our community together.

6:00–9:00 p.m.
Early-Onset Video Game Mixer
John Wayne A/B

Calling all teens, tweens, and young adults! Join us for a fun and welcoming mixer where you can relax, play video games, and connect with others who understand life with FSHD. Whether you're catching up with old friends or meeting new ones for the first time, this is a fun way to start the weekend in a space designed just for you.

SATURDAY
JUNE 27

Empowerment through Knowledge and Connection

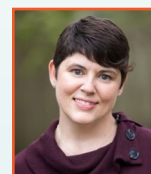
Uniting patients, families, and experts to equip and connect for life with FSHD

8:00–9:00 a.m.
Registration Open
Rosemont Foyer

8:00–9:00 a.m.
Breakfast
Entry Level Foyer

Morning Plenary Sessions

9:00 a.m.–12:05 p.m.
Rosemont Ballroom



Meet Your Host: Chelsea Moeller

Chelsea Moeller serves as the director of development at the FSHD Society, where she leads fundraising and partnership efforts to support research, education, and community programs for individuals living with FSHD.

She is passionate about building meaningful relationships with donors, partners, and families to advance the Society's mission and drive progress toward treatments. Chelsea brings a collaborative and community-centered approach to her work, helping ensure that every initiative is grounded in impact and connection.

9:00 a.m.
Welcome & Opening Remarks
Chelsea Moeller, Director of Development, FSHD Society
Mark Stone, President & CEO, FSHD Society



9:10 a.m.

Keynote: The Future in Motion

Ray Huml, MS DVM RAC-US, a rare disease strategy advocate aligned with this year's theme, The Future in Motion: Empowerment, Connection, and Care for Life with FSHD, will explore how the FSHD community can stay

informed, connected, and prepared for what lies ahead. Drawing on both lived experience and engagement with the evolving research and care landscape, the discussion will highlight the power of collaboration among patients, families, clinicians, researchers, industry partners, and advocates, and how these partnerships can strengthen lifelong care and accelerate progress in FSHD.

Dr. Huml is an executive leader in the healthcare and biopharmaceutical industries. With more than three decades of leadership experience in the contract research organization sector, he has held global roles spanning rare diseases, biosimilars, and due diligence, and his strategic work has helped secure nearly \$3 billion in capital commitments for transformative partnerships. A prolific author and thought leader, Dr. Huml has published 150+ articles, contributed to numerous book chapters, authored four books, and has been recognized with awards from the North Carolina Veterinary Medical Association, Triangle Business Journal, the Regulatory Affairs Professionals Society, and industry leadership honors at Quintiles Transnational Corporation (now IQVIA). A Returned Peace Corps Volunteer (Ghana) and former member of North Carolina State University's Board of Visitors, he holds an MS in biology (East Stroudsburg University) and a DVM (North Carolina State University).



9:50 a.m.
The FSHD Journey: Past, Present, and Future of Research and Care
Russell Butterfield, MD PhD, University of Utah

This session will take a wide-angle view of the FSHD ecosystem – where we’ve been, where we are, and where we’re headed. We’ll look back at the history of FSHD discovery and advocacy, review the progress made in research and clinical care, and examine ways to navigate the exciting next stage of the journey.

10:20–10:40 a.m.
Break



10:40 a.m.
Advancing Early–Onset FSHD Research
Ian Woodcock, The Royal Children’s Hospital Melbourne
Katy De Valle, The Royal Children’s Hospital Melbourne



Ian Woodcock and Katy De Valle will present an overview of their work advancing the understanding of pediatric FSHD over the past 4 to 5 years. This session will highlight natural history data from an Australian cohort, including functional outcome measures,

MRI findings, and laboratory data generated in collaboration with research partners.



