



## Thursday, July 11, 2019

Lunch will be on your own today. (This meal is not included in your conference registration fee.)

10 a.m. - 11 a.m. Registration for all First-Time Conference Attendees.

11 a.m. - 1 p.m. Registration for all Returning Conference Attendees.

11:15 a.m. - 1 p.m. Beginners' Session: What are Ectodermal Dysplasias?

Members of the NFED Scientific Advisory Council will lead a general discussion on the ectodermal dysplasias and related concerns.

1:30 p.m. - 2:30 p.m. Conference welcome - General Session

2:40 p.m. - 3:20 p.m. Which Muppet Are You? - **NEW** Session - General Session

Learn about two different fun ways to understand yourself better and how you interact with the people closest to you. You will become acquainted with 4Mat and Muppet Theory and how they can help improve your communication with family, co-workers and health care professionals. You will learn how to reduce stress through new frameworks that reflect your personality.

3:30 p.m. - 5 p.m. Family Panel - General Session

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

5:15 p.m. - 5:45 p.m. Getting to know you activity - General Session

6 p.m. - 7:30 p.m. Dinner for all registered conference attendees and speakers. (This meal is included in your conference registration fee.)

## Friday, July 12, 2019

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

- 9 a.m. - 10:45 a.m.    General Session 1
- Listen to members of the medical field discuss general pediatric and adult topics including dermatology and ENT concerns related to ectodermal dysplasias.
- 10:45 a.m. - 11:45 a.m. General Session 2
- Listen to members of the medical field discuss ophthalmology and genetic concerns related to ectodermal dysplasias.
- 12 p.m. - 1:30 p.m.    Lunch for all registered conference attendees and speakers. Children registered for Kids Camp will eat in Kids Camp. Teens registered for the Teen Program will eat with the adults.
- 1:30 p.m. - 2:30 p.m. Ask The Experts
- Have a question that doesn't relate to a session topic or need a one-on-one discussion with one of the medical or dental experts? This is the time to ask! Drop by Ask the Experts. Tables will be marked with the expert's name and area of specialty.
- 2:45 p.m. - 4 p.m.    Syndrome Specific Sessions
- 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
- Professionals will discuss address oral health care issues and treatment options children, adolescents, and adults, including dental implants face.
- 6 p.m. - 9 p.m.    Dinner, pool party and outdoor activities for all registered conference attendees and speakers.

## Saturday, July 13, 2019

- 8 a.m. - 9:30 a.m.    Breakfast for all registered conference attendees and speakers.
- 8:45 a.m. - 9 a.m.    Group Photo
- 9 a.m. - 12 p.m.    Dental Evaluations
- A schedule will be available at Conference check-in.
- 9 a.m. - 10 a.m.    Syndrome photos
- A schedule will be available at Conference check-in.
- 10:15 a.m. - 11 a.m.    Insurance - Breakout session

	Learn general tips on how to submit your dental claims to your medical insurance company.
10:15 a.m. - 11 a.m.	School Advocacy - Breakout session  Learn general tips on how to advocate for your child in school regardless of the available resources in your area.
12 p.m. - 1 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.
1:15 p.m. - 2 p.m.	Update on XLHED Treatment and Research
2 p.m. - 2:30 p.m.	Advocacy Update - General Sessions  You will learn an update on future legislation that will cover treatment expenses related to ectodermal dysplasias symptoms.
2:30 p.m. - 3 p.m.	Finale - General 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.)**

Teens and chaperones will visit local attractions throughout the Conference. Transportation, entry fees and lunch are covered by registration fees and a generous donor.

A separate schedule will be available at a later date. Make sure that you've signed a permission slip for your teenagers. They won't want to miss the fun.

*\*Schedule subject to change\**

