Location
Sheraton Pentagon City
900 S. Orme St.
Arlington, VA 22204
(This upscale hotel is a 4.2 mile-drive from the White House and a 5.2-mile drive from the iconic United States Capitol.)

Accommodations
Book your room online at https://book.passkey.com/e/50018542. Or, call 1-800-325-3535, ask for Sheraton Pentagon City Hotel, then ask for the NFED Family Conference block or use Hotel Mini code "NFE".

If you want to reserve rooms outside of the block dates, please contact the Sheraton by phone.

Room block deadline is Thursday, June 4. Room rate is $159 plus taxes. Reserve your room early. The rate will not be available when our room block is full.

How To Register
You can register online at www.nfed.org on or before Monday, May 11.

Fees
Includes Tuesday, continental breakfast, lunch and dinner; Wednesday breakfast, lunch at Capitol Hill and dinner; and Kays’ Kids Camp and Tweens/Teens Program. Each paid registration will receive a Conference t-shirt.

Adult (18 and older) - $100
Children (birth–17) - $75

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 refund allowed on or after May 29.

Bev Meier’s Golden Ticket Fund
Travel stipends are available to help you attend the Family Conference. Funding is limited. Apply online by February 28.

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.
Attend the 2020 Family Conference to connect with other families and build your support network. You can participate in activities that enable you to meet others who share your syndrome or concerns or live in your area.

You’ll also learn from family experts who will discuss their experience with ectodermal dysplasias. These special sessions are designed for you to learn from their wisdom, ask questions and discover you are in good company! You’ll have an opportunity to break into small groups to discuss what it’s like living with ectodermal dysplasias. Explore and share your feelings in a safe place, where others understand.

Finally, empower yourself by learning how to confidently tell your story and be your own best advocate – at home and on Capitol Hill. On Wednesday, we will storm Capitol Hill together! You will be a part of a team and visit your respective legislators to ask for their support of the Ensuring Lasting Smiles Act. We will schedule your legislative meetings in advance.

Monday, June 22
6:00 p.m. - 8:00 p.m.
Registration

Tuesday, June 23
8:00 a.m. - 9:00 a.m.
Registration
9:00 a.m.
Kids Camp Opens
9:00 a.m.
Tweens & Teens Session
9:30 a.m.
Welcome – Mary Fete, NFED Executive Director
9:30 a.m.
Tweens & Teens 12-17
10:00 a.m. - 10:45 a.m.
Motivational Speaker
10:50 a.m. - 12 p.m.
Connect Our Families - Family Experts Panel
12:00 p.m. - 1:15 p.m.
Lunch with Families Who Share Your Syndrome
12:00 p.m. - 1:15 p.m.
Lunch with Families Who Share Your Syndrome
1:30 p.m. - 2:15 p.m.
Share Our Experiences - Small Group Discussions
2:30 p.m. - 4:30 p.m.
Empower Our Voices - Learn How To Advocate
4:30 p.m. - 4:45 p.m.
Advocacy Training for Tweens/Teens
4:45 p.m. - 5:00 p.m.
Final Thoughts
6:00 p.m.
Dinner
7:30 p.m.
Family Party

Wednesday, June 24
NFED Advocacy Day on Capitol Hill
7:00 a.m.
Grab Breakfast To Go
7:30 a.m.
Buses Depart for Capitol Hill
8:00 a.m.
Families Storm Capitol Hill
9:00 a.m. - 4:00 p.m.
Families Meet With Legislators
4:30 p.m.
Bus Departs for Hotel
5:30 p.m.
Advocacy Recap
6:00 p.m.
Dinner

Kays’ Kids Camp and Tweens/Teens Program

Sponsored by Louis J. and June E. Kay Foundation

Kays’ Kids Camp is available for children ages infant-11 years-old. The Tweens/Teens Program is for children 12-17 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. Tweens/Teens who register for their program will participate in off-site activities.