



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. **NEW** Session - More details to follow.- General Session
- 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. Panel of Experts * **NEW** General Session
Listen to members of the medical field discuss topics related to ectodermal dysplasias.

- 11 a.m. - 12:30 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.
- 12:30 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. - 4 p.m. Syndrome Specific Sessions
- These workshops are geared to your particular syndrome. Members of the Scientific Advisory Council and expert researchers present. Families lead group.
- A detailed schedule will be available at a later date.*
- 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 and Learn

During our working lunch, you will learn an update on future legislation that will cover treatment expenses related to ectodermal dysplasias symptoms.

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. – 2:30 p.m. Update on XLHED Treatment and Research

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



Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

www.nfed.org