2022 FSHD CONNECT

The FSHD Society's international networking conference for patients, families, clinicians, and researchers

FSHD SOCIETY
LIGHTING THE WAY TO A CURE

2022
FSHD
CONNECT

June 18–19, 2022

Waldorf Astoria and
Hilton Bonnet Creek Hotel

Orlando, Florida

Wi-Fi network:
bonnetcreek_meeting
Passcode: FSHD

For social sharing
#FSHDConnect
#CureFSHD
Tag @FSHDSociety in your posts

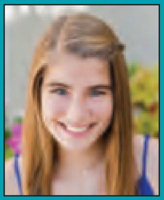
LET’S CONNECT!

The Florida chapters of the FSHD Society are very excited to co-host the 2022 FSHD Connect conference in our home state this year!

The FSHD Society is lucky to have three chapters in the state of Florida helping us cover this large territory. The Northeast Florida, Tampa, and Southwest Florida chapters are working diligently to push us toward a cure for FSHD through community engagement, awareness, and involvement in local events, as well as in local clinical trials.

We value the importance of having an engaged and connected community, and it is empowering to know there are people so close to you geographically going through the same struggles. Local events are a great way to meet these people and share advice and support. They also make medical practitioners and researchers take notice and recognize that there is a real community here that they can and must serve. Each one of us alone can only do so much – but if we connect and act together, we are an unstoppable force.

We are thrilled to be a part of the 2022 FSHD Connect and are looking forward to a wonderful weekend of inspiration and connection!



Heloise Hoffmann
SWFloridaChapter@fshdsociety.org

Jane Pollock
TampaChapter@fshdsociety.org

Christina Thissen
NEFloridaChapter@fshdsociety.org

WELCOME!

After four years and several virtual meetings and conferences, it is my pleasure to welcome you personally to the FSHD Society's biennial Connect Conference!

Tom Vilsack, the former governor of Iowa, once asserted that "people, working together in a strong community with a shared goal and a common purpose, can make the impossible possible." And so, too, when the FSHD Society comes together, anything is possible.

Because of your involvement and investment, we are accelerating research toward safe and effective therapies for FSHD while igniting an army of activists. And because of you – your heart, determination, passion, and perseverance – you have inspired a global movement that.won't be stopped, stalled, or stymied.

Over the past four years…

Together, we have gathered researchers, clinicians, companies, and regulatory agencies (FDA) to collaborate in identifying the obstacles in our path and launching projects to eliminate them through our Therapeutic Accelerator initiative.

Together, we have raised and invested more than $15 million to fuel our progress and accelerate the pace of therapy development.

Together, we have prevailed through a global pandemic and lockdown while moving our mission forward — even "testifying" before the FDA through the Voice of the Patient Forum.

Together, we have launched a movement resulting in 33+ chapters throughout North America, ensuring that no one has to make this journey alone.

Together, we have sparked a global mission in more than 20 countries, growing a community speaking with one voice tens of thousands strong.

We are stronger together – and we are stronger than FSHD!

In choosing to attend this conference, you are joining a powerful coalition of individuals and families who are achieving world-changing results. It is my hope that you enjoy the conference and community, are enriched and empowered by the presentations, and that when you return home, you remain fired up to participate in our collective quest for a cure for FSHD.

On behalf of the families we serve and stand alongside, thank you.

Forward Together,

Mark

Mark Stone
Chief Executive Officer, FSHD Society

FRIDAY, JUNE 17 – Pre-conference Events

REGISTRATION OPEN

5:30–7:00 p.m.

Grand Ballroom Foyer (#14 on map)

RE:CONNECT RECEPTION

Sponsored by Fulcrum Therapeutics

6:00–8:00 p.m.

Promenade (#15 on map)

SATURDAY, JUNE 18 – Connect Day 1

REGISTRATION AND BREAKFAST

8:00–8:50 a.m.

Grand Ballroom (#14 on map)

WELCOME

8:50–9:00 a.m.

