



National Foundation for
Ectodermal Dysplasias

ADVOCACY TOOL KIT

A Guide to Help You Voice Your Opinion to Legislators
Explaining the Need for Federal Law Protecting the Oral
Healthcare Needs of Those Affected by Ectodermal
Dysplasias

nfed

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

Join Us

Dear members of the National Foundation for Ectodermal Dysplasias (NFED),

Are you tired of fighting your health insurance company or your employer sponsored self-insured health benefit plan for medically necessary care and treatments affecting teeth due to ectodermal dysplasia, a congenital anomaly? Aren't we all tired of this?

Our goal is clear. We want a federal law mandating that health insurance & 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.

Through sharing our stories, we will educate members of the U.S. Senate and U.S. House of Representatives on the following:

1. What is ectodermal dysplasias?
2. We will explain our issues with missing teeth, and the bone that holds them in place.
3. Explain that most of the 50 states have congenital anomaly laws. Benefits for our TEETH are auto-denied because our congenital anomaly, our medical condition, our affected body part is our TEETH. Claims people go right to the dental exclusion and deny treatment, rather than going straight to the congenital anomaly language where the coverage is.
4. Share your experience and frustration working with your insurance company or your employer sponsored self-insured health benefit plan (that often include this language), and the time it takes per claim per year to get paid (if you get paid), year after year for a lifetime.

To achieve this goal, we need every NFED member to advocate, contact thier legislators and share their stories. Make your needs known and your voices heard. We look forward to seeing you there.

Please contact your legislators. Urgent: Send them the letter included in this kit and be heard.

Sincerely,

Becky Abbott, Beth Pond

NFED Family-Driven Legislative Advocacy Committee Co-Chairs

Julie Claeys & Laura Zemen

Legislative Tool Kit Workgroup

TIPS FOR Successful ADVOCACY

Here are some helpful hints and tips that will hopefully allow your advocacy journey to go smoothly.

1. When contacting your legislators, ask for the Senior Health Staffer or Health Aide. These staffers are usually very knowledgeable on health and insurance issues.
2. You may not meet with your legislators. Instead, you will likely meet with a member of their staff. These staffers are very knowledgeable and will usually be the point of contact for any follow-up meetings or correspondence. These staffers and administrative aides are just as important to meet as legislators.
3. Meetings are usually between 15-20 minutes long. Briefly explain ectodermal dysplasia (congenital anomaly). Focus on the many problems with the teeth. Tell them your health insurance coverage problems and most importantly, tell them the need for a federal law that will mandate health insurance coverage for teeth and the bone that holds teeth resulting from congenital anomaly. Share your story.
4. Relax and enjoy your time sharing your story. Legislators want to know the needs of their constituents.
5. Be sure to thank your legislators and their staff for taking time to meet with you.

NFED FAMILY-DRIVEN ADVOCACY CHECKLIST

Below is a step-by-step list of what you'll need to do to prepare in advance to have a successful advocacy meeting:

1. Write your personal story.

Sample letters are included in the Tool Kit. Tailor your letter to your family's story. Use the uniform ASK paragraph (see item #2) at the beginning of the story that defines our mission.

2. Include the ask.

Thank you for the opportunity to meet with you on behalf of the National Foundation for Ectodermal Dysplasias (NFED) and other NFED families affected by ectodermal dysplasias.

We need your help to get a federal law passed to protect us.

Ectodermal dysplasia is a rare congenital anomaly that affects 3.5 in 10,000 individuals. People born with ectodermal dysplasia lack the ability to properly develop and grow hair, nails, mammary glands, sweat glands and TEETH. When a person lacks two or more of these body parts, they are diagnosed with ectodermal dysplasia. It is the extensive problems with TEETH (no teeth, many absent teeth, defective teeth, missing or diminished bone to hold TEETH) that we are here today.

Health insurance is regulated by the states. Most of the 50 states have congenital anomaly laws. Benefits for our TEETH are auto-denied because our congenital anomaly, our medical condition, our affected body part is our TEETH. Claims people go right to the dental exclusion and deny treatment, rather than going straight to the congenital anomaly language where the coverage is.

