

July 23, 2026

THURSDAY

11:30 a.m. – 5 p.m.

Registration & Information Station Conference Center Foyer

Stop by the Conference Registration & Info Desk to check in, pick up materials, and get answers to any questions you may have. Our friendly team will be available to help you get oriented and make the most of your conference experience. Make sure to buy your NFED swag!

11:30 a.m. – 5 p.m.

Hospitality Room Open Conference Room C

A calm, quiet space will be available for those who want to step away from the bustle, whether to gather their thoughts, enjoy calming activities, recharge, or enjoy low-key conversation in a peaceful setting.

Browse the ART-vocacy gallery of submitted art pieces and bid on original works at auction.

11:30 a.m. – 2 p.m.

Mix and Mingle Conference Center Foyer

Use this time before the conference begins to review welcome bag materials, get to know other attendees, eat lunch, and explore the hotel. (Please note that lunch is not included today, but many nearby restaurants will deliver to the hotel or are a short drive away).

1 p.m. – 5 p.m.

Individual/Family Photos Conference Room J (lower level)

Help the NFED with marketing photos by scheduling your photo shoot with our photographer through the event app.

1:30 p.m. – 5:30 p.m.

Kays' Kids Camp (Ages infant – 8th grade) Conference Rooms (lower level)

1:30 p.m. – 5:30 p.m.

Kays' Teens Program (High school 9th - 12th grades) Conference Room I (lower level)

Kays' Kids Camp and Teens program is for registered conference attendees. Workshops, arts and crafts, games, and social time offer a rare chance for young people to build friendships and enjoy dedicated peer connection with others affected by ectodermal dysplasias or who have siblings with the condition. A detailed schedule is available in your packet and on the app.

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

Conference Welcome Great Room

Charley Richter, Family Conference Master of Ceremonies, and Greg Klimovitz, NFED Executive Director, welcome everyone to the NFED Family Conference.

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

All Things NFED Great Room

Learn what the NFED has to offer you in this presentation. You'll gain a deeper understanding of the programs, services, and personalized guidance designed to help you succeed and make the most of your experience.

3:10 p.m. - 4:10 p.m.

Choose your Adventure (pick one)

What are Ectodermal Dysplasias? Great Room

This introductory session is designed for first- and second-year attendees or anyone that wants a refresher.

This session offers a clear, compassionate overview of what ectodermal dysplasias are and how they can affect an individual. You will learn the basics, common signs and symptoms, and where to find trusted resources and support as you begin your journey.

Returning Member Forum Ballroom D

This open forum is for attendees who have participated in three or more conferences.

This session offers a space to share insights, experiences, and questions with peers. You will engage in meaningful discussions about ongoing challenges, successes, and ways to stay connected within the community.

4:15 p.m. - 5 p.m.

Ask Me Anything Panel Great Room

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

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5 p.m. - 5:15 p.m.

Closing Session Great Room

Recap of the day and learn what is in store for the rest of the weekend.

6 p.m. - 9 p.m.

45th Anniversary Celebration Dinner and Dance Party Ballroom A-D

(for all registered conference attendees and speakers)

This special event will honor our journey, reflecting on the breakthroughs we've achieved together and looking ahead to the exciting future of ectodermal dysplasias care and research. And yes... we're taking it way back with an '80s-themed celebration. Get ready to rock those bold patterns, neon colors, and parachute pants. Whether you're "totally '80s" or just coming as you are, we can't wait to celebrate with you!

9 p.m. - 10 p.m.

Young Adult Social Activity (Peer-led) Great Room A

This event is for attendees 18-35 years old.

Join other young adults for a fun gathering filled with games, great conversations, and opportunities to connect with new people. Whether you're looking to relax, laugh, network, or build meaningful friendships, this activity offers an engaging space to hang out and enjoy the conference experience together.

9 p.m. - 10 p.m.

Women's/Moms' Mixer - The "We Need a Break" Break (Peer-led) Great Room B

A relaxed, peer-led evening to share stories, swap advice, and build a supportive community with women who truly understand the unique challenges of managing an ectodermal dysplasia while navigating life and/or parenting.

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

Breakfast (for all registered conference attendees and speakers)
Ballroom A-D

8 a.m. - 5 p.m.

Registration & Information Station
Conference Center Foyer

Stop by the Conference Registration & Info Desk to get answers to any questions you may have. Our friendly team will be available to help you get oriented and make the most of your conference experience. Make sure to buy your NFED swag!

8:30 a.m. - 5:30 p.m.

Kays' Kids Camp Hours (Ages infant - 8th grade)
Conference Rooms (lower level)

8:30 a.m. - 5:30 p.m.

Teens Program Hours (High school 9th - 12th grades)
Conference Room I (lower level)

Kays' Kids Camp and Teens program is for registered conference attendees.