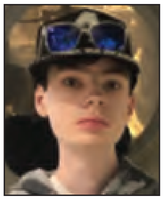
Grand Ballroom Foyer (#14 on map)

Mark Stone, President & CEO,
FSHD Society

Mark has served as an executive leader of research-focused patient advocacy nonprofit organizations for the past 18 years. Prior to joining the FSHD Society, he was the chief executive officer of NephCure Kidney International. From 2004-2011, he was executive vice president and COO of the Polycystic Kidney Disease (PKD) Foundation. Passionate about helping organizations work to accelerate treatments and cures in diseases that are both rare and of a genetic origin, he has successfully engaged patients, families, and friends in raising up an "army of activists" while advocating with pharmaceuticals, the National Institutes of Health (NIH), and the FDA to increase funding levels and enlarge the pipeline of potential therapies.

BREAKOUT SESSION A

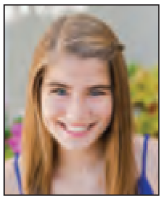
9:00–10:00 a.m.



Floridian G

Moving the Future, Sam Ray

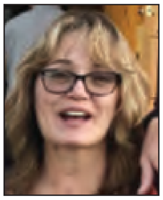
Sam is a 16-year-old junior at Andrada Polytechnic High School in Vail, Arizona. In addition to his normal classes, he takes evening classes working toward an FAA drone pilot license. He was a member of the high school robotics team for two years and has been interested in exoskeleton technology since shortly after being diagnosed with FSHD when he was six years old. Sam visited an exoskeleton facility in California and attempted to construct his own exoskeleton arm as a science fair project. He firmly believes the exoskeleton field is the future, and its technology can greatly improve the quality of life for non-ambulatory persons such as himself.



Floridian H

GenZ of FSHD, Heloise Hoffmann

Heloise was diagnosed at age 13 with FSHD and recently graduated from high school. She feels passionate about activating the community to join the march for a cure, and this led her to found the Southwest Florida Chapter and take part in the GenZ of FSHD initiative to maximize youth involvement. She strives to get involved in science and research for FSHD. In addition to the sleep study, she has worked in the laboratory of Dr. Angela Lek at Yale University and plans to attend Stanford University this fall.



Floridian I

Early-Onset FSHD Families Unite!

Ally Roets, Yi-Wen Chen

Ally Roets would like to meet other families and strategize about advocating for better understanding of early-onset FSHD, and making sure early-onset patients will have access to treatments that are being developed. Ally and he son Sam Ray (see bio at left) lead the Early-onset FSHD Chapter. Ally is retired from the United States Air Force and is a substitute teacher.

Yi-wen Chen, PhD DVM, is an associate professor at Children's National Hospital in Washington, DC. Her team has been studying FSHD for more than 20 years, including the cause of FSHD, disease mechanisms, and the natural history of early-onset FSHD. More recently, the team has focused on therapeutic development and clinical trial readiness, including antisense therapy, circulating biomarkers, and genetic diagnosis. Her lab is also investigating the FSHD disease process in children and adolescents.

Floridian J

Community Room

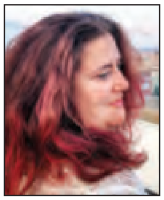
A hangout room for conversation and socializing.

Floridian K

Interabled Relationships, Jenny and Tony Teel

Jenny and Tony Teel are a married couple who explore issues in interabled relationships on their YouTube channel. Tony's life with FSHD has set them on a journey to discover better ways to problem solve together and live life to the fullest. The motto and mindset they promote on their channel is: "You're stronger than you know." They live in Louisiana with their three children, Noelle, Nathan, and Alex.

Floridian L



Mindfulness Meditation, Jen Egert, PhD

Dr. Egert is a clinical psychologist living with FSHD and based in New York City. She integrates mindfulness-based cognitive therapy (MBCT), ACT, and mindfulness meditation in her work in private practice with adults.

BREAK/SWITCH ROOMS

10:00–10:10 a.m.

BREAKOUT SESSION B1

10:10–11:00 a.m.

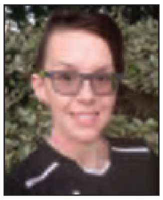
All Session B1 sessions except "For Unaffected Family & Friends" will be repeated during Session B2.

