

Location

DoubleTree by Hilton
16625 Swingley Road
Chesterfield, Missouri

Accommodations

Book your room by calling 800-315-5459 (ask for the NFED 2022 Family Conference block) or by going online <https://group.doubletree.com/gurh6s>.

Room block deadline is Tuesday, June 14, 2022. Room rate is \$146 plus taxes.

How To Register

You can register online at www.nfed.org on or before Monday, May 24.

Fees

Includes Thursday dinner; Friday breakfast, lunch and dinner; Saturday breakfast and lunch; Kays' Kids Camp and Teens Program activities; and an invitation to the NFED Gala and 40th Anniversary Celebration on Friday evening. Each paid registration will receive a Conference T-shirt.

Adult (18 and older) - \$185

Children (birth-17) - \$125

Late Registration (Register May 25 or later)

Adult (18 and older) - \$260

Children (birth-17) - \$200

Registration Cancellation Policy

If you register but are unable to attend the Family Conference, the NFED will refund your total conference registration fees less a \$30 administration fee. There will be no refunds allowed on or after July 1.

Bev Meier's Golden Ticket Fund

Scholarships are available to help you attend the Family Conference. Funding is limited. Apply online at time of registration.

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

Disclaimer

The NFED 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. Family Conference events are subject to change based on local and CDC guidelines. Our number one priority is and always will be the safety of you and your family.



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



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Family Conference 2022



Thursday, July 14 through
Saturday, July 16, 2022



Thursday, July 14
10:00 a.m. — 7:30 p.m.

Friday, July 15
6:30 a.m. — 9:00 p.m.

Saturday, July 16
8:00 a.m. — 3:00 p.m.

About

The National Foundation for Ectodermal Dysplasias (NFED) Family Conference is for everyone affected by ectodermal dysplasias and their loved ones. Come and spend three full days that will enhance your life! Join us in celebrating the NFED's 40th Anniversary and returning to an in-person conference!

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. At the conference, you will:

- Develop a support network of others affected by ectodermal dysplasias and learn from their practical tips and ideas.
- 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.
- Discuss recommended treatment options and 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.

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. While parents and adults are participating in sessions, kids and teens are kept busy with activities in Kays' Kids Camp and Teen Program.

View a detailed schedule at <https://www.nfed.org/events/2022-family-conference/>.

Kays' Kids Camp and Teens Program

Sponsored by the Louis J. and June E. Kay Foundation

Kays' Kids Camp is available for children ages infant - 13 years old (8th grade). The Teens Program is for children 14-17 years old (high school). 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.

40th Anniversary Celebration

Adult attendees are invited to the NFED's 40th Anniversary Celebration Friday night. The evening will celebrate a history of achievements in the understanding, treatment and future of ectodermal dysplasias.

Dinner is included with your Conference registration. Take your children to Kays' Kids Camp and Teens Program. Then come and enjoy the entertainment and live and silent auctions. A cash bar will be available. If you would like to learn more about sponsoring NFED's 40th Anniversary Year, please contact Tim Mickelson, tim@nfed.org.

Chance Auction

Continued by popular demand: the Chance Auction. A fun and exciting way to raise a little money for the NFED. You put your purchased tickets into the bags of the items you'd most like to win. However, we need your HELP. We are accepting donations of children's items as well as some adult items for the auction. Please bring them to the conference on Thursday by 3 p.m. For more info: lea@nfed.org or 618-566-6871.