Workshops, arts and crafts, games, and social time offer a rare chance for young people to build friendships and enjoy dedicated peer connection with others affected by ectodermal dysplasias or who have siblings with the condition. A detailed schedule is available in your packet and on the app.

8:30 a.m. - 5:30 p.m.

Individual and Family Photos
Conference Room J (lower level)

Help the NFED with marketing photos by scheduling your photo shoot with our photographer through the event app.

8:30 a.m. - 5:30 p.m.

Hospitality Room Open
Conference Room C

A calm, quiet space will be available for you if you want to step away from the bustle, whether to gather your thoughts, enjoy calming activities and art, or recharge in a low-key and peaceful setting.

Browse the ART-vocacy gallery of submitted art pieces and bid on original works at auction.

8:45 a.m. – 8:55 p.m.

**Friday Welcome
Great Room**

Let's get this day started!

9 a.m. - 9:15 a.m.

**Story of Hope (Peer-led)
Great Room**

Virginia Higgins will share her story of navigating life with a rare condition while raising a family and remaining actively connected to their community. The session highlights the importance of understanding, support, and authentic inclusion, offering both inspiration and a practical perspective for professionals, caregivers, advocates, and community members alike.

9:20 a.m. - 9:50 a.m.

**Lived and Learned Experiences: An Interactive Session
Great Room**

Dr. Patricia Marik

This interactive session creates a welcoming space for you to ask questions, share experiences, and learn directly from individuals and families living with ectodermal dysplasia. Through open conversation and peer connection, you will gain practical insights, emotional support, and real-world perspectives from others who understand the challenges and opportunities of navigating life with ectodermal dysplasia.

Breakout Sessions

10 a.m. - 12 p.m.

Syndrome Specific Sessions (Peer-led)

Families will lead discussions based on their personal experiences. Take advantage of this opportunity to share what has worked for you and your family and to learn from others. Conversations will address a wide range of topics from how to advocate at school to how to explain ectodermal dysplasia to loved ones. Keep the conversations going by sitting with others affected by your syndrome during lunch.

Hypohidrotic Ectodermal Dysplasia (HED) - Great Room
TP63-Related Syndromes - Conference Room A
Goltz Syndrome - Conference Room B
Incontinentia Pigmenti (IP) - Board Room 1
Other/Unknown Syndromes - Ballroom A

12:15 p.m. – 1 p.m.

**Lunch (Syndrome Tables)
Ballroom A-D**

Children registered for Kays' Kids Camp eat in Kids Camp. Teens registered for the Teens Program eat with the adults. Adults are encouraged to keep the conversations going and sit with attendees in your same syndrome group.

Breakout Sessions
1:15 p.m. - 1:55 p.m.

**Option 1: All There Is to Know about Skin, Hair, and Nails
Great Room**

Dr. Elaine Siegfried

Learn common symptoms and treatments related to skin, hair, and nails.

**Option 2: Pediatric Health Concerns
Conference Room A**

Dr. Clayton Butcher

This session focuses on common pediatric health concerns associated with ectodermal dysplasias, with an emphasis on early identification and ongoing care. You will gain practical insights into managing symptoms, partnering with healthcare providers, and supporting your child's overall health and development.

**Option 3: Genetics and Genetic Counseling
Ballroom A**

Dr. Kathy Grange

Learn about the genetics and inheritance patterns of ectodermal dysplasias and the benefits of genetic counseling.

Breakout Sessions
1:15 p.m. - 1:55 p.m.

Option 1: All There Is to Know about Skin, Hair, and Nails
Great Room

Dr. Elaine Siegfried

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Option 2: Genetics and Genetic Counseling
Ballroom A

Dr. Kathy Grange

Learn about the genetics and inheritance patterns of ectodermal dysplasias and the benefits of genetic counseling.

Option 3: Insurance and Legislative Advocacy Session
Conference Room A

Kelley Atchison and Kristin Matus-Kelso

Learn tips on how to submit dental claims to your medical insurance company. Find out about NFED efforts to get the Ensuring Lasting Smiles Act passed and how you can help.

2:40 p.m. - 2:50 p.m.

Break

2:50 p.m. - 3:30 p.m.

Option 1: Adult Health Concerns (including Ear, Nose, and Throat)
Great Room

Dr. Clayton Butcher

This session addresses adult health concerns related to ectodermal dysplasias, focusing on how needs and symptoms may change over time. You will learn practical strategies for managing health, navigating care, and advocating for themselves as adults.

Option 2: Insurance and Legislative Advocacy Session
Conference Room A

Kelley Atchison and Kristin Matus-Kelso

Learn tips on how to submit dental claims to your medical insurance company. Find out about NFED efforts to get the Ensuring Lasting Smiles Act (ELSA) passed and how you can help.

3:40 p.m. - 5 p.m.

**Dental Session
Great Room**

Dr. Clark Stanford, Dr. Beau Meyer
Experts address oral health care issues and treatment options that children, adolescents, and adults face.