11:10 a.m.
Humans.... Being: The Understanding and Practice of Emotional Well–Being
Jennifer Egert, PhD, private practice

Jennifer Egert will lead us in a personal exploration of the experience of emotional well-being. Together, we will consider the meaning of well-being, how we define it personally, and ways we can enhance it in our daily lives. Grounded in shared human experience, this session recognizes that emotional well-being impacts everyone – regardless of their connection to FSHD – and offers a space for thoughtful discussion, connection, and insight.



11:40 a.m.
Data Collection at Connect: 2024 Collection Update & 2026 Opportunity
Suja Jagannathan, PhD, University of Colorado Anschutz
Russell Butterfield, MD PhD, University of Utah



This session will highlight the impact of community-driven research at Connect. Suja Jagannathan will share updates from the 2024 data collection in Denver, and Russell Butterfield will discuss opportunities to participate in 2026 and how these efforts support the development of a smartphone-based tool to measure FSHD progression, improving the ability to detect meaningful changes in function and accelerate clinical trial development.

12:05–1:00 p.m.
Lunch
Entry Level Foyer

Afternoon Breakout Sessions

1:00–4:50 p.m.
Lambert A/B | Harbor A/B | Lindberg A/B

This year’s breakout sessions are designed to meet you where you are on your FSHD journey. With three distinct tracks – General FSHD Care, Research in FSHD, and Whole–Person Care – participants can choose sessions that best match their interests, needs, and stage of experience. Whether you are newly diagnosed, exploring research opportunities, or focused on daily living and well-being, there is something for everyone. Attendees are not limited to a single track and are encouraged to move between sessions to create a personalized experience that is most meaningful to them.

TRACK 1: General FSHD Care Lambert A/B

Build a strong foundation for living with FSHD through sessions focused on understanding the condition, navigating care teams, and managing day-to-day health. This track offers practical guidance and evidence-based strategies to support informed care and quality of life.



1:00–1:50 p.m.
FSHD 101: Understanding the Basics
Charu Nagar, MD, Northwestern Medical Group

What is actually happening in the body with FSHD, and what can we do about it? Dr. Nagar will take us inside the science, breaking down the underlying mechanisms of FSHD and sharing practical knowledge to help patients and families navigate life with FSHD with greater confidence and clarity. Whether you’re newly diagnosed or have been on this journey for years, this session is designed to meet you where you are. It will also include a Q&A and give you an opportunity to have your most pressing questions answered by an expert who understands FSHD inside and out.



2:00–2:50 p.m.
Building Your Care Team: Navigating Specialists, Clinics, and Support Resources
Marvella Bowen, RN MSGH, Northwestern Medical Group
Janet Robinson, RN MSN, Northwestern Medical Group



This session will provide guidance on finding the right providers, coordinating care, and using advocacy resources to manage your journey effectively.



3:00–3:50 p.m.
Physical Therapy and Adaptive Exercise for FSHD
John Moynihan, PT DPT OCS, Northwestern Medical Group

This session will introduce the purpose of physical therapy in FSHD and provide safe exercise options, stretching routines, and guidance on maintaining mobility and strength.



4:00–4:50 p.m.
Living Well with FSHD: Whole–Person Health and Quality of Life
June Kinoshita, FSHD Society Executive Editor Emerita

This session will draw from the newly released Standard of Care Guidelines to highlight what we know so far about navigating life with FSHD. Together, we’ll look at how the latest evidence-based recommendations can empower individuals and families to take an active role in their care and quality of life.

TRACK 2: Research in FSHD Sky Harbor A/B

Explore the latest advances shaping the future of FSHD. From the drug development pipeline to emerging therapies, biomarkers, and the role of patient data, this track provides insight into how research is progressing and how the community can play an active role.



1:00–1:50 p.m.
The Road to Treatments: Understanding the FSHD Drug Development Pipeline
Amanda Hill, MBA ACRP–CP, FSHD Society

This session will provide an overview of the FSHD drug development pipeline, outlining how potential therapies move from preclinical research through Phase 1 through 3 clinical trials, and what each stage means for patients and families. We will also walk through how individuals can get involved in clinical trials, including where to find opportunities, key considerations when deciding whether to participate, and what to expect before, during, and after a study.