Floridian G

Orthotics 101, Bob Meier

Bob Meier has been active in the fields of orthotics, therapeutic exercise, and biomechanics since 1978, and has conducted education programs since 1982. His special interest is in applied closed chain biomechanics and muscle function. He has taught numerous courses across North America and Europe on gait assessment, rehabilitation, and orthotics. He holds six patents involving orthotics and applied biomechanics for spine and lower extremity applications.

Floridian H



Choosing the Right Mobility Device, Wendy Gonzalez

Wendy Gonzalez is vice president at Care Mobility, a growing durable medical equipment company in Ocoee, Florida. This five-star company services, sells, and rents wide vehicle lifts, power chairs, up-walkers, wheelchair ramps, hospital beds, and bathroom safety products. Wendy is passionate about enhancing mobility in the Central Florida market and is eager to provide affordable and achievable services to people with disabilities while creating a caring atmosphere.

Floridian I

Exercises for Shoulder Issues, Jos IJspeert

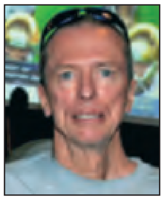
Jos IJspeert, a physiotherapist and PhD candidate at Radboud University Medical Center in the Netherlands, will be giving a plenary this afternoon on insights from his research on shoulder issues in FSHD. This breakout session provides an opportunity to discuss specific issues you are having.

Floridian J

Community Room

A hangout room for conversation and socializing.

Floridian K



Traveling Near and Far, Ray Jordan, Cyndi Segroves, Jane Earl

Ray Jordan and Cyndi Segroves met at an FSHD Society conference many moons ago, fell in love, and got married, all while commuting in power wheelchairs between Ray's home in Australia and Cyndi's home in Arizona. They have figured out every travel trick in the book. Jane Earl, a universal design advocate, recently took her first wheelchair van trip from Wisconsin to Florida and will share what she has learned.

Floridian L

For Unaffected Family & Friends,

Jenny Teel

Jenny Teel is married to Tony, who has FSHD. She is a work-from-home mom, and together they have three children, Noelle, Nathan, and Alex. Jenny has been on a journey of learning about FSHD alongside Tony, as they navigate interabled life together. She hopes to encourage and support other non-affected family members and friends through sharing in a group setting.

BREAK/SWITCH ROOMS

11:00–11:10 a.m.

BREAKOUT SESSION B2

11:10 a.m.–12:00 p.m.

Floridian G

Orthotics 101, Bob Meier

See description from Session B1 above.

Floridian H

Choosing the Right Mobility Device, Wendy Gonzalez

See description from Session B1 above.

Floridian I

Exercises for Shoulder Issues, Jos IJspeert

See description from Session B1 above.

Floridian J

Community Room

A hangout room for conversation and socializing.

Floridian H

Traveling Near and Far, Ray Jordan, Cyndi Segroves, Jane Earl

See description from Session B1 above.

Floridian L

Meet the Scientist (or Genetics for Dummies),

Russell Butterfield, MD PhD

Russell Butterfield is an associate professor in the Pediatrics and Neurology departments at the University of Utah, where he directs the Muscular Dystrophy Clinic at the University of Utah and Neuromuscular Clinic at Primary Children's Hospital. He is principal investigator for the FSHD Clinical Trial Research Network site at the University of Utah. His research involves studying hundreds of members of an extended FSHD family in Utah to search for genetic factors that influence the disease.

LUNCH

12:00–12:30 p.m.

Grand Ballroom

KEYNOTES

Grand Ballroom

12:30–1:00 p.m.

Discovery in a Digital Age,

Jamie Heywood

As technology exponentially advances the ability to measure biology, measure humans, integrate data, and compute, how does that affect how we treat, research, and invent new ways of managing disease? What is it telling us about the limitations of our current knowledge and approach? What are the implications for research, collecting data, and sharing methods and discoveries? What new systems, cultures, and roles are needed to leverage the potential of emerging technology and deliver value, and how will we interact with it?

Jamie Heywood is an MIT-trained mechanical engineer and entrepreneur who entered biomedicine after his brother was diagnosed with ALS in 1999. Prior to founding Alden Scientific, a digital biology company that develops advanced individual predictions to manage health, disease, and aging, Jamie founded the ALS Therapy Development Institute, PatientsLikeMe, and AOBiome, and co-founded Genetic Networks, The SocialMedwork, and iCarbonX International. Jamie's work has been profiled in The New Yorker, 60 Minutes, TEDMED, *Pulitzer Prize-winner Jonathan Wiener's book,* His Brother's Keeper, *and the Sundance award-winning documentary* So Much So Fast.