5 p.m. - 5:10 p.m.

**Closing Session
Great Room**

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 A-D**

7 p.m. - 9 p.m.

**Pool Party, Indoor and Outdoor Games, STL Ice Shack
Pool Deck and The Canopy**

Enjoy an evening of fun, social time, and outdoor activities at the pool party. STL Ice Shack truck will be offering a shaved ice or an ice cream treat for all registered conference attendees and speakers.

8:30 p.m. - 10 p.m.

**Young Adult Social Activity (ages 18-35) (Peer-led)
Great Room A**

Join other young adults for a fun gathering filled with games, great conversations, and opportunities to connect with new people. Whether you're looking to relax, laugh, network, or build meaningful friendships, this activity offers an engaging space to hang out and enjoy the conference experience together.

9 p.m. - 10 p.m.

**Men's/Dads' Mixer - From "I'm Fine" to Honest Times (Peer-led)
Great Room B**

A casual, no-pressure space to connect with other dads and affected men, sharing honest experiences about parenting and/or living with ectodermal dysplasia while building lasting friendships with men who understand.

July 25, 2026
SATURDAY

Wear Your Conference T-shirt!

Before 11 a.m.

Hotel Check-Out and Luggage Storage

Hotel check-out is at 11 a.m. but you can store your luggage at the front desk if needed. This allows you to enjoy the conference or explore the area without worrying about your bags.

8 a.m. - 1 p.m.

**Registration & Information Station
Conference Center Foyer**

Stop by the Conference Registration & Info Desk to get answers to any questions you may have. Our friendly team will be available to help you get oriented and make the most of your conference experience. Don't forget to purchase NFED swag!

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

**Breakfast (for all registered conference attendees and speakers)
Ballroom A-D**

8:45 a.m. - 9 a.m.

All Attendee Group Photo

Don't miss the all attendee group photo. Make sure to wear your Conference t-shirt. Location will be announced in the app.

9 a.m. - 11 a.m.

**Group Photos by Ectodermal Dysplasia Syndrome
Conference Room J (lower level)**

9 a.m. HED (Location will be announced in the app.)

9:35 a.m. Goltz

9:55 a.m. EEC

10:15 a.m. AEC

10:30 a.m. Other and Unknown Syndromes

9 a.m. - 11 a.m.

**Dental Evaluations
Conference Room B**

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

9 a.m. - 11 a.m.

**Ask the Experts
Conference Room A**

Receive focused, one-on-one guidance from a trusted advisor in a brief, 10-15 minute session to answer your specific questions. This informational guidance does not replace regular medical care. Appointments are first-come, first-served and not guaranteed.

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

**Turn Stories into Action
Great Room**

Isabella Redding

Discover how families and advocates have transformed personal stories into powerful tools for building awareness, inspiring support, and strengthening community connections. This session will guide you through the key steps to planning and hosting a successful family fundraiser, with practical tips and real-life examples to help you get started with confidence.

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

**Grandparents & Extended Family Members Session (Peer-led)
Ballroom D**

This session explores ways to provide support, encouragement, and care for loved ones affected by ectodermal dysplasias. You can I share experiences, ask questions, and gain resources to strengthen family connections.

10 a.m. - 2:30 p.m.

**Kays' Kids Camp Hours (Ages infant - 8th grade)
Conference Rooms (lower level)**

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10 a.m. - 11:15 a.m.

**Kays' Teens Program Hours (High school 9th - 12th grades)
Conference Room I (lower level)**

Teens will wrap up their conference this morning, join the adults for lunch, and will have organized visits to Kids Camp after lunch.

10:15 a.m. - 11:15 a.m.

**School and Kids' Sports Advocacy (Peer-led)
Great Room**

This session provides practical tools and strategies for advocating for children affected by ectodermal dysplasias in school and sports settings. You will learn how to communicate effectively with educators and coaches to ensure your child's needs are understood and supported.

10:15 a.m. - 11:15 a.m.

**Young Adults - Navigating Life and Self-Advocacy (Peer-led)
Ballroom D**

Affected adults (18 - 35 years old) have an opportunity to share your experiences and challenges and how you have overcome them.

11 a.m. - 12 p.m.

**Individual and Family Photos
Conference Room J (lower level)**

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11:15 a.m. - 12:15 p.m.

**Lunch (for all registered conference attendees and speakers)
Ballroom A-D**

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

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

**Emotional Wellbeing
Great Room**

Dr. Patricia Marik
Learn ways to talk to others about a diagnosis. Plus, it's been an emotional and informative weekend. Now what?!

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

**Closing Session
Great Room**

Don't miss your chance to say goodbye to friends and hear closing remarks from Executive Director, Greg Klimovitz. Plus, find out where the Family Conference will be in 2027!

Schedule subject to change