2:00–2:50 p.m.
Different Roads to Treatment: Understanding Research Approaches in FSHD
Lucienne Ronco, PhD, FSHD Society

A comparative look at current and emerging treatment strategies – from gene therapy (adeno-associated virus) and antibody-oligonucleotide conjugates to small molecules and other innovative approaches – with clear explanations of how they work, and their potential and challenges.



3:00–3:50 p.m.
Biomarkers and Imaging: How They Are Changing the Future of FSHD Research
Amanda Rickard, Global FSHD Innovation Hub

Discover how emerging tools like MRI and blood-based biomarkers are transforming the way researchers measure disease activity and progression in FSHD. This session will show how these advances help track changes over time and better evaluate whether potential treatments are making a meaningful impact.



4:00–4:50 p.m.
The Voice of the Patient: How Your Data and Experiences Drive Research Forward
Kayleigh Worek, FSHD Society

This session will highlight how patient registries, surveys, and natural history studies contribute to advancing FSHD research and shaping healthcare policy. Participants will learn how real-world data and lived experiences play a critical role in informing drug development, improving care, and driving meaningful progress for the FSHD community.

TRACK 3: Whole–Person Care in FSHD Lindberg A/B

Focus on the full experience of living with FSHD, including physical health, emotional well-being, caregiving, and life beyond the clinic. This track highlights supportive strategies and resources to promote resilience, independence, and overall well-being.



1:00–1:50 p.m.
Breathing with FSHD: Pulmonary and Sleep Medicine
Alejandra Lastra, MD, University of Chicago Medicine

Breathing and sleep health are important aspects of living with FSHD that can change over time. This session will explore pulmonary and sleep-related considerations in FSHD, including common symptoms, screening and monitoring, and when to seek specialty care. Participants will gain a better understanding of how proactive respiratory and sleep management can support overall health and quality of life.



2:00–2:50 p.m.
FSHD in the Workforce: Vocational Rehabilitation Services
Marisa Spain, Disability Rights Michigan

Living with FSHD can present unique and evolving challenges in the workplace – often requiring specialized services, training, or equipment to maintain our employment as our condition progresses. This session will explore the services available through state Vocational Rehabilitation programs and how to maximize these services to thrive in a career alongside FSHD.



3:00–3:50 p.m.

Caring for the Caregiver: Managing Stress and Avoiding Burnout

Andrea Kosten, PsyD, The Sacred Vessel Therapy and Wellness

Caregivers play a vital role in the FSHD community, often balancing care responsibilities with their own needs. This session provides space to discuss the challenges of caregiving, identify stressors, learn strategies to manage stress, set boundaries, and prevent burnout.



4:00–4:50 p.m.

Humans.... Being: The Understanding and Practice of Emotional Well-Being, a Deeper Dive

Jennifer Egert, PhD, private practice

In this workshop, Jennifer Egert and all participants will dive deeper into the experience of emotional well-being presented in the plenary session. Together, we will examine our personal experience of well-being and ways to support practices that build this in our daily lives. Grounded in shared human experience, this session recognizes that emotional well-being impacts everyone – regardless of their connection to FSHD – and offers a space for thoughtful discussion, connection, and insight.



Gathering Place Support Groups

5:00–6:00 p.m.

Experience the power of connection in this special Gathering Place session at Connect. Designed as a sample of our online peer support groups, this session offers a welcoming space to meet others, share experiences, and build meaningful connections within the FSHD community. Led by FSHD Society volunteer leaders, it's an opportunity to find your circle, feel supported, and discover how ongoing peer connection can be a valuable part of your journey.

Group 1: Wellness Hour | Moderated by Ranae Beeker
Tips, Tricks, and Everyday Hacks for Living with FSHD

Lambert A/B

A relaxed, supportive space to share the little things that make a big difference. From daily routines and adaptive tools to creative problem solving, this session is all about learning from one another. Whether you have something to share or just want to listen, all are welcome.