1:00–1:45 p.m.

Ignite! Mark Stone, CEO of FSHD Society and the Community Engagement Team

Every one of us has a role to play – one that fits our unique situation, personality, and talents – to transform the future for our community.

BREAK
1:45–2:15 p.m.

PLENARY SESSIONS
2:15–4:10 p.m.

Toward an Empowered Community
Grand Ballroom

2:15–2:35 p.m.

The Remarkable History of FSHD Research, Russell Butterfield, MD PhD

Dr. Butterfield (see biosketch on page 6) will share the exciting scientific story of the hunt for the genetic cause of FSHD Type 1 in a large family in Utah traced to one man who immigrated from England in the early 19th century. This research has shown that even with the same genetic cause, there is wide variability in age of onset and symptom severity. Today, the search has extended to other genes that may help explain these differences – and point to possible new strategies to treat FSHD. Find out if your family could also contribute such insights – or might even be related to this historic Utah pedigree! Along the way, you'll learn about the complicated genetics and typical symptoms that are the hallmarks of FSHD.

2:35–2:55 p.m.

Frontiers of Physical Therapy, Jos IJspeert

Jos IJspeert, a physiotherapist and PhD candidate at Radboud University Medical Center in the Netherlands, has been conducting research on the potential for exercises to improve shoulder function in FSHD patients. He has found that shoulder problems caused by FSHD can sometimes be treated with physiotherapy. Targeted shoulder function training may even delay muscle weakness.

2:55–3:15 p.m.

What Should I Take? The Science of Dietary Supplements, Matthew Beke, MS RDN LDN

Ever wondered which dietary supplements are bogus and which ones are useful? "Should I be taking a multivitamin?" "Do I need a protein supplement if I'm not working out?" "Can probiotics help with my GI symptoms?" "What supplements may be helpful for FSHD?" Bring your supplement and diet questions to be answered by Matt Beke, dietician and nutritional sciences PhD candidate at the University of Florida. He currently serves the patients of the Norman Fixel Institute for Neurological Diseases at UF Health. His research focuses on modulating gastrointestinal function with diet and dietary supplements.

3:15–3:35 p.m.

Caring for Our Mental Health while Living with FSHD, Jennifer Egert, PhD

Caring for our physical health helps our mood, sense of well-being, and ability to cope with the demands of the disease. Similarly, caring for our mental health facilitates a positive sense of self, fosters good relationships, and impacts physical healing. This talk will focus on the mind-body aspects of living with FSHD, exploring what a "mental health journey" might look like, identifying the concerning symptoms, and the many treatments and practices that help along the way. Dr. Egert is a clinical psychologist living with FSHD and based in New York City. She trained in health psychology at Duke University and has more than 20 years of experience working with individuals with depression and anxiety, medical illness, disability, and at end of life. For further information, visit jenniferegert.com.

3:35–4:05 p.m.

Q&A and Discussion Panel

CONNECT BANQUET
6:00–8:00 p.m.

Grand Ballroom

Welcome, James Chin Sr., chair, FSHD Society Board of Directors

Award presentations, Mark Stone, President and chief executive officer, and Beth Johnston, chief community engagement officer

SUNDAY, JUNE 19 – Connect Day 2

BREAKFAST SOCIAL HOUR
8:00–8:55 a.m.
Grand Ballroom

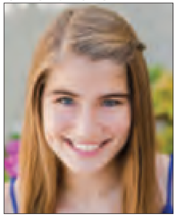
DAY 2 WELCOME
8:55–9:00 a.m.
Grand Ballroom

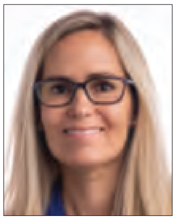
9:00 a.m.–10:30 a.m.
Drug Development for FSHD
Grand Ballroom

9:00–9:30 a.m.
Drug Development 101,
Jamshid Arjomand, PhD
What does the drug development process involve, from research in the laboratory to clinical trials of experimental therapies in patients? Why are there inclusion and exclusion criteria? What determines how many volunteers are needed for a trial? What is the FDA's role? What is the patient's role? We answer your frequently asked questions and explain the terminology of drug development geekdom.

