

Location

DoubleTree by Hilton Portland
1000 NE Multnomah St
Portland, Oregon

Accommodations

Book your room by calling, 800-996-0510 and request the National Foundation for Ectodermal Dysplasias room block. Room block deadline is June 4. The room block rate is valid July 1 - July 7.

Standard Single Queen - \$139
Premium Single King or Double Queens - \$154
Triple/Quad Occupancy - Each additional adult 18 and older will be an additional \$15 per person.

How To Register

You can register online at www.nfed.org on or before Monday, May 25.

Fees

Includes Friday, breakfast, lunch and dinner, Saturday breakfast and lunch; Kays' Kids Camp and Teens Program.
Adult (18 and older) - \$150
Children (birth-17) \$100
Late Registration (Register May 26 or later)
Adult (18 and older) - \$200
Children (birth-17) \$150

Bev Meier's Golden Ticket Fund

Scholarships are available to help attend the Family Conference. Funding is limited. Deadline to apply is March 1.

A special thank you to our sponsor(s) for their generous contributions to our 2018 NFED Family Conference.

Visit www.NFED.org to find a detailed schedule and to learn more about all aspects of Family Conference. Or, contact Kelley Atchison at Kelley@nfed.org or 618-566-2020.

Disclaimer

The National Foundation for Ectodermal Dysplasias Family Conference is not intended as a substitute for medical advice. Only a healthcare provider with a full medical history may determine the proper treatment options. Opinions shared in the sessions do not necessarily reflect those of the NFED. Conference topics are subject to change.



6 Executive Dr., Ste. 2
Fairview Heights, IL 62208-1360



Family Conference 2018



**FRIDAY, JULY 6 AND
SATURDAY, JULY 7, 2018**

About the NFED



The National Foundation for Ectodermal Dysplasias Family Conference is for everyone affected by ectodermal dysplasias and their loved ones. Come and spend two days that will transform your life!

Our caring staff and families will welcome you with open arms and understanding. You will quickly experience – not just know – that you are not alone. You will develop a support network of others affected by ectodermal dysplasias and learn from their practical tips and ideas. See your future as you learn from others who are older or who have had experiences that await you. You will meet people who want to take charge of their ectodermal dysplasias, their health and their life. These friends can last a lifetime.

Meet medical and dental experts and have the unique opportunity to talk with them one-on-one to ask questions. They are not just knowledgeable but compassionate. Learn about current therapies and discover ways to cope with the emotional challenges of ectodermal dysplasias. Learn how to advocate for yourself, for your loved one and for the entire ectodermal dysplasias community. Be motivated by inspirational speakers. You also can share your insights and story to inspire and help others. Stay in the know by hearing the latest research developments for your type of ectodermal dysplasia.

Lastly, come and have fun in Portland, Oregon. Family Conference is about supporting you. Supporting each other.



Thursday, July 5

7 pm - 8:30 pm Early Registration

Friday, July 6

8 am - 9:30 am Registration for new arrivals

General Sessions: all sessions are general sessions

10 am - 10:45 am Conference Welcome –
Mary Fete, Executive Director

10:45 am - 11:30 am Getting to know you activity

11:30 am - 1 pm Lunch

11:30 am - 2:30 pm Dental Screenings (by appt. only)

1:30 pm - 2:30 pm General Overview –
Dr. Clayton Butcher, University of Missouri, Columbia, Missouri

2:40 pm - 3:40 pm Genetics –
Dr. Virginia Sybert, University of Washington, Seattle, Washington

3:50 pm - 5 pm Family Panel (Representation of Syndromes/Ages, etc)

5:30 pm - 8 pm Dinner/Social Activity

Kays' Kids Camp and Teens Program

Sponsored by Louis J. and June E. Kay

Kays' Kids Camp is available for children ages infant-12 years old. Teens Program is for children 13-17 years old.

Both programs include fun, age-appropriate workshops, entertainment, arts and crafts, and social time with others who are affected by ectodermal dysplasias or who have siblings that are.

Saturday, July 7

8:30 am - 9:20 am Ophthalmology –
Dr. Richard Lewis and Dr. Lauren Blieden, Baylor College of Medicine, Houston, Texas

9:30 am - 11:45 am Dental Sessions – Sequence of Care
Dr. Clark Stanford, University of Illinois, Chicago, Illinois
Dr. Timothy J. Wright, University of North Carolina Chapel Hill, North Carolina

12 pm - 1 pm Lunch and Learn (Advocacy and Insurance) –
Becky Abbott, Public Health Consultant and Co-Chair NFED Family-Driven Legislative Advocacy Committee

1:15 pm - 2:15 pm Dermatology Concerns and Treatments–
Dr. Virginia Sybert, University of Washington, Seattle, Washington

1:15 pm - 2:15 pm 504 plan, School Advocacy Working Session

2:30 pm - 4 pm Ask the Experts
Liaison Regional Stations

4:30 pm - 5 pm Closing Remarks –
Mary Fete, Executive Director

