



Schedule subject to change

Thursday, July 14, 2022

- 11 a.m. - 12 p.m. **Registration** (First and second time attendees) Lobby
- 12 p.m. - 1 p.m. **Registration** (All attendees) Lobby
- 12:30 p.m. - 5:30 p.m. **Kays' Kids Camp Hours**
Kays' Kids Camp (Designed for children ages infant - 13 years-old.)
Kays' Teens Program (Designed for children ages 14 - 17.)
- 1 p.m. - 1:30 p.m. **Conference Welcome** Great Room A-B
Karl Nelsen, Family Conference master of ceremonies, and Mary Fete, NFED executive director, welcome everyone back to the NFED Family Conference.
- 1:30 p.m. - 3 p.m. **New Attendee Session** Great Room A-B
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 Attendee Session** Conference Room B
Been to MANY NFED Family Conferences? Catch up with friends during this time!
- 3 p.m. - 4:30 p.m. **Family Panel** Great Room A-B
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** Great Room A-B
Recap of the day and learn about what is in store for the rest of the weekend.
- 5:30 p.m. - 6:30 p.m. **Dinner** Ballroom
Dinner will be served for all registered conference attendees and speakers. (This meal is included in your conference registration fee.)
- 5:30 p.m. - 8 p.m. Chance Auction bidding
- 8 p.m. - 9 p.m. Chance Auction drawing and item pick up
- 6:30 p.m. - 9 p.m. **Pool Party** Outdoor Pool
Pool party and outdoor activities for all registered conference attendees and speakers.

Friday, July 15, 2022

- 7 a.m. - 8:30 a.m. **Breakfast** Ballroom (for all registered conference attendees and speakers)
- 8:30 a.m. - 9 p.m. **Kays' Kids Camp Hours**
- 8:30 a.m. - 5:30 p.m. **Family Photos** Conference Room B
Appointments for family photo sessions with our photographer should be scheduled through the event app.
- 9 a.m. - 9:40 a.m. **All there is to know about Skin, Hair, Teeth and Nails** Great Room A-B
Learn common symptoms and treatments related to skin, hair, teeth and nails.
- 9:40 a.m. - 10:20 a.m. **Ears, Nose and Throat Concerns and Treatments** Great Room A-B
Learn more about common ear, nose and throat concerns and treatments.
- 10:20 a.m. - 11 a.m. **Eye Concerns and Treatments** Great Room A-B
Learn about potential ophthalmology concerns and treatments.
- 11 a.m. - 12 p.m. **Potential XLHED Treatment Update** Great Room A-B
Cutting edge research! Join us to learn about the exciting EDELIFE clinical trial, which is investigating the potential of a prenatal treatment for XLHED. Initial trials have shown that babies who received the treatment *in utero* had normal sweat gland development as well as increased tooth bud, salivary gland and Meibomian gland development. If approved, this cutting-edge therapy would be the first of its kind to correct a genetic condition before birth. Hear from principal investigator, Dr. Holm Schneider, about the potential treatment. Trial sponsor, EspeRare, will also share information on how the trial will work.
- 12 p.m. - 1:00 p.m. **Lunch** Ballroom (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.
- Hypohidrotic Ectodermal Dysplasias (HED)** - Great Room A
Focal Dermal Hypoplasia (Goltz syndrome) - Conference Room A
Incontinentia Pigmenti (IP) - Conference Room A
P63 - Conference Room C
Other and Unknown Syndromes - Great Room A
- 4:15 p.m. - 5:30 p.m. **Dental Session** Great Room A-B
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 Ballroom

Conference attendees 13 years of age and older are invited to the NFED's 40th Anniversary Celebration Gala. Join us to celebrate a history of achievements as well as our future impact. Dinner is included with your Conference registration.

Take your children to Kays' Kids Camp for dinner and activities, then come enjoy the entertainment and live and silent auctions. A cash bar will be available.

Saturday, July 16, 2022

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

Breakfast Ballroom (for all registered conference attendees and speakers)

9 a.m. - 12 p.m.

Dental Evaluations Conference Room A

If you requested a dental evaluation, check your folder for your appointment time.

9 a.m. - 12 p.m.

Syndrome Group Photos Conference Room B

Check your folder for your scheduled group photo appointment.

9 a.m. - 12 p.m.

Ask the Experts: MASK REQUIRED Ballroom D

Appointments for one-on-one discussions with our medical experts should be scheduled through the event app.

10 a.m. - 3:30 p.m.

Kays' Kids Camp Hours

11 a.m. - 12 p.m.

Lunch Ballroom (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 Great Room A-B

General tips on how to submit dental claims to your medical insurance company will be shared.

We will also talk about our efforts to get the Ensuring Lasting Smiles Act passed and how you can help.

1:30 p.m. - 2:15 p.m.

Understanding Genetic Testing, Results and Genetic Counseling Great Room A-B

Learn the importance of knowing genetic testing and understanding results.

2:30 p.m. - 3 p.m.

Closing Session Great Room A-B

Don't miss your chance to say good-bye to friends and hear closing remarks from executive director, Mary Fete.

Schedules subject to change. We recommend downloading the Cvent app on your mobile device to stay up-to-date on any schedule changes. You should have received an email message with instructions on how to download the application on your Android or Apple device.

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, and we need your HELP. We are seeking volunteers to donate items for children and adults that auction participants can win. Suggested items include toys, gift cards (\$5 - \$10), or small, themed gift baskets. Drop off your donation at the Volunteer Table, located outside of the ballroom, by 4:30 p.m. 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 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. We are monitoring the pandemic closely to make the best decisions to ensure our community's health and safety. Although mask wearing is not mandatory, our Scientific Advisory Council (SAC) strongly recommends that all conference attendees wear a Mask. Study after study has shown that wearing a mask significantly decreases the risk of acquiring and spreading COVID.

All NFED staff members and all SAC members will be wearing a mask at all times that they are in a public space, unless they are eating. SAC members will NOT do any person-to-person consultations unless all parties are wearing a mask, no exceptions.

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.