9:30–10:00 a.m.
Industry Panel Discussion
We will ask companies with FSHD programs to describe their proposed therapy and where it is in the development process. Participating companies include Avidity Biosciences, Dyne Therapeutics, Fulcrum Therapeutics, and miRecule.

10:00–10:30 a.m.
Patient Experience Panel, Heloise Hoffmann, Christina Thissen, Michaela Walker, and Rick Whitehead
We will share perspectives on patients' expectations and experiences with participating in clinical research and trials.



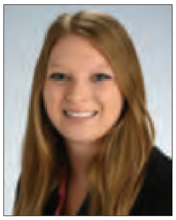


BREAK
10:30–10:45 a.m.

10:45 a.m.–12:30 p.m.
Clinical Trials Are Coming. Are We Ready?
Grand Ballroom

10:45–11:00 a.m.
Our PACT with Patients,
Leigh Reynolds
Leigh is chief program strategist at the FSHD Society. Therapeutic development in FSHD is building and growing at a rapid pace. The need for more patients to participate in research is critical. Your information is powerful, and now is the time to get involved. Learn more about how the FSHD Society is putting the power to impact change at your fingertips.

11:00–11:15 a.m.
TestFSHD, Jamshid Arjomand, PhD
Jamshid is chief science officer of the FSHD Society. Getting genetic testing for FSHD has been difficult for many patients. Jamshid will describe the Society's sponsored genetic testing program, which is designed to grow our "trial ready" community by helping individuals who otherwise are likely to qualify for FSHD clinical trials to obtain genetic testing to confirm their diagnosis.

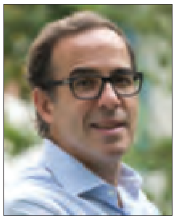


11:15–11:30 a.m.
The MOVE and MOVE+ Studies,
Michaela Walker
Michaela is a research project manager at the University of Kansas Medical Center for the FSHD Clinical Trial Research Network (FSHD CTRN), and is managing MOVE and MOVE+, the largest natural history studies to date of FSHD and why they are so important to the drug development effort. She believes strongly in patient education, advocation, and working to better the care and therapies that are available to patients.

11:30–11:45 a.m.
The True Cost of FSHD,
June Kinoshita

June is the director of research and patient engagement for the FSHD Society. She will describe the FSHD Society's research initiative to determine the true cost of living with FSHD, and why this information is critical to government and private payor policies determining patients' access to services and future treatments.

11:45 a.m.–12:00 p.m.
International Advocacy: Brazil and UK Case Studies, Fabio Figueiredo