Group 2: Care Partner Hour | Moderated by Selina Lai
Supporting a Loved One with FSHD

Sky Harbor A/B

A dedicated space for caregivers to connect with others who understand the unique joys and challenges of supporting someone with FSHD. This conversation offers a chance to share experiences, exchange advice, and simply feel less alone in the journey.

Group 3: Feeling Fit with FSHD | Moderated by Michael King
Staying Active with FSHD – at Your Own Pace

Lindberg A/B

An encouraging and inclusive conversation about movement and wellness. Participants will share what staying active looks like for them – whether it's stretching, chair yoga, short walks, or mindfulness practices. This is a judgment-free space where all ability levels are welcomed and celebrated.

Group 4: Parents' Roundtable | Moderated by Ally Roets
Raising and Supporting a Child with FSHD

McCarran A/B

A compassionate space for parents, grandparents, and other family members to connect around the experience of caring for a child with early-onset FSHD. This session offers an opportunity to share stories, ask questions, and learn from others who are navigating similar paths.

6:00–7:00 p.m.

Break

7:00–9:00 p.m.

The Future in Motion: An Evening of Celebration & Community

Rosemont Ballroom

Join us for this year's dinner banquet – an evening of connection, reflection, and celebration – as we come together to honor the strength and spirit of the FSHD community. Throughout the evening, we will recognize our dedicated volunteers and individuals whose contributions inspire progress, connection, and hope for the future as we reflect on the people and moments that continue to move our community forward.

Early-Onset Programming – Day 1

John Wayne A/B

Day 1 of this year's Youth Program offers dedicated programming for children and teens (ages 10 to 18) living with early-onset FSHD – creating a space to connect, learn, and have fun alongside peers who share similar experiences. The day features a dynamic lineup of activities, including art and connection time, a careers panel, an escape room, and interactive sessions designed to build confidence and community. Families are also an important part of the experience, with opportunities to engage through an interactive panel and the Parents' Roundtable, a supportive space for parents, caregivers, and loved ones to connect and share insights.



We can't POWER THE PATH FORWARD Without YOU



Become part of a growing research community contributing vital data – every day, over time, in real life. Input today, impact tomorrow.

By joining BetterLife FSHD and completing surveys, you may benefit from personalized resources, symptom tracking, sharing data safely, and finding additional opportunities to participate in FSHD research.

“After navigating my disease alone for so many years, I am thrilled to have a website designed to support me and my family.”



–Mollie Garrett
BetterLife FSHD User



Visit BetterLifeFSHD.org or scan the QR code to get started.



Captain a team for the annual Walk & Roll to Cure FSHD, choose your favorite endurance event and participate in the Movement for Muscle, or host a DIY Fundraiser!

Join the Movement to Cure FSHD



Walk & Roll to Cure FSHD

Join a local event and become part of a powerful community walking, rolling, and fundraising for a cure.

FSHDSociety.org/Walk-Roll

Movement for Muscle

Run, ride, lift, climb, or compete. Turn your passion for movement into real impact for the FSHD community.

Create Your Own Fundraiser

Birthdays, workplace challenges, community events, and more. Host fundraisers your own way.

FSHDSociety.org/Fundraise-Your-Way/

SATURDAY JUNE 27 | Empowerment through Knowledge and Connection

9:00–11:00 a.m.

Art Activity & Connection Time

11:00 a.m.–12:00 p.m.

Your Future in Motion: Careers, Possibilities, and Pathways with FSHD

Living with early-onset FSHD can raise important questions about the future – including what a career might look like. This panel brings together individuals who are navigating their professional journeys while living with FSHD to share their experiences, challenges, and successes. Through honest conversation, panelists will discuss how they explored career paths, adapted to changes along the way, and found opportunities that align with their goals and abilities. Designed for youth and young adults, this session aims to inspire confidence, provide practical insights, and create space for questions – helping participants see that meaningful, fulfilling careers are possible.