We need your help. We need a federal law that will mandate health insurance companies and employer sponsored self-insured health benefits 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.

My Personal Story: Follows the Ask

3. Find the contact information for your legislators.

Contact your legislator by mail or email. Send a copy of your personal story and let them know you would like to meet with them. If you don't know who your legislators are (you have two senators and one representative), do the following:

U.S. Senate

- Go to: www.senate.gov
- Top left, click on Senators
- Top left, choose your state and click. You will see your two U.S. senators for your state.

U.S. House of Representatives

- Go to: www.house.gov
- Top right says FIND YOUR REPRESENTATIVE. Enter your zip code and click GO
- The name of your U.S. Representative for your state district will appear at top left side of page

4. Bring a copy of your personal story letter as a leave behind, one for each of the legislators you are meeting with.

5. Please be sure to include your family's contact information on your personal story letter so staff can follow up after the meeting. The NFED will give you folders to leave behind.

6. Bring your phone or camera and ask your legislators for a picture after your meeting. They are usually willing and happy to take pictures with their constituents.
7. Post a picture of each meeting to social media with our hashtags #mysmile, #teetharenotcosmetic
8. If you are using Facebook or Twitter you can also tag the legislators with whom you met.
9. Send a follow-up letter or email, thanking your legislators and their staff for meeting with you. Ask them to follow up with you with any information they may have after your meeting.
10. Keep in touch and keep them posted.

SAMPLE LETTERS TO LEGISLATORS

SAMPLE LETTER 1

Dear (insert name of your legislator),

Thank you for the opportunity to meet with you on behalf of the National Foundation for Ectodermal Dysplasias (NFED) and other NFED families affected by ectodermal dysplasias.

We need your help to get a federal law passed to protect us.

Ectodermal Dysplasia is a rare congenital anomaly that affects approximately 3.5 in 10,000 individuals. People born with ectodermal dysplasia lack the ability to properly develop and grow hair, nails, mammary glands, sweat glands and TEETH. When a person lacks two or more of these body parts, they are diagnosed with ectodermal dysplasia. It is the extensive problems with TEETH (no teeth, many absent teeth, defective teeth, missing or diminished bone to hold TEETH) that we are here today.

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My Personal Story:

My brother and two sons were born with x-linked hypohydrotic ectodermal dysplasia. Philip and Nolan were born with four teeth. When they were three years old, they were fit for dentures. Our health insurance denied our claim based on their decision that dentures are cosmetic and are not covered under our insurance policy. After fighting the decision for a year, we won our appeal and insurance paid for their dentures.

As the boys grew older, they started to lose bone in their jaw. After seeing their oral surgeon, it was determined that the only medically necessary treatment was bone grafting to build the bone and dental implants for proper functioning and nutrition. We started this process with Philip in early 2013 and finished in late 2016.

The total cost for this medically necessary treatment was \$120,000. As he went through the process, the doctor would present the treatment plan to our insurer for payment and it would get denied. I would spend many hours appealing the decisions. After several months of fighting it would get approved so the next step in the process could get completed.

This went on for over two years with the end result being insurance paid for \$85,000. Our out-of-pocket cost was \$35,000. If Philip was born with teeth and he lost them in an accident, health insurance would cover the cost of replacing them. Why do health insurance companies not recognize missing and deformed teeth are one of the major pieces with people born with ectodermal dysplasias?

We need your help.

Thank you,

Beth, Michael, Nolan, Philip, Dylan Pond
89 Barre Road
Hubbardston, MA 01452
978-928-3388

SAMPLE LETTER 2

Thank you for the opportunity to meet with you on behalf of the National Foundation for Ectodermal Dysplasias (NFED) and other NFED families affected by ectodermal dysplasias.

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My Personal Story:

I am a rare disease advocate & the mother of Aidan Abbott, a child with x-linked hypohidrotic ectodermal dysplasia or XLHED. Our family lives in Washington County. After many years of appointments with specialists at Children's Hospital of Wisconsin, a dental resident as well as a geneticist diagnosed my son with XLHED. This disease affects Aidan's skin, hair, nails, sweat glands and teeth. His skin is very sensitive and gets rashes easily. His nails are sensitive and hurt when clipped. His sweat glands don't function properly so he has a hard time regulating fevers and overheats easily. He was also born without many of his teeth, which affect his quality of living.

When he first started his dental procedures after diagnosis, we were told that since teeth were a medical necessity and this was a congenital abnormality, that his complex dental work should be covered by insurance. We soon discovered that very little is covered, and our insurance will not make an exception to cover further work. Each time we submitted a claim, we have had to appeal several times. Now that Aidan is older, and the majority of his dental work needs to begin, we have been told that they have made their final decision to deny dental work.

While our state does have legislation to include coverage of congenital abnormalities/ anomalies, my husband's employer, Washington County Sheriff's Department, has a self-funded/pay policy and refuse to follow the statutes. Many insurance companies and employers also do not feel they have to cover oral health care and treatments due to congenital abnormalities, because it is not specifically mentioned in legislation.

Aidan has had several issues due to his lack of teeth, including speech, swallowing, chewing, eating, and being made fun of by other kids. He has had to go through invasive procedures, just to determine that his issues are due to his lack of teeth. Other families that have had these complex dental issues and absence of teeth have had to pay over \$100,000 for dental work. If teeth are not replaced at an appropriate age, it could lead to further issues including loss of bone and a need for bone grafts and dental implants in the future. Teeth are not just esthetic, they are a medical necessity and important for quality of life.

Thank you for taking the time and listening to my family's needs,

Becky M. Abbott, MPH

SAMPLE LETTER 3

Thank you for the opportunity to meet with you on behalf of the National Foundation for Ectodermal Dysplasias (NFED) and other NFED families affected by ectodermal dysplasias.

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My Personal Story:

Our son, Carver, is now 21 years old and affected by hypohidrotic ectodermal dysplasia. It is a congenital abnormality in which he has no sweat glands and can easily overheat; eczema; sparse hair; and was born without teeth. He has worn dentures since the age of two and has had many sets remade as he grew and his dental needs changed.

He cannot eat and chew well without his dentures. He is bullied if seen without his teeth by other kids. He has stomach aches if he does not chew his food well with his dentures. Because he has no teeth, he did not develop healthy bone along the jaw line.

Carver was fitted for lower implants at the age of 13 (the age when the male lower jaw matures) and is now undergoing upper implants after a bone grafting surgery heals in order to hold the new implants at the age of 21. Implants are by far the best fit and best improvement that give Carver a normal set of teeth that function the closest thing to real teeth, and they promote bone growth!

We estimate we have paid over \$75,000 in dental claims thus far. Our "self-funded Aetna/UPS plan" denies medical and dental coverage for any dental needs. They will only insure teeth one is born with. We have tirelessly submitted years of documentation to help support his needs of proper dental care and prosthetics, yet we are denied every time. His dental needs will never end throughout his lifetime.

We are asking our legislators to pass a law for people born with ectodermal dysplasias to obtain dental care through their MEDICAL INSURANCE PLAN as this is a birth defect, congenital abnormality, similar to cleft lip, and absolutely needed in order to function with a healthy lifestyle. This is NOT COSMETIC as the insurance company describes in their reason for denial.

Thank you,

Julie Claeys

SAMPLE LETTER 4

Thank you for the opportunity to meet with you on behalf of the National Foundation for Ectodermal Dysplasias (NFED) and other NFED families affected by ectodermal dysplasias.

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My Personal Story:

Our son, Dylan, who is now 19 months old, has h-linked hypohydrotic ectodermal dysplasia (XLHED), a rare, genetic, birth disorder. Our family lives in Lake County, Indiana.

Dylan seemed completely healthy at birth. He had no body hair whatsoever; no eyelashes, eyebrows, or hair on his head, but we didn't think much about it. He didn't get any teeth until a little after 12 months. He only got two on the top and they were spaced far apart and conical in shape. As a nurse of 12 years and a mother of three, I knew something was wrong. My pediatrician didn't seem concerned.

I diagnosed him myself through Google. I came across XLHED and up popped pictures of other little boys that looked just like my Dylan. I took him to my pediatric dentist who did X-rays and confirmed Dylan had no other teeth. My dentist had actually treated another patient with XLHED and knew what it was. He referred us to a University Children's hospital where Dylan was officially diagnosed.

Along with only having two teeth, his sweat glands don't function properly, making a fever or even a warm environment very dangerous for him. He has sensitive skin and gets rashes easily. He is also very fair skinned, with thin light scalp hair and no body hair. Dylan also has high blood pressure and thickening of his heart because of the high blood pressure. He has to take medication three times a day. We see 10 different specialists at the children's hospital, plus speech therapy. Dylan already has difficulty speaking and eating a nutritious diet. He has already been admitted in the hospital five times. Luckily, our insurance covers all of this, except the dental care he will need in the future.

Dylan will get dentures around the age of four. He will need replacement sets about every two years as he grows. The plan will then be to have bone grafting, possible jaw reconstruction, and dental implants around the age of 17. The cost of all of this is astronomical >\$150,000, more than any middle class family can afford. Dentures and dental implants are not cosmetic for kids with XLHED. My son needs teeth for his jaw to develop, to eat, chew, speak clearly, and for his self-esteem to fit in with his peers. It is a medical necessity for him. Insurance claims the dental care needed is cosmetic, and many other families of children with XLHED older than my son have spent years getting denied by insurance and fighting appeals.

Thank you for taking the time and listening to my family's needs,

Rick, Laura, and Dylan Steyer

LEAVE BEHIND MATERIALS

WRITE YOUR LETTER

(YOUR PERSONAL STORY LETTER TEMPLATE—Copy, paste and customize)
(Prior to your visit, email or mail to your TWO senators and your ONE representative.)
(Print and bring 1 copy of your personal story letter as a leave behind, one for each of your three legislators.)

(Your Name)
(Your Address)
(Your Email)
(Your Phone)
(Date)

(Today's Date)

Office of Senator (Name)
United States Senate
Washington, D.C. 20510
(202) 224-3121

Re: Health—Federal Congenital Anomaly Law

Dear Senator (Name),

On July 19, 2017, families affected by ectodermal dysplasias, a congenital anomaly, traveled from 35 states to Capitol Hill to tell our stories. We need your help and support to get a bill drafted, introduced and signed into law. The law will protect our families from health insurance denials for TEETH, when benefits should have been covered and paid.

Ectodermal dysplasia is rare and affects an estimated 3.5 in 10,000 individuals. People born with ectodermal dysplasia lack the ability to properly develop and grow hair, nails, breast tissue, sweat glands, and TEETH. It is the extensive problems with TEETH (no teeth, many absent teeth, defective teeth, and associated maxillary/mandibular bone loss) that we are focused on legislatively.

As a first step to raise awareness for ectodermal dysplasias, Senator Tammy Baldwin of Wisconsin on July 20, introduced Senate Resolution S. Res. 226. Representative Jackie Speier of California introduced the same Resolution in The House, H.Res. 464.

We are your constituents and are affected by ectodermal dysplasia. We ask that you co-sponsor S.Res. 226. We ask that you show support for us and National Ectodermal Dysplasias Awareness Week, designated to raise awareness and understanding of ectodermal dysplasias. We need bipartisan support. The Resolution explains our congenital anomaly and our struggle in getting insurance companies and ERISA and non-ERISA plans across the nation to pay for our necessary medical care and treatment for our TEETH. This Resolution is our first step toward a federal law mandating medical coverage for our medically necessary oral restoration care.

Health insurance is regulated by the states. Most of the 50 states have congenital anomaly laws. Benefits for our TEETH are auto-denied because our congenital anomaly, our medical condition, our affected body part is our TEETH. Claims people go right to the dental exclusion and deny treatment, rather than going straight to the congenital anomaly language where the coverage is.

Many self-funded ERISA and non-ERISA employer-sponsored health benefit plans offer congenital anomaly protections too and all with the same results. Benefits for TEETH are auto-denied. It's as though TEETH and the bone that holds them in place aren't body parts.

While dental benefits are routinely excluded under health benefit plans, almost all states have Regulations providing an exception to the dental exclusion for “accidental injury to sound and natural” TEETH. If you’re in a car accident and all of your sound and natural teeth land all over the dashboard, your health insurance plan will pay benefits for treatment. Clearly, the states understand the value and importance of having TEETH. So why are we excluded? We believe that when these state Regulations were written, lawmakers simply had no idea that people like us could actually come into this world without any TEETH or bone to hold them in place. We have been fighting with our health plan providers generation after generation. A federal law will put “TEETH” into existing congenital anomaly laws written by our sovereign states that are failing us. Dental treatments, including dentures and implants, for people with ectodermal dysplasias can cost up to \$150,000 in a lifetime, out of reach for many of us.

(ADD YOUR INDIVIDUAL & UNIQUE STORY/FAMILY STORY HERE)

We need your help. Senator Baldwin, Rep. Speier, Rep. Khanna, Rep. Peterson, Rep. McGovern, Rep. Schiff, Rep. Costello and others are helping us raise awareness for ectodermal dysplasias. Please join them and support our families by co-sponsoring S.Res. 226, our first step to getting the federal law we need. It will mandate health insurance companies and self-insured ERISA and non-ERISA health benefit plans to ensure that:

Coverage from the moment of birth shall consider congenital defects and birth abnormalities as an injury or sickness and shall cover the functional repair or restoration of any body part and may not exclude any body part, including the TEETH and bone that holds the teeth, when necessary to achieve normal body functioning, but shall not cover cosmetic surgery performed only to improve appearance.

Sincerely,

(YOUR NAME HERE)

WRITE YOUR LETTER

(YOUR PERSONAL STORY LETTER TEMPLATE—Copy, paste and customize)
(Prior to your visit, email or mail to your TWO senators and your ONE representative.)
(Print and bring 1 copy of your personal story letter as a leave behind, one for each of your three legislators.)

(Your Name)
(Your Address)
(Your Email)
(Your Phone)
(Date)

Today's Date

Office of Representative (Name)
U.S. House of Representatives
Washington, DC 20515
(202)-224-3121

Re: Health—Federal Congenital Anomaly Law

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We are your constituents and are affected by ectodermal dysplasia. We ask that you co-sponsor H.Res. 464. We ask that you show support for us and National Ectodermal Dysplasias Awareness Week, designated to raise awareness and understanding of ectodermal dysplasias. We need bipartisan support. The Resolution explains our congenital anomaly and our struggle in getting insurance companies and ERISA and non-ERISA plans across the nation to pay for our necessary medical care and treatment for our TEETH. This Resolution is our first step toward a federal law mandating medical coverage for our medically necessary oral restoration care.

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(ADD YOUR INDIVIDUAL & UNIQUE STORY/FAMILY STORY HERE)

We need your help. Senator Baldwin, Rep. Speier, Rep. Khanna, Rep. Peterson, Rep. McGovern, Rep. Schiff, Rep. Costello and others are helping us raise awareness for ectodermal dysplasias. Please join them and support our families by co-sponsoring H.Res. 464, our first step to getting the federal law we need. It will mandate health insurance companies and self-insured ERISA and non-ERISA health benefit plans to ensure that:

Coverage from the moment of birth shall consider congenital defects and birth abnormalities as an injury or sickness and shall cover the functional repair or restoration of any body part and may not exclude any body part, including the TEETH and bone that holds the teeth, when necessary to achieve normal body functioning, but shall not cover cosmetic surgery performed only to improve appearance.

Sincerely,

YOUR NAME HERE)

TEETH ARE NOT JUST COSMETIC



I will only ever have two teeth because I was born with **ectodermal dysplasia**. **BUT**

I need teeth to help me chew, eat and digest nutritious food so I can grow.

I need teeth in order to speak words clearly.

I need teeth to help me smile without being made fun of.

Insurance companies say teeth are cosmetic.

Because of that, my parents and I will have to spend about \$150,000 in my lifetime for dentures and dental implants so that I always have teeth.



**DO YOU
STILL THINK
TEETH ARE
COSMETIC?**



Contact us at NFED.org, info@nfed.org or 618-566-2020



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