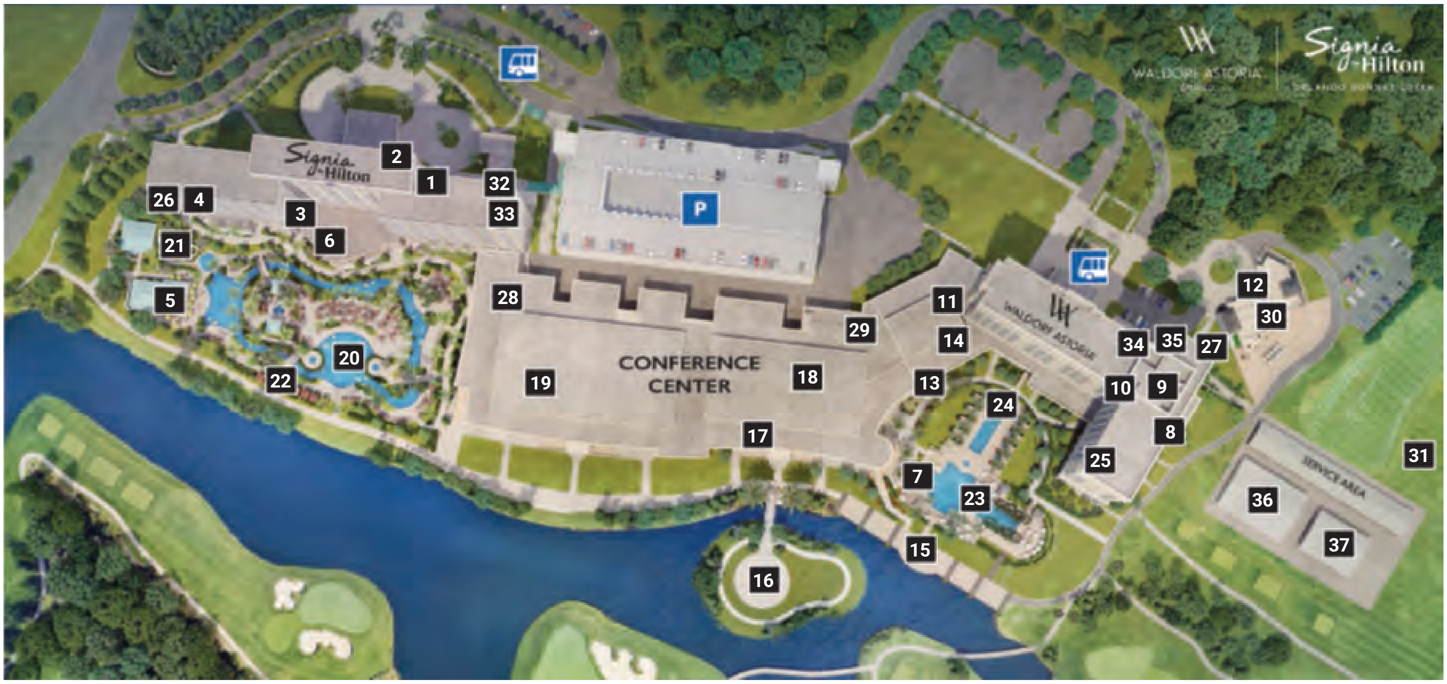
Fabio Figueiredo is a co-founder and president of ABRAFEU, the Brazilian Association for Facioscapulohumeral Dystrophy. He graduated in economics, with an MBA in marketing. He is collaborating with international partners to bring affordable genetic diagnosis to patients in Brazil and develop a mobile app for a patient registry.

***Raj Badiani** started FSHD UK in July 2021 with the idea of bringing together key stakeholders to collaborate and coordinate in getting the UK ready for FSHD clinical trials. She began her career in banking and became IT & business projects/portfolio/services manager for a global consumer company. She now volunteers at Kew Gardens and loves to travel, watch tennis, and play bridge.*

Q&A
12:00–12:30 p.m.

LUNCH & FINALE
12:30–1:30 p.m.
Grand Ballroom

COMPLEX RESORT MAP



RESTAURANTS & LOUNGES

1	Zeta Asia
2	MUSE
3	Harvest Bistro
4	La Luce®
5	Beech®
6	MYTH Bar
7	Aquamarine
8	Bull & Bear®
9	Peacock Alley®
10	Oscar's®
11	Sir Harry's Lounge
12	The Clubhouse Grille