12:00–1:00 p.m.

Lunch

1:00–3:00 p.m.

Escape Room
McCarran A/B

Do you have what it takes to crack the code? Join us for an exciting Escape Room experience where teamwork, creativity, and problem-solving are the keys to success. Work together to uncover clues, solve puzzles, and beat the clock in this interactive challenge designed to spark connection and fun. Open to youth and young adults, this is your chance to connect, challenge yourself, and see if your team can make it out in time!

4:00–5:00 p.m.

Every Voice Matters: Advancing Inclusive Access to FSHD Treatments

Access to treatments for FSHD must include all individuals affected by the disease, including those who are non-ambulatory and those with early-onset FSHD. In this interactive session, members of the early-onset community will share lived experiences that reflect the types of perspectives being brought forward in patient listening efforts with regulators. Attendees will hear directly from individuals and families navigating these realities, and gain a deeper understanding of the challenges and priorities that must be considered. This session will highlight the urgent need to ensure that young individuals and those with more advanced disease are meaningfully included in research, clinical trials, and future treatment access discussions. This session is open to all Connect participants.

SUNDAY JUNE 28 | The Future in Motion

Preparing together for what lies ahead in research, treatment, and lifelong care

8:00–9:00 a.m.

Breakfast

Entry Level Foyer

8:30–9:00 a.m.

Registration Open

Rosemont Foyer

9:00 a.m.–12:30 p.m.

Early-Onset Trip to Shedd Aquarium

Meet at Entry Level Foyer

Take a trip to the Shedd Aquarium, one of Chicago's most iconic and immersive attractions. Explore vibrant underwater worlds, from colorful coral reefs to fascinating freshwater and ocean habitats, and experience up-close encounters with incredible marine life from around the globe. Designed with accessibility in mind, the Shedd Aquarium offers a welcoming and inclusive environment for all participants.

9:00–12:30 p.m.

Day 2 Plenary Sessions

Rosemont Ballroom

9:00 a.m.

Welcome Back

Chelsea Moeller, FSHD Society



9:15 a.m.

The State of FSHD Research: From Discovery to Therapies

Lucienne Ronco, PhD, FSHD Society

Building off Dr. Butterfield's presentation on the history of FSHD, this session will provide a big-picture overview of where FSHD research stands today, highlighting key advances in genetics, biomarkers, and clinical trials. Participants will gain a clearer understanding of how discoveries in the lab are translating into potential therapies, and what the current pipeline means for the future of treatment. The discussion will also explore the most promising areas of progress, how researchers are measuring disease activity and progression, and what questions remain as the field continues to evolve. Designed to bridge science and real-world impact, this session will help attendees better understand where we are today, and where we are headed next in FSHD research.

10:00 a.m.

The Future in Motion: Industry Perspectives on the Path to Treatments

Panel Moderated by Lucienne Ronco

Following Lucienne Ronco’s big-picture overview of where FSHD science stands today, this panel brings together representatives from leading biopharmaceutical companies advancing therapeutic development in FSHD. Panelists will share insights into how research is progressing, the role of patient and caregiver perspectives in shaping study design and development priorities, and where their programs currently stand.

11:00–11:20 a.m.
Break



11:20 a.m.
Becoming a Treatment-Ready Community
Michelle Mellion, MD, FSHD Society

A dynamic session on what it means to prepare as a patient, family, and community for the first generation of FSHD therapies. Topics include genetic confirmation, building strong care teams, and ensuring equitable access to treatments once approved.



11:50 a.m.
The Power of Community: Shaping Research, Care, and Policy
Anna Gilmore, FSHD Society

This session will highlight how getting involved in the community drives research priorities, influences clinical care, and informs healthcare policy. By joining your local chapter, contributing to BetterLife, sharing personal

stories, and connecting with others, every voice and action plays a vital role in accelerating progress and shaping the future of FSHD.



