

Successful Strategies to Improve Third Party Payment

Mary K. Richter

Oral health care for children affected by ectodermal dysplasia is extraordinary in scope and cost. Typically, the cost of this care is not covered under traditional insurance policies. As a result, care may create enormous financial constraints on the family or treatment may be withheld. The National Foundation for Ectodermal Dysplasias has implemented a multi-step strategy to assist families in obtaining insurance benefits through existing policies or to change state regulations governing insurance benefits for oral health care. This presentation will include 1) insurance data collected from member families; 2) the contents of our parents as advocates insurance packet; and, 3) details of a successful effort in New York State, which changed insurance regulations to mandate oral health benefits for all children with congenital diseases or anomalies. In the absence of applicable federal regulations, the goal has been to enable parents to be advocates for their children in their respective states. Successes from Texas to New York and beyond indicate that parents can conquer the obstacles frequently encountered during efforts to acquire third party payment.

Effective: December 8, 1999

This benefit is available to you, the Insured, on the date your policy next renews.

**NEW YORK STATE
INSURANCE DEPARTMENT
TWENