



STAND TOGETHER NFED ADVOCACY CONFERENCE 2024

ADVOCACY

Sunday, July 7, 2024

- 6:00 p.m. - 8:00 p.m.
Registration and Reception
- 8:00 p.m. - 9:00 p.m.
Kickoff - Walk to the Hill for ELSA

Monday, July 8, 2024

- 8:00 a.m. - 9:00 a.m.
Registration - Grand Foyer
Breakfast - Grand Foyer
- 10:30 a.m. - 6:00 p.m.
Kays' Kids Camp & Teen Program
- 11:00 a.m. - 11:45 a.m.
Welcome - Mary Fete, NFED Executive Director
- 11:50 a.m. - 12:30 p.m.
Edelife Clinical Trial Update
- 12:30 p.m. - 1:00 p.m.
Break
- 1:00 p.m. - 2:00 p.m.
Lunch
- 2:00 p.m. - 2:30 p.m.
Break
- 2:30 p.m. - 3:15 p.m.
The More You Know - Dr. Beau Meyer
- 3:20 p.m. - 4:05 p.m.
Look Out For Yourself - Dr. Patricia Marik
- 4:10 p.m. - 6:00 p.m.
Advocacy Training
- 6:00 p.m. - 6:30 p.m.
Break
- 6:30 p.m. - 9:00 p.m.
Dinner, Youth Advocacy Training

Tuesday, July 9, 2024

- 7:00 a.m. - 7:55 a.m.
Breakfast to Go - Grand Foyer
- 7:55 a.m. - 8:00 a.m.
Board Buses and Depart for Capitol Hill
- 8:20 a.m.
Arrive at ADA Townhouse
- 8:35 a.m.
Group Picture on Capitol Hill Steps
- 9:00 a.m. - 5:00 p.m.
Families Meet with Legislators
- 9:30 a.m. - 10:15 a.m.
Bill Leads Speak in Dirksen Senate Bldg, Rm. 106
- 5:00 p.m. - 5:15 p.m.
Board Bus and Depart for Grand Hyatt
- 6:30 p.m. - 9:00 p.m.
Dinner, Yoga/Mindfulness, Advocacy Recap

Edelife Clinical Trial Update

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. EspeRare, will also share information on how the trial will work.

The More You Know

Beau Meyer, DDS, MPH
Assistant Professor
Pediatric Dentistry
The Ohio State University

Dr. Meyer will share his views on the importance of quality care, and finding a care provider. He will share his thoughts on when to seek a second opinion and how to determine what treatment plan option is best for you.

Look Out for Yourself

Patricia K. Marik, PsyD
Assistant Professor
Medical College of Wisconsin
Division of Pediatric Psychology and
Developmental Medicine
Pediatric Psychologist, Children's
Wisconsin

Dr. Marik will share the importance of advocating for your emotional well-being and how to advocate for your child at school.

Advocacy Day Training

Members of the NFED Family Advocacy Committee and experienced youth advocates will provide an advocacy training session. Advocates will learn what to expect during their visit to Capitol Hill, how to share their personal and powerful stories with their legislators and/or their staff, why advocacy is important, how to access their legislative meeting schedules and more. These training sessions are filled with valuable tips and information needed to ensure legislative meetings are impactful and successful. Advocacy training session attendance is mandatory to attend legislative meetings on Hill Day.