12:10 p.m.
The Future in Motion: Moving Forward, Together
Mark Stone, FSHD Society

As we conclude the conference, this session will bring together the key themes of the weekend: Empowerment, connection, and care for life with FSHD. Grounded in the spirit of unity, this closing moment will reinforce our shared commitment to staying informed, connected, and prepared for what lies ahead – leaving participants inspired, supported, and ready to take the next steps in their FSHD journey.



12:20 p.m.
Closing Remarks from Our Community Engagement Committee Chair
Jack Gerblich, FSHD Society

Thank you for joining us at the 2026 FSHD Connect Conference. Before you head out, join us for closing remarks from Community Engagement Committee Chair Jack Gerblich, as he reflects on this year’s conference experience and the strength of the FSHD community.

A Farewell from Your Chicagoland Chapter Co-Directors
Mary Mauch & Suzy Kosten

And just like that—Connect 2026 is a wrap. We are so glad you were here.

When we heard that FSHD Connect was coming to our hometown, we may have done a little happy dance. (FSHD and all, we still move when it matters!) Watching this weekend unfold in our own backyard has been one of the greatest honors of our lives.

As the Chicagoland Chapter co-directors since 2024, we have had the privilege of participating alongside this incredible community—and this weekend reminded us exactly why we do what we do. 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, and where the connections you make can carry you through even the hardest days.

We hope this weekend gave you exactly that – and then some.

The Future in Motion is not just a theme. It is a promise. Living with FSHD means we’ve all had to redefine what motion looks like. It isn’t always what we planned. But it is still forward. It is still ours. And after this weekend, we hope you feel it a little more deeply: It is best traveled together.

We poured our hearts into helping plan this conference because every single person here—patients, caregivers, family members, newly diagnosed and long-timers alike—deserves to feel seen, celebrated, and part of something bigger than themselves. Looking out at this community, we can say with full hearts: You showed up for each other. That means everything.

We hope you laughed. We hope you learned something that changes how you navigate the road ahead. And we hope you leave with at least one new friendship that started with a shared meal, asking a stranger about their wheelchair, or a conversation that began with, “Wait, you, too?”

The future is still in motion
—and so are all of us.

Thank you for making Connect 2026 something truly special. Until next time, carry this community with you.

With so much love and gratitude,
Mary Mauch & Suzy Kosten

CHICAGOLAND CHAPTER CO-DIRECTORS, FSHD SOCIETY



Volunteer
with us



Our volunteers are creating real change by bringing people together, raising awareness, and strengthening the FSHD community, one connection at a time.

“Knowing that I am giving back to something that is deeply personal for me and my family has fulfilled me in ways I can’t explain.”

Kenna Montgomery
Leader, North Texas Walk & Roll

Your time and talent can make a lasting difference for everyone living with FSHD. We’ll give you the tools, training, and support – you bring the passion!



Volunteer.FSHDSociety.org

Because What You Do MATTERS

Our local chapters allow you to connect with others who understand FSHD, support you in your journey, and provide you with valuable resources to keep you informed.

Whether you’re living with FSHD, or supporting a loved one, our chapters offer a caring community to face FSHD together. These chapters also give you a place to learn, share experiences, and raise your voice to make a difference in improving care and advancing research and treatments for everyone affected by FSHD.

Find your local chapter & join our chapter mailing list.



FSHDSociety.org/Local-Chapter

Find strength
in community



Iowa Chapter luncheon, March 2026

WE THANK OUR GENEROUS SPONSORS

PRESENTING SPONSOR



SAVE THE DATE:

FSHD Europe Connect Conference

June 2027 • Spain

Details Coming Fall 2026

EVENT SPONSOR



**JAMES CHIN, SR.,
SCHOLARSHIP FUND**

FLOOR MAP KEY

■ Meeting/Conference Rooms ■ Amenities ■ Public Space