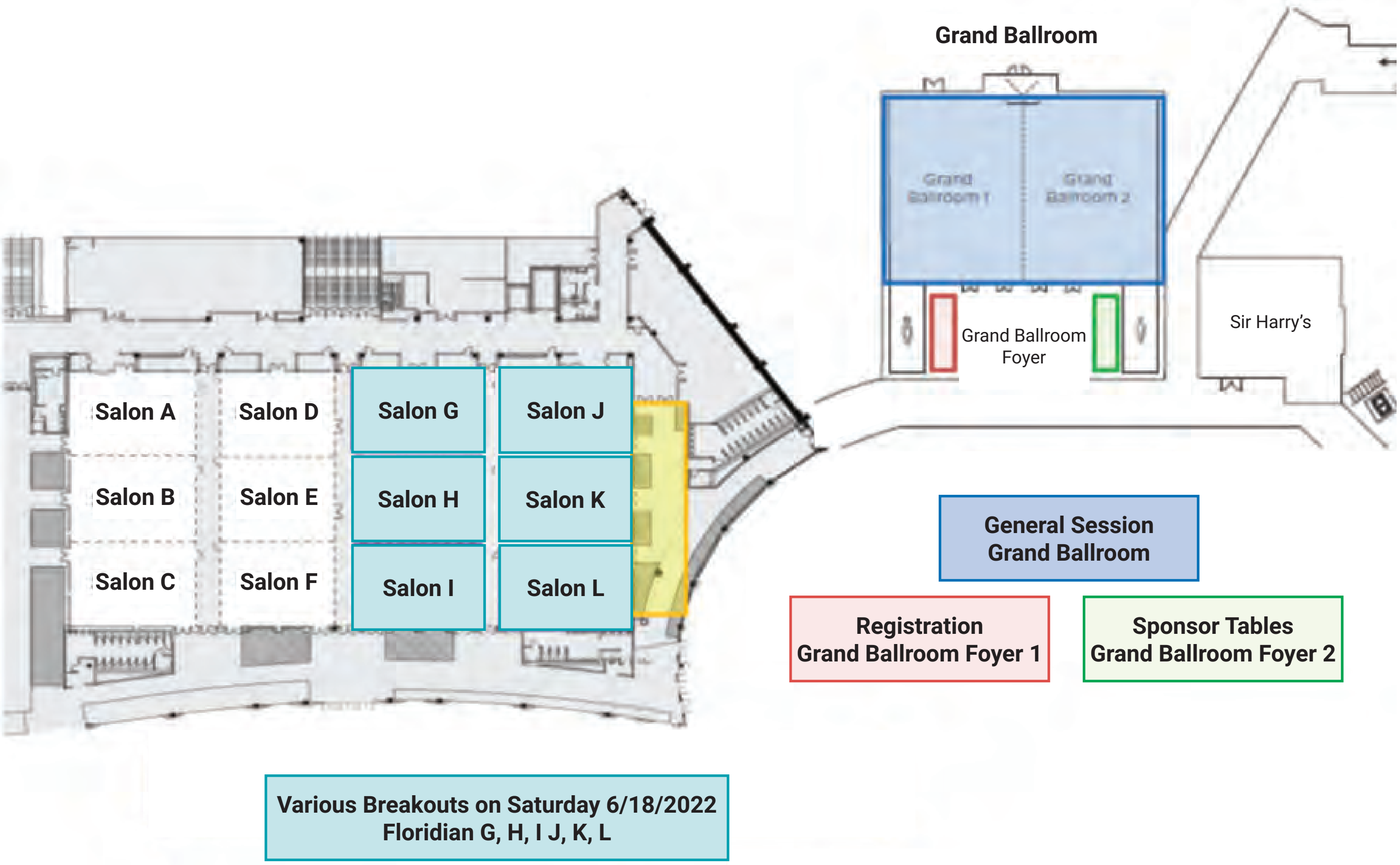
FUNCTION SPACE

13	Waldorf Astoria Meeting Rooms
14	Waldorf Astoria Grand Ballroom
15	Promenade
16	Signature Island
17	Signia by Hilton Meeting Rooms
18	Floridian Ballroom
19	Bonnet Creek Ballroom

AMENITIES & TRANSPORTATION

20	Signia by Hilton Pool & Lazy River
21	Signia by Hilton Water Slide
22	Signia by Hilton Private Cabanas
23	Waldorf Astoria Private Cabanas
24	Waldorf Astoria Pool Cabanas
25	Waldorf Fitness Center
26	Signia by Hilton Fitness Center
27	Waldorf Astoria Spa
28	Full-Service Business Center
29	Self-Service Business Center (24-Hour)
30	Waldorf Astoria® Golf Pro Shop
31	Waldorf Astoria® Golf Club
32	FunZone Arcade
33	Disney Store
34	Sundries Shop
35	Daniella Ortiz
36	Golf Pavilion
37	Golf Pavilion Gardens
🚌	Shuttle Pick-Up Station
P	Signia by Hilton & Conference Parking

ROOM LAYOUT



General Session
Grand Ballroom

Registration
Grand Ballroom Foyer 1

Sponsor Tables
Grand Ballroom Foyer 2

Various Breakouts on Saturday 6/18/2022
Floridian G, H, I J, K, L

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LIGHTING THE WAY TO A CURE