NFED Family Driven Legislative Advocacy

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NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

GETTING READY FOR A DAY ON CAPITOL HILL

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WHAT YOU WILL LEARN

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- A little about Beth and Becky
- Why we are doing this Webinar?
- How we will educate our U.S. Senators and Representatives
- The importance of Family Driven Advocacy
- The importance of your story for first time visiting Legislators
- How to prepare for Wednesday, July 19th
- Tools on NFED Website
- Ready, Set, Go to the Hill

MEET BECKY & BETH

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- Mother of Aidan (affected by XLHED) & Ryder & Married to Tom
- Proud to live in Wisconsin (Go Bucks Go!)
- Rare Disease Advocate
- Masters of Public Health

- Beth-mom of 3 adult sons Nolan and Philip affected by HED, married to Michael
- Proud to live in Massachusetts (Go Pats, Sox's, Celtics and Bruins!)
- Senior Manager for a family-run, non-profit Organization that advocates on behalf of Children's Mental health

WHY WE ARE DOING THIS WEBINAR

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WE WANT TO:

- Share our excitement
- Share advocacy experiences
- Help you prepare
- Walk you through a day on Capitol Hill
- Answer your questions
- Excite you to join us and be NFED Family Driven Advocacy Strong

CHANGING LAWS-CHANGING LIVES

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Our goal is clear.

We NEED a federal law mandating that health insurance companies & employer sponsored

self-insured health benefit plans cover congenital anomalies and birth abnormalities from the moment of birth as an injury or sickness, covering the functional repair or restoration of any body part, including the teeth and bone that holds the teeth, when necessary to achieve normal bodily function.

EDUCATING OUR U.S LEGISLATORS

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We will............

explain congenital anomaly called ectodermal dysplasia and the the many problems with teeth and the bone that holds them in place.

explain that although many states already have health insurance laws that: provide medical benefits to people who lose their "sound natural teeth" due to accidental injury yet insurance companies auto-deny those same benefits for people whose <u>accident happened in-utero</u> and have laws that provide medical benefits to people born with a congenital anomaly with defective body parts—yet auto-deny necessary medical care and treatment regarding the teeth—a body part.

share your experience and frustration working with your insurance company or your employer sponsored self-insured health benefit plan (that often include this language), the time it takes per claim per year to get paid (if you get paid), year over year for a lifetime.

EDUCATING OURSELVES

https://www.nfed.org/blog/health-insurance-claims-teeth-101/

If you are new to advocacy, it would be best for you to do some homework before you meet your legislators.

Click on the link above to learn

FAMILY DRIVEN ADVOCACY

Family driven:

Families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation.

Becky & Aidan’s Story

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- After many years of raising awareness for Ectodermal Dysplasias, fighting insurance denials, and contacting legislators on both a state and federal level, trying to fight for insurance law changes with my family, I decided it was time to help other families struggling with this disorder. Last year our family made a few trips to meet with our federal legislators on Capitol Hill. My son Aidan was able to share his story of living with Ectodermal Dysplasias and our struggles with insurance coverage. Our U.S. Senator was sympathetic to Aidan's story. We have kept in touch and we were able to build a relationship with the Senator's office over the past year. We now have an ally in our corner who is willing to help families with congenital anomalies and put an end to our insurance coverage battle on a national scale.

PREPARING FOR THE DAY ON THE HILL

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- First you need to register at https://www.nfed.org/events/nfed-day-capitol-hill/
- You can still attend Advocacy Training and Day on the Hill, if you can't attend Family Conference.
- Write your personal story *(see samples in toolkit)*
- Attend the training session on Tuesday, July 18th. 3:30 p.m. – 6 p.m.
- We will provide you with materials
- We will guide you on what to say when meeting with them.
- *Why not send them an email telling them you care looking forward to speaking with them or their staff on July 19th.*

Do not contact your Legislators for appointments.

We will schedule your appointments with your legislators.

SNAPSHOT OF ADVOCACY DAY

- How to dress
- Transportation is provided. (what does that look like?)
- Leaving Hotel
- A light breakfast on Capitol Hill.
- Hospitality Room & snacks at Capitol Hill
- Walking to Legislators offices
- What you will be leaving behind (your letter with ask, your contact info & NFED packet)
- Relax, have fun and take a photo! Post your photo to social media, tag the NFED and use hashtags, #mysmile and #teetharenotcosmetic
- Return to the hotel and debrief during dinner.

CAN'T ATTEND? YOU CAN STILL HELP.

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Find out who your US Legislators are

Write them a letter with your personal story. (sample on website in toolkit at https://www.nfed.org/learn/library/advocacy-tool-kit/)

Visit them in their area office

Check out our Toolkit

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- **Members letter**
  - https://www.nfed.org/learn/library/advocacy-tool-kit/
- **Tips for Advocacy Day**
- **Family-Driven Advocacy Checklist**
- **Sample letters from families**


ttps://www.nfed.org/get-involved/advocate/

ADVOCATE FEDERAL LEGISLATION FOR TEETH

Questions?

Becky Abbott, co-chair
beckymabbott@gmail.com

Beth Pond, co-chair
bethpond5@gmail.com

Mary Fete, NFED Executive Director mary@nfed.org

Kelley Atchison, Director, Family and Community Programs kelley@nfed.org

THANK YOU!

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