



DESSH FAMILY CONFERENCE

Understanding DESSH ♦ Living with
DESSH ♦ Shaping the Future

SEPTEMBER 16, 2026





LUCINDA ANTONACCI-FULTON

Board President, The DESSH Foundation

✓ Scientific Leadership

✓ Genetics and Research

✓ Strategic Partnerships



WELCOME TO OUR COMMUNITY



BEFORE WE GET STARTED

Make yourself at home

- ✓ Food and Drinks - Breakfast until 10:15 | Lunch 12:20 | Refreshments all day
- ✓ Patio + Lobby - Feel free to use these spaces throughout the day
- ✓ Parking passes available
- ✓ Recording of conference and presentations will be posted at www.desshclinic.com soon
- ✓ Questions? Find Caitlin or Colleen



WiFi Network: Rentals
Password: Komodo



HOW TODAY WORKS

A few things to know

- ✓ **Meet Savannah** – Clinic Coordinator + Office Hours
- ✓ **Office Hours** – Sign up during presentations for 10-min conversations
- ✓ **Cameras Are Rolling** – Photos, video + family interviews throughout the day
- ✓ **Kids Are Welcome Everywhere** – Zoo adventures + activity room available
- ✓ **Clinic Families** – see Savannah today | security check-in tomorrow



Need Help?

Colleen – Conference and Zoo

Savannah – Clinic and Hospital

Caitlin – Everything in between 🙄





Your
feedback
matters!



YOU TOLD US WHAT YOU WANTED

WE ASKED. YOU ANSWERED. WE LISTENED.

What does DESStH
look like over time?

What treatments
might be possible?

What are we
learning?

What can we do to help
our children today?

TODAY'S STORY



What do we know today?

What can help us now?

Where do we go from here?



LOOK HOW FAR WE'VE COME

.....



2019



TODAY



- Families finding one another.
- Very little dedicated DESSH infrastructure.

-  Global DESSH community
-  Multidisciplinary clinic
-  Natural history research
-  Research models
-  Medical Advisory Board
-  Growing scientific partnerships

WHERE WE'RE GOING

2027 → *2030*



DESSH International

Build an organization that reflects our global community

Expand The DESSH Clinic Model

Additional clinic sites nationally & internationally
Move toward consistent care guidance

Become Clinical Trial Ready

Stronger data, research, collaborations, readiness

Build The Organization To Support It

Dedicated Expertise, stronger partnerships, sustainable growth

One global DESSH Community

THANK YOU

To the people who make this possible



Washington University

St. Louis Children's Hospital

Expert Clinicians

Dr. Marwan Shinawi, Dr. Judith Weisenberg, Dr. Margaret Reynolds,
Dr. Sarah Girresch-Ward, Kathleen Sisco, RN, CPNP

Clinical Research Coordinators

Savannah Fisher, Dana Kiley, Michelle Oliva

Intellectual & Developmental Diseases Research Center (IDDRC)

Harrison Gabel, PhD., Anna Abbacchi, MA, MS, LPC

Pediatric Clinical Research Unit staff

**Speakers • Clinical & Research Partners •
Volunteers • Families**

DESSH Foundation

Board of Directors

Lucinda Antonacci-Fulton, Veronica Sandra Addae, Patty Cardona,
Susan Ford, Amanda Murphy, Melissa Sidebottom, Carter Smith,
Colleen Tosti

Medical Advisers

Drs. Harrison Gabel, CH Kim, Marwan Shinawi, Amanda Smith,
Daniel Vogt

Clinic Planning Committee

Susan Ford, Stephanie Sallam, Melissa Sidebottom, Colleen Tosti

Symposium Speakers, Language Translators, and Child Care Volunteers

CITIZEN HEALTH AND RARE-X

Your records in one place you own, and a personal AI teammate for the daily work of DESSH care. Setup takes about 5 minutes.

FOR FAMILIES

The hardest part of rare disease care is keeping it all in one place. Ari does that part.

- Point Ari at your health portals and it pulls your records
- Your scattered history, in one place you own
- Then ask it anything, or have it prep your next appointment
- Ari can check in on you, so nothing slips

*Get
Started*



FOR RESEARCH

The information Ari already organizes for you can help researchers understand DESSH faster.

- Help build knowledge from real-world DESSH medical histories
- Complements our existing DESSH research
- Participation is voluntary

The more families who take part, the faster the whole community moves toward answers.



FADE

LIV QUIGLEY

Singer / Songwriter

'Fade' is about how I felt so trapped and alone when I was younger before I got my diagnosis as I could never understand why I constantly had this feeling. It also has positive message about letting go and not caring what anyone thinks of you.



Liv Q @livquigleyy



@LivQuigleyMusic



livquigleyyy



EPILEPSY ACTION NETWORK

The DESSH Foundation stands with epilepsy organizations across the country in calling for a National Plan For Epilepsy [S. 494 and H.R. 1189.]

To pass this legislation, we need HELP from people who LIVE all across the US.

- Scan the QR code.
- Enter your street address and zip code.
- Send your Members of Congress a message
- Personalize it about why passing the plan is important to YOU.

epilepsiesactionnetwork.org
#NationalPlan4Epilepsy



Scan me

***"We need faster
access to genetic
testing and
answers."***

***"Families like mine living
with DESSH need faster
diagnosis, better coordinated
care, and access to specialists
no matter where they live."***

CREATE YOUR C.R.I.D.

The Clinical Research ID (CRID) is a service that enables patients involved in clinical research the opportunity to create their own Unique Universal ID. By sharing your CRID, researchers can then reuse, merge, and share your research data (without using your private health information or identifying information).

- ✓ **Always free for parents and patients**
- ✓ **CRID can be added to research studies retrospectively.**
- ✓ **CRID data is always private**



SCAN ME





GROUP PHOTO

**Grab your family members
and strike a pose!**



Smile