



2017
INTERNATIONAL
FAMILY
CONFERENCE
June 29–July 1, 2017 • Washington DC



Because we don't know
what's possible

Welcome

to the Mowat-Wilson Syndrome Foundation 2017 International Family Conference

The Board of Directors of the Mowat-Wilson Syndrome Foundation welcome all of you to the Mowat-Wilson Syndrome Foundation 2017 International Family Conference!

We would like to thank all of our speakers, workshops leaders, volunteers, exhibitors, and generous donors for making this event a reality for our Mowat-Wilson Syndrome community of families!

We hope that you will have a wonderful time this weekend, filled with useful ideas and information, fellowship with families and hope for the future---

Because we don't know
what's possible

Sincerely,

*The Mowat-Wilson Syndrome Foundation
Board of Directors*

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CHILDCARE INFORMATION
PROFESSIONAL CHILD CARE PROVIDED BY
KIDDIECORP, INC.

FRIDAY, JUNE 30TH & SATURDAY, JULY 1ST

1. CHILDREN 5YRS OR UNDER----**JACKSON MEETING ROOM-LOBBY FLOOR**
2. CHILDREN 6-11 YEARS-----**JEFFERSON MEETING ROOM-LOBBY FLOOR**
3. TEENS & ADULTS (MWS)-----**LEE MEETING ROOM-LOBBY FLOOR**

MORNING DROP OFF TIME: 8:30 AM - 9:00 AM

LUNCH PICK-UP TIME: 12:00 PM - 12:30 PM

AFTERNOON DROP OFF TIME: 1:00 PM - 1:30 PM

AFTERNOON PICK-UP TIME: 4:30 PM - 5:00 PM

PLEASE NOTE THAT KIDDIECORP HAS
COSTLY LATE PICKUP FEES

CONFERENCE SCHEDULE

Thursday, June 29, 2017		
TIME	SESSION	LOCATION
3:00 PM – 7:00 PM	Registration Mowat-Wilson Syndrome Foundation 2017 International Family Conference	Grand Ballroom Foyer 1st Floor
4:00 PM +	Marriott Crystal Gateway Hotel Check-In Marriott Crystal Gateway Hotel Registration Desk	Lobby Floor
6:30 PM – 8:30 PM	Meet & Greet Pizza Party	Grand Ballroom – Salons F, G, H, J, K
Friday, June 30, 2017		
7:00 AM – 9:00 AM	Continental Breakfast	Grand Ballroom – Salons F, G, H, J, K
7:30 AM – 8:45 AM	Registration Mowat-Wilson Syndrome Foundation 2017 International Family Conference	Grand Ballroom Foyer
9:00 AM – 12:00 PM	Childcare	See Childcare Room Lists
8:45 AM – 5:00 PM	Information Desk	MWSF Registration Grand Ballroom Foyer
9:00 AM – 10:00 AM	Sibling Seminar Ages 13-17 Yrs	Skyview Lounge
9:00 AM – 12:00 PM	General Session	Grand Ballroom – Salons A, B, C, D, E
10:00 AM – 5:00 PM	Exhibits for the MWS Community Hospitality Seating for Attendees	Skyview Lounge
12:00 PM – 1:30 PM	Boxed Lunch Break Childcare Break for Lunch	Grand Ballroom – Salons F, G, H, J, K
1:30 PM – 4:30 PM	Childcare	See Childcare Room Lists
1:30 PM– 5:00 PM	Family Photo Sessions	See Signup Sheet
1:30 PM– 2:45 PM	Workshops #1 - #4	Grand Ballroom – Salons A, B, C, D, E
2:45 PM – 3:15	Light Coffee Break	Grand Ballroom –Foyer
3:15 PM – 4:30 PM	Workshops #1 - #4	Grand Ballroom – Salons A, B, C, D, E
5:00 PM	Last Call for Childcare Pickup	See Childcare Room Lists
N/A	Dinner on your own	

CONFERENCE SCHEDULE

Saturday, July 1, 2017		
TIME	SESSION	LOCATION
7:00 – 9:00 AM	Full American Breakfast Buffet	Grand Ballroom – Salons F, G, H, J, K
9:00 AM – 12:00 PM	Childcare	See Childcare Room Lists
9:00 AM – 5 PM	Information Desk	MWSF Registration Desk
9:00 AM – 12:30 PM	Family Photo Sessions	See Signup List
9:00 AM – 10:15 AM	Workshops #5 - #8	Grand Ballroom – Salons A, B, C, D, E
10:00 AM – 5:00 PM	Exhibits for the MWS Community Hospitality Seating for Attendees	Skyview Lounge 1 St Floor
10:15 AM – 10:45 AM	Light Coffee Break	Hallway
10:45 AM – 12:00 PM	Workshops #5 - #8	Grand Ballroom – Salons A, B, C, D, E
12:00 AM – 1:30	Lunch on Your Own Childcare Break for Lunch	N/A
1:30 – 4:30 PM	Childcare	See Childcare Room Lists
1:30 PM – 4:30 PM	General Session	Grand Ballroom – Salons A, B, C, D, E
5:00 PM	Last Call for Childcare Pickup	See Childcare Room Lists
6:30 PM – 8:30 PM	Conference Closing Dinner Susan Triunfo, MWSF President Video/Picture Collage Annette Arnold Musical Entertainment David Arnold & Sell Family	Grand Ballroom – Salons A, B, C, D, E

Program Agenda

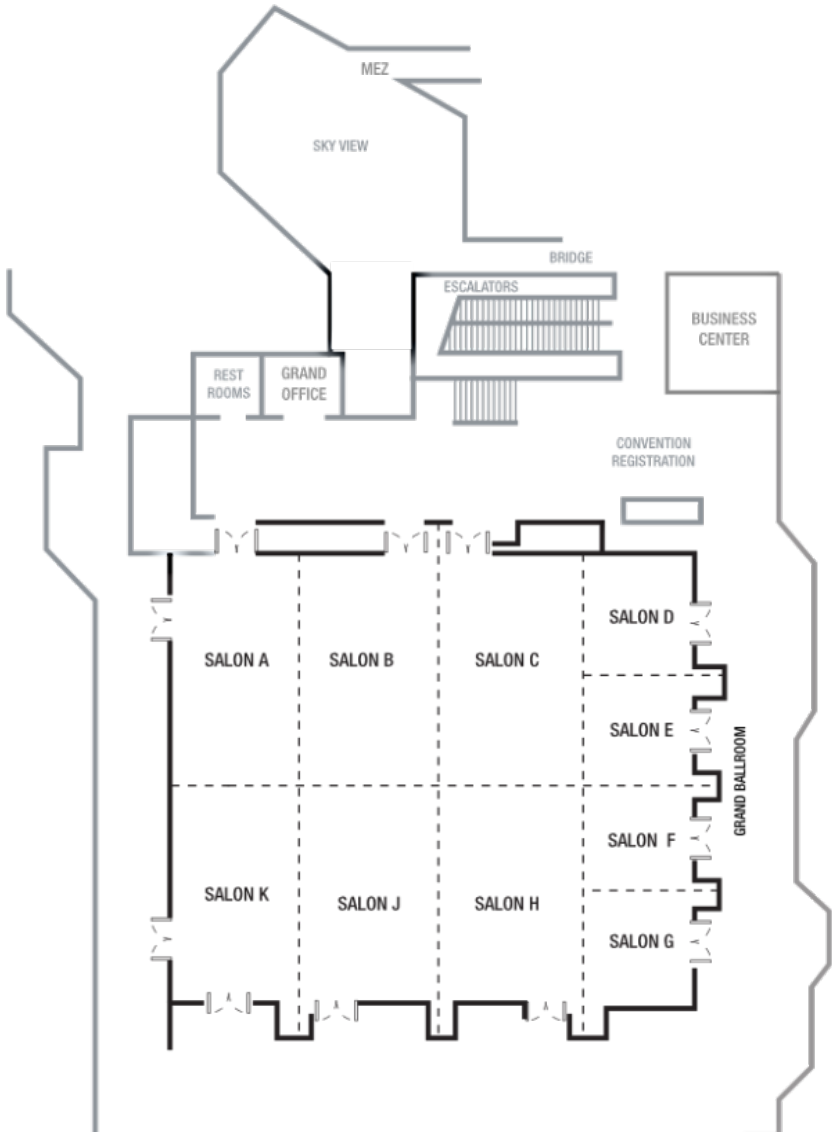
Friday June 30, 2017		
TIME	SESSION	LOCATION
9:00 AM – 9:15 AM	Welcome & Orientation Susan Triunfo, President of the Mowat-Wilson Syndrome Foundation	Grand Ballroom – Salons A, B, C, D, E
9:15 AM – 10:15 AM	Mowat-Wilson Syndrome: Overview and Updates Dr. Meredith Wilson Update on Recent MWS Medical Literature Dr. David Mowat	Grand Ballroom – Salons A, B, C, D, E
10:15 AM – 10:45 AM	Light Coffee Break	Grand Ballroom Foyer
10:45AM – 11:15 AM	Power to the People: Rethinking Registries for Research Katherine Lambertson	Grand Ballroom – Salons A, B, C, D, E
11:15 AM – 12:00 PM	MWS Registry: Patient/Physician Partnership to Improve Care Margaret Adam, M.D.	Grand Ballroom – Salons A, B, C, D, E
12:00 PM – 1:30 PM	Boxed Lunch Break	Grand Ballroom – Salons F, G, H, J, K
1:30 PM– 2:45 PM	Workshops	
	Workshop #1 – Gannet’s Journey: Planning and Creating a Legacy for Life Amy Hosa, Mother to Gannet Alex Gallego, B.A., B.S.	Grand Ballroom – Salon A
	Workshop #2 – Strategies of Bowel Management in the Mowat-Wilson Syndrome Patient Belinda Dickie, M.D., Ph.D.	Grand Ballroom – Salon B
	Workshop #3 – When will my child walk and what equipment will I want? Ginny Paleg, Ph.D., Physical Therapist	Grand Ballroom – Salon C
	Workshop #4 – Your Child CAN learn-Foundations for Successful Learning Cindy Dougherty, B.A., Educational Consultant	Grand Ballroom – Salon D/E
2:45 PM – 3:15 PM	Light Coffee Break	Grand Ballroom Foyer
3:15 PM – 4:30 PM	Workshops	
	Workshop #1 – Gannet’s Journey: Planning and Creating a Legacy for Life Amy Hosa, Mother to Gannet Alex Gallego, B.A., B.S.	Grand Ballroom – Salon A
	Workshop #2 – Strategies of Bowel Management in the Mowat-Wilson Syndrome Patient Belinda Dickie, M.D., Ph.D.	Grand Ballroom – Salon B
	Workshop #3 – When will my child walk and what equipment will I want? Ginny Paleg, Ph.D., Physical Therapist	Grand Ballroom – Salon C
	Workshop #4 – Your Child CAN learn-Foundations for Successful Learning Cindy Dougherty, B.A., Educational Consultant	Grand Ballroom – Salon D/E

Program Agenda

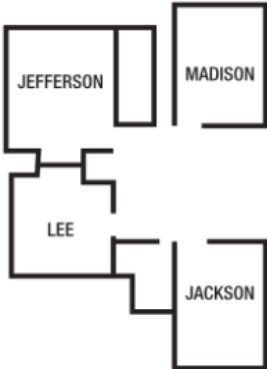
Saturday July 1, 2017		
TIME	SESSION	LOCATION
9:00 AM – 10:15 AM	Workshops	
	Workshop #5 – Augmentative and Alternative Communication- What? Who? Where? When? Why? and How? Kim Singleton, MS, CCC-SLP	Grand Ballroom – Salons A
	Workshop #6 – The Science of Behavior-What Can It Do for Me? Christy Evanko, BCBA, LBA	Grand Ballroom – Salon B
	Workshop #7 – Seizure and Epilepsy in Mowat-Wilson Syndrome John Schreiber, M.D.	Grand Ballroom – Salons C
	Workshop #8 – Be the Changes You Want to See: Advocacy in School and Beyond Kim Jachim-Mellethin, Learning Behavior Specialist & Parent Advocate	Grand Ballroom – Salons D/E
10:15 AM – 10:45 AM	Light Coffee Break	Hallway
10:45 AM – 12:00 PM	Workshops	
	Workshop #5 – Augmentative and Alternative Communication- What? Who? Where? When? Why? and How? Kim Singleton, MS, CCC-SLP	Grand Ballroom – Salon A
	Workshop #6 – The Science of Behavior-What Can It Do for Me? Christy Evanko, BCBA, LBA	Grand Ballroom – Salon B
	Workshop #7 – Seizure and Epilepsy in Mowat-Wilson Syndrome John Schreiber, M.D.	Grand Ballroom – Salon C
	Workshop #8 – Be the Changes You Want to See: Advocacy in School and Beyond Kim Jachim-Mellethin, Learning Behavior Specialist & Parent Advocate	Grand Ballroom – Salon D/E
12:00 PM – 1:30 PM	Lunch on your own	N/A
1:30 PM – 2:15 PM	Recent Research Advances in Mowat-Wilson Syndrome and Future Challenges Jay Vivian, Ph.D. Merlin Butler, M.D., PhD.	Grand Ballroom – Salons A, B, C, D, E
2:15 PM – 3:00 PM	MWS Elimination Study Justine Niemczyk, Psychotherapist Catharina Wagner, M.D.	Grand Ballroom – Salon A
3:00 PM – 3:30 PM	Light Coffee Break	Hallway
3:30 PM – 3:45 PM	Music Therapy Kathlynn Sell, B.M. in Music Therapy	Grand Ballroom – Salon A, B, C, D, E
3:45 PM – 4:30 PM	Parent Panel Parent #1 –Communication – Heleen Trippas, mom to Jorik Parent #2 – Lessons Learned From a Parent’s Perspective – Stacey English, mom to Addison Parent #3 – Collaboration, Community Building & Big Dreams, - Alicia Delashmutt, mom to Neva	Grand Ballroom – Salon A, B, C, D, E

Hotel Information

FIRST FLOOR



LOBBY LEVEL



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EXHIBITOR SCHEDULE

Skyview Lounge-1st Floor

Friday, June 30th, 12:30pm – 4:30pm

- Invitae
- Genetic Alliance
- Tobli Dynavox
- National Seating and Mobility

Saturday, July 1st, 8:30am – 1:00pm

- Invitae
- Genetic Alliance
- Assistive Technology Works
- National Seating and Mobility

SPONSOR APPRECIATION

The Mowat-Wilson Syndrome Foundation wants to thank the following sponsors for providing resources and financial support for our conference and the MWS community.

Marriott Crystal Gateway



Audio Visual Dynamics



Flawlessly Executing Audiovisual Technical Productions

Our mission is to earn and maintain the loyalty of our customers by flawlessly executing their audiovisual technical productions. We will accomplish this by being an audiovisual resource with unmatched customer service, value, consistency, reliability and innovative solutions. Through teamwork and partnering, we will enable our customers to exceed their event goals and objectives.

Desert Lumber & Truss



Desert Lumber & Truss, a division of U.S. LBM Holdings, is a building material supplier in Las Vegas, NV. They have been a major source of building supplies in the Las Vegas Valley for over 25 years. Both Dave and Deby Curry are employed by Desert Lumber & Truss. The company has been very supportive of the Mowat-Wilson Syndrome Foundation since it was founded, in 2013.

SPONSOR APPRECIATION

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Invitae



Jackie Tahiliani, M.S., CGC, Invitae Genetic Counselor

Invitae is a genetic information company whose mission is to bring genetic information into mainstream medical practice to improve the quality of healthcare for billions of people. Specializing in genetic diagnostics for hereditary disorders. Invitae is aggregating the world's genetic tests into a single service with better quality, faster turnaround time, and a lower price than most single-gene tests today. The company currently provides a diagnostic service for a variety of genetic disorders associated with oncology, cardiology, neurology, pediatrics, and other rare disease areas, as well as a clinical whole exome analysis.

SUPPORTER APPRECIATION

The Mowat-Wilson Syndrome Foundation wants to thank the following supporters for providing support and information to help the MWS community.

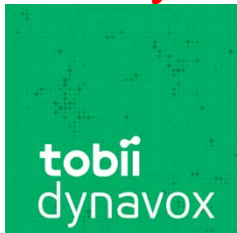
Assistive Technology Works



Teresa Dubovsky, MEd, MEd, CCC-SLP

Assistive Technology Works, Inc. (ATW) is an independent speech generating device distributor supporting Prentke Romich Company and Saltillo products. We are a unique group of speech language pathologists who specialize in Augmentative and Alternative Communication across five states and the District of Columbia. ATW's primary focus is in the use of speech generating devices for any person with complex communication needs regardless of age or diagnosis. Communication solutions using a variety of access methods including touch, switch scanning, head tracking, and eye gaze are available.

Tobii Dynavox



Alex Kurth OT, ATP, Regional Sales Consultant – Washington, D.C., Northern Virginia, Richmond

Tobii Dynavox is a worldwide company dedicated to supporting individuals with communication needs. We offer robust communication systems that may be specified to the individuals needs and will grow with them as they develop their skills. Our product line includes tablets and eye-gaze systems that supports individual communication needs and also computer access, access to telecommunications (texting and phone calls), and access to environmental controls (remote control, fan and light switches). Our portfolio of products will be available for individuals to have hands on use.

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The Mowat-Wilson Syndrome Foundation wants to thank the following supporters for providing support and information to help the MWS community.

Genetic Alliance



Katherine Lambertson and KyungSun Lee

Since its founding, Genetic Alliance has been the voice of advocacy in genetics. We empower others to make their voices heard. Advocacy in the 21st century, however, requires new definitions and new focus. We dissolve boundaries to foster dialogue that includes all stakeholders: from industry professionals, researchers, healthcare providers, and public policy leaders to individuals, families, and communities.

NATIONAL SEATING AND MOBILITY



John Buchbach, ATP, Sales & Branch Manager

National Seating and Mobility is committed to providing custom mobility solutions for its clients. Across three decades, we've grown from five locations to a national network of professional Assistive Technology Providers (ATPs) serving clients, therapists and physicians across the U.S.

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