

DESSH Medical Clinic and Family Outings Agenda
September 11 – 13, 2024
St. Louis, MO

Wednesday – September 11, 2024

6:00 p.m. DESSH Welcome Dinner

ALOFT Hotel, 4245 Duncan Ave, St. Louis MO 53110
Room: Tactic One Meeting Room

Please join us Wednesday evening for dinner and a chance to meet and spend time with our DESSH Families.

Dinner provided from Hacienda Mexican Restaurant. Water and soda will be served.
The hotel bar is also available for anyone who wishes to purchase a drink.

Thursday – September 12, 2024

See Schedule Clinic Appointments – Please refer to your personal schedule of appointments.
St. Louis Children's Hospital
One Children's Place, St. Louis, MO 63110
Pediatric Clinical Research Unit (PCRU) – 11th Floor

8:00 a.m. Coffee/Danish – 11th floor

12:00 p.m. Lunch – Pizza and buttered pasta (from Anthonino's Taverna)
PCRU Room – 11th Floor Children's Hospital

5:00 p.m. **The Botanical Garden**
4344 Shaw Blvd, St. Louis MO 63110
Join this DESSH sponsored event on a stroll through the beautiful gardens and Children's Garden with playground!
Boxed "dinner" will be provided.
<https://www.missouribotanicalgarden.org/>

Note: We have arranged for therapy dog(s) to visit the 11th floor during the clinic hours on Thursday and Friday.

Friday – September 13, 2024

- See Schedule Clinic Appointments – Please refer to your personal schedule of appointments.
St. Louis Children's Hospital
One Children's Place, St. Louis, MO 63110
Pediatric Clinical Research Unit (PCRU) – 11th Floor
- 8:00 a.m. Coffee/Danish – 11th Floor
- 12:00 p.m. Lunch on your own
- 5:30 p.m. **The Shack**
731 S Lindbergh Blvd., Frontenac, MO 63131
Please join us for this DESSH sponsored ~~dinner~~ BREAKFAST.
Yes, that is correct – we are having Breakfast for Dinner. The Shack is well known for
their delicious breakfast and we thought – who doesn't like Breakfast for Dinner!

Saturday – September 14, 2024

- 8:00 a.m. DESSH Family Conference
Eric P. Newman Education Center
600 E. Euclid Ave, St. Louis, MO 63110
2nd Floor and 3rd Floor

Join us Saturday for the DESSH Family Conference where you will have the opportunity to hear Dr. Marwan Shinawi and other medical professionals speak and answer your questions. DESSH scientific advisors Dr. Daniel Vogt and Dr. Alyssa Erickson will share the latest updates on their research.

***Refer to the DESSH Symposium Agenda for details of the day.
Childcare will be provided.***

DESSH Family Symposium Agenda
Eric P. Newman Education Center
600 E. Euclid Ave, St. Louis, MO 63110
Saturday, September 14, 2024
Seminar Room B
8:00 am – 1:00 pm

- 8:00 a.m. DESSH Breakfast
 Loge Room – 2nd Floor
 Menu will include: Breakfast Wraps, Fruit, Assorted Pastries,
 Coffee, Tea, Juice and Water.
- 8:20 a.m. Child Care Sign In
 Room 309 – 3rd Floor
 See separate Child Care Agenda for planned events.
- 8:30 a.m. Opening Remarks
 Seminar Room B - 2nd Floor
 Caitlin Piccirillo, DESSH Foundation Founder and President
- 8:40 a.m. DeSanto Shinawi Syndrome Overview
 Dr. Marwan Shinawi, MD – Genetics
- 9:30 a.m. Gastrointestinal Symptom Management
 Dr. Karine Amirikian, MD – Gastroenterology
- 10:15 a.m. DESSH Patient Story
 Kelly Graham, Leo Bouckhout's Mom
- 10:45 a.m. Break
- 11:00 a.m. Behavior Management in DESSH
 Dr. Paul Glaser, MD, PhD – Child & Adolescent Psychiatry
- 11:45 a.m. DESSH Research: Vogt and Kim Labs.
 Dr. Daniel Vogt, PhD
- 12:15 p.m. DESSH Research: Gabel Lab
 Dr. Alyssa Erickson
- 12:35 p.m. DESSH Foundation Update and Closing Remarks
 Caitlin Piccirillo, Founder and President
- 12:45 p.m. Childcare Pick Up and Group Photo – 3rd Floor

**DESSH Family Symposium
Child Care Agenda
8:00 am – 1:00 pm**

- 8:00 a.m. **DESSH Breakfast**
 Loge Room - 2nd Floor
 Menu will include: Breakfast Wraps, Fruit, Assorted Pastries,
 Coffee, Tea, Juice and Water.
- 8:20 a.m. **Child Care Sign In – Room 309**
 Please make your way to the 3rd floor for Child Care
 The DESSH Foundation has hired a Child Care company, STL Sitters, to care for the
 children so you can participate in the conference. We have scheduled the following
 activities for any child who wishes to participate:

Open Activities

- 8:30 a.m. **Sign in / Crafts /Movie**

 Room 309. Please sign in your child. The DESSH Foundation will have assorted crafts,
 games, and a movie.
- 9:00 a.m. **Entertainment by Babaloo**

Room 308: Babaloo is no run-of-the-mill kids' crooner. Babaloo is high energy, over-
 the-top, and FUN. With Singing Dancing and Music, Magic and Mayhem. And Laughing...
 Lots of Laughing!
- 10:00 a.m. **Vitality Ballet**

Room 308: Ballerinas from Vitality Ballet will visit to dance with the children, tutus
 and all!
- 10:30 a.m. **Snack, Juice and Water will be provided on the 3rd floor**
- Open **Quiet Room**

Room 307: This room will also be used for anyone needing to take a break and have
 some quiet time.
- Per **Neuro-Cognitive Assessments**
 Schedule **Room 301 and 305:** These rooms are designated for anyone scheduled
 for neuro-cognitive assessments

NOTE: *Anyone who has luggage or any items they need to store, Room 307 is available*

Third Floor Layout – *Keep in mind there is another group utilizing Room 302 at the top of the stairs.*
Please be mindful when in the hallway.

