

## Location

The Westin Tyson's Corner  
7801 Leesburg Pike  
Falls Church, Virginia

## Accommodations

Special Room Rate: \$109/night plus taxes. Book your room by calling 888-627-8970 or online at [www.starwoodmeeting.com](http://www.starwoodmeeting.com). Room block deadline is June 20. The room block rate is valid July 17-July 24.

## How To Register

You can register online at [www.nfed.org](http://www.nfed.org) on or before Thursday, June 15.

### Fees

Includes Thursday dinner, Friday breakfast, lunch and dinner; and Saturday breakfast and lunch; Kays' Kids Camp and Teens Program

Adult (18 and older) — \$185  
Children (birth-17) — \$125

### Late Registration (Register June 16 or later)

Adult (18 and older) — \$250  
Children (birth-17) — \$185

### 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 2017 NFED Family Conference.

Visit [www.NFED.org](http://www.NFED.org) to find a detailed schedule and to learn more about all aspects of Family Conference, Advocacy Day on Capitol Hill and Research Day. Or, contact Kelley Atchison at [Kelley@nfed.org](mailto: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 2017

2017 NFED  
**Family  
Conference**  
JULY 20 — JULY 22 • FALLS CHURCH, VA



# About

The National Foundation for Ectodermal Dysplasias Family Conference is for everyone affected by ectodermal dysplasias and their loved ones. Come and spend three 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 the historic and scenic United States capital! Falls Church is right outside of Washington D.C. Family Conference is about supporting you. Supporting each other.

**Training for Advocacy Day on Capitol Hill** — Tuesday, July 18

**Advocacy Day on Capitol Hill** — Wednesday, July 19

**Family Conference** — Thursday, July 20-Saturday, July 22

## Sessions

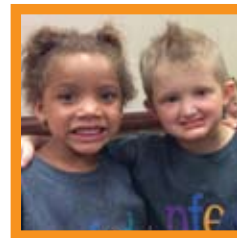
- **Newbies Session** — First and second-time attendees will register early on Thursday, receive a special welcome and hear an overview of the ectodermal dysplasias.
- **Inspirational Speakers** — Listen to families speak on their experiences.
- **Syndrome Specific Workshops** — Learn information about your syndrome from members of the Scientific Advisory Council (SAC), researchers and other families.
- **Ask the Experts** — Meet one-on-one with members of the SAC and family experts to ask questions about your personal concerns.
- **Dental Treatment Options** — Learn and understand what are appropriate best practices for adults, tweens and kids.
- **Dental Evaluations** — Meet one-on-one with a dentist to discuss your concerns.

## Kays' Kids Camp & 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 who are.

## Pre-Conference Event on Capitol Hill



Join us before the Family Conference on Wednesday, July 19 on Capitol Hill. You will have the opportunity to talk to lawmakers about legislative issues that matter most to the ectodermal dysplasias community. This is the first step in our advocacy campaign to have legislation in all 50 states mandating medical benefits for the dental treatment of ectodermal dysplasias. You will be trained for these visits on Tuesday, July 18.

## Volunteers needed for a new NIH study for Craniofacial Anomalies

Doctors at the National Institutes of Health (NIH) are conducting a study that will identify the conditions of craniofacial abnormalities, including ectodermal dysplasias, in an effort to develop treatments specific to the type of the condition.

The research team invites volunteers with the condition, their family members, and healthy volunteers to participate. Eligibility conditions will be sent to you soon. Please visit our web site to sign-up to participate.

NIH will schedule appointments for individuals and families affected by ectodermal dysplasias the week of July 17th-21st.

All study-related tests and procedures are provided at no cost.

- All participants will receive a medical, and dental exam.
- DNA sample (blood or buccal swab) and/or Cone Beam CT scan of the face, head and neck.



# A Monumental Experience