



DETAILED SCHEDULE

The National Foundation for Ectodermal Dysplasias (NFED) Family Conference is for everyone affected by ectodermal dysplasias and their loved ones. [Visit our website](#) for more information.

Times and topics subject to change

Thursday, July 20, 2017

All attendees must begin at registration to receive their detailed conference registration materials and name tags which are required to attend all sessions and meal functions.

10:30 a.m. – 11:30 a.m.

Registration for first and second-year attendees only

12 p.m. – 2 p.m.

Registration for all other attendees.

Lunch On Your Own

This is not a Conference meal. There is a hotel restaurant or restaurants nearby.

11:30 a.m. – 3:30 p.m.

Dental Evaluations by appointment only

2 p.m. – 3 p.m.

Prosthetic Replacement of the Ocular Surface Ecosystem (PROSE) Treatment Discussion

Dr. Hessen will discuss the benefits of PROSE treatment in patients affected by ectodermal dysplasias. She will explain the details of what patients should expect during their consultation and treatment period and how to find a PROSE treatment provider.

1 p.m. – 3 p.m.

Beginners Session: What are Ectodermal Dysplasias?

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

3:30 p.m. – 4:15 p.m.

General Session: Conference Welcome
 Executive Director Mary Fete welcomes conference attendees.

4:15 p.m. – 5 p.m.

Motivational Speaker

Ryan Haack, CEO, Living One Handed
 Ryan has created a program and authored a children's book, *Different Is Awesome! Acknowledging, Accepting and Celebrating What Makes Us Unique!*

5 p.m. – 6 p.m.

General Session: Family Panel
 Individuals affected by ectodermal dysplasias share their personal stories and answer questions on ectodermal dysplasias based on their personal experiences.

6 p.m. – 7:30 p.m.

Mix & Mingle

Adults have a chance to mingle and enjoy heavy hors d'oeuvres while children and teens enjoy dinner in their Kids' Camp and Teens Program locations.

Friday, July 21, 2017

6:30 a.m. - 8 a.m.
Breakfast

8:30 a.m. - 11:30 p.m.
Syndrome Specific Sessions
Workshops geared to your particular syndrome.
Members of the Scientific Advisory Council and expert researchers present.

Focal Dermal Hypoplasia (Goltz syndrome)
8:30 a.m. - 9:30 a.m.
Introductions - Tell Your Story

9:35 a.m. - 10:30 a.m.
Ophthalmology: Tips & Treatments - Dr. Richard Lewis

10:35 a.m. - 11:30 a.m.
Dermatology: Tips & Treatments - Drs. Alanna Bree and Elaine Siegfried

Hypohidrotic Ectodermal Dysplasias (HED)
8:30 a.m. - 9:30 a.m.
Introductions - Tell Your Story

9:35 a.m. - 10:30 a.m.
ENT: Tips & Treatments - Dr. Timothy Fete

10:35 a.m. - 11:30 a.m.
Pediatrics and Cooling Discussion - Dr. Timothy Fete

10:35 a.m. - 11:30 a.m.
Adults affected by HED meet separately. -
Dr. Clayton Butcher

P63
8:30 a.m. - 9:30 a.m.
Introductions - Tell Your Story.

9:35 a.m. - 10:30 a.m.
Research Update - Dr. Maranke Koster

10:35 a.m. - 11:30 a.m.
Ophthalmology: Tips & Treatments - Dr. Richard Lewis

Other/Unknown
8.30 a.m. - 9:30 a.m.
Introductions - Tell Your Story

9:35 a.m. - 10:30 a.m.
General Genetic and Diagnostic Q & A - Pilar Magoulas

10:35 a.m. - 11:30 a.m.

The Value of a Diagnosis - Pilar Magoulas

11:30 a.m. - 12:15 p.m.
General Session: Hair, Skin, Nails
Dr. Alanna Bree will share information on how the ectodermal dysplasias can affect the hair, skin and nails and how to treat them

12:30 p.m. - 1:30 p.m.
Lunch
Continue the conversations from the morning. Sit at a table that is marked with the name of the syndrome that affects your family.

1:45 p.m. - 2:30 p.m.
General Session: Advocacy and Insurance
We've been to Capitol Hill. Now what do we do?

Breakout Sessions
2:45 p.m. - 4 p.m.

Affected Adults

Men and Women separate into two rooms.

We need to know what is important to our adult community. At this time, adult Men and Women gather to discuss being an adult affected by ectodermal dysplasia.

Be Your Own Advocate
You're all grown up, what do you do now? A peer led discussion on being in charge of yourself and your health.

Parents and Caregivers

Behavior: Coping skills
Deidre Garland Olsen will lead a discussion on coping skills for families.

School Advocacy
Guest speaker, Erin Hurley will offer general tips on how to advocate for your child in school regardless of the available resources in your area.

4 p.m. - 4:15 p.m.
Break

3:45 p.m. - 5:15 p.m.
Scientific Advisory Council Meeting

4:30 p.m. - 5:15 p.m.
General Session: Erin Hurley will share how mindfulness can improve your wellbeing, physical and mental health. Learn some simple techniques to build a mindfulness practice in your every day life.

6 p.m. - 9 p.m.
Dinner

Saturday, July 22, 2017

Wear Conference T-shirt.

6:30 a.m. - 8 a.m.
Breakfast

Conference Group Photos

9 a.m. - 9:30 a.m.	Full Group
9:30 a.m. - 9:45 a.m.	HED Group
9:45 a.m. - 10 a.m.	Goltz Group
10 a.m. - 10:15 a.m.	EEC Group
10:15 a.m. - 10:30 a.m.	AEC Group
10:30 a.m. - 10:45 a.m.	Unknown/Other Group

8 a.m. - 10 a.m.
Dental Evaluations continue if needed.

8 a.m. - 10 a.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 speaking? This is the time to ask! Drop by Ask the Experts. Tables will be marked with the expert's name and area of specialty.

10 a.m. - 11 a.m.
Update on XLHED Research

Prof. Dr. med. Holm Schneider

11 a.m. - 1 p.m.
Board of Directors Meeting

11 a.m. - 12 p.m.
Lunch

12 p.m. - 1:15 p.m.
Dental Treatment Options for Adults
Dr. Clark Stanford will discuss dental treatment options for adults including dental implants.

Dental Treatment Options for children & Adolescents
Dr. Timothy Wright will address oral health care issues children face, excluding dental implants.

1:15 p.m. - 2 p.m.
It's a Wrap!
Executive Director Mary Fete says, "It's a wrap!" Now it's time to say good-bye to all our friends.

Kids' Finale

**Times and Sessions may vary.*

***The Kays' Kids Camp and Teens Program schedules will be available at a later date.*