



NFED 2022 Family Conference Schedule-at-a-Glance

Schedule subject to change

Thursday, July 14, 2022

11 a.m. - 12 p.m.

Registration (First and second time attendees)

12 p.m. - 1 p.m.

Registration (All attendees)

12:30 p.m. - 5:30 p.m.

Kays' Kids Camp Hours*

1 p.m. - 1:30 p.m.

Conference Welcome

1:30 p.m. - 3 p.m.

New Attendee Session:

Speakers will discuss how ectodermal dysplasias can affect the body from head to toe. They will address general pediatric and adult topics including dermatology and ear, nose and throat concerns. A family will share their personal story.

1:30 p.m. - 3 p.m.

Returning Attendees - New Session!:

Been to MANY NFED Family Conferences? Catch up with friends during this time!

3 p.m. - 4:30 p.m.

Family Panel:

Individuals affected by ectodermal dysplasias and family members share their personal stories and answer questions based on their personal experiences.

4:30 p.m. - 5 p.m.

Closing Session

5:30 p.m. - 6:30 p.m.

Dinner:

Dinner will be served for all registered conference attendees and speakers. (This meal is included in your conference registration fee.)

6:30 p.m. - 9 p.m.

Pool Party:

Pool party and outdoor activities for all registered conference attendees and speakers.

Friday, July 15, 2022

7 a.m. - 8:30 a.m.

Breakfast (all registered conference attendees and speakers)

8:30 a.m. - 9 p.m.

Kays' Kids Camp Hours*

9 a.m. - 9:40 a.m.

All there is to know about Skin, Hair, Teeth and Nails (General Session)

9:40 a.m. - 10:20 a.m.

Ears, Nose and Throat Concerns and Treatments (General Session)

10:20 a.m. - 11 p.m.

Eye Concerns and Treatments (General Session)

11 a.m. - 11:40 a.m.

Understanding Genetic Testing, Results and Genetic Counseling (General Session)

12 p.m. - 1:30 p.m.

Lunch (for all registered conference attendees and speakers):

Children registered for Kays' Kids Camp will eat in Kids Camp. Teens registered for the Teen Program will eat with the adults.

- 1:30 p.m. - 4 p.m. **Syndrome Specifics** (family-led):
Meet with others who are also affected by the particular syndrome that affects your family. Families will lead discussions based on their personal experiences. Take advantage of this opportunity to share what has worked for your family and to learn from others. A wide range of topics will be covered, from how to advocate at school to how to explain ectodermal dysplasia to loved one. Attendees will have time to separate into smaller groups, if preferred.
- 4:15 p.m. - 5:30 p.m. **Dental Session** (General Session):
Experts will address oral health care issues and treatment options that children, adolescents, and adults face.
- 6 p.m. - 9 p.m. **Anniversary Celebration Gala and Dinner:**
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 for dinner and activities. 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.
- Saturday, July 16, 2022**
- 8 a.m. - 9:30 a.m. **Breakfast** (for all registered conference attendees and speakers)
- 9 a.m. - 12 p.m. **Dental Evaluations:**
Make sure to request your dental evaluation on your registration form (late requests cannot be guaranteed).
- 9 a.m. - 12 p.m. **Syndrome Group Photos**
- 9 a.m. - 12 p.m. **Ask the Experts**
- 9 a.m. - 12 p.m. **Research** (TBD)
- 10 a.m. - 2:30 p.m. **Kays' Kids Camp Hours***
- 11 a.m. - 12 p.m. **Lunch** (for all registered conference attendees and speakers):
Children registered for Kays' Kids Camp will eat in Kids Camp. Teens registered for the Teen Program will eat with the adults.
- 12:30 p.m. - 1:30 p.m. **Insurance and Advocacy Update** (General Session):
General tips shared on how to submit your dental claims to your medical insurance company.

We will talk about our efforts to get the Ensuring Lasting Smiles Act passed and how you can help.
- 1:30 p.m. - 2 p.m. **XLHED Update** (General Session)
- 2 p.m. - 2:30 p.m. **Women, Mom's, Men's, Dad's** (Breakout Sessions)
- 2:30 p.m. - 3 p.m. **Closing Session:**
Closing remarks from executive director, Mary Fete and performance from the children registered in Kays' Kids Camp.

***Kays' Kids Camp (Designed for children ages infant - 12 years-old)**

A separate schedule will be available at Kids Camp registration.

***Kays' Teens Program (Designed for children ages 13 - 17)**

A separate schedule will be available at Kids Camp registration.

Additional Happenings at Conference

Photo Room:

Schedule a time for your family photo or photos with friends be taken.

Hospitality Room:

Visit the NFED Selfie Station and schedule time to meet with families throughout the conference.

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 most like to win. However, we need your HELP. Please, donate boys/girls and some items for adults and bring to the family conference on Thursday. For more info: Lea@nfed.org or 618-566-6871.

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. The NFED's number one priority is the health and safety of our families. Although the COVID pandemic hasn't allowed us to meet the past two years, we are hopeful we will be able to see you in person this July! Because we cannot predict what the COVID landscape will look like this summer, it is hard to establish protocols for event safety this far in advance.

We are monitoring the pandemic closely to make the best decisions to ensure our community's health and safety. Please know that we will follow the most current recommendations on safety practices at the time of Family Conference, and we will communicate our COVID response plan closer to the event date.

Learn More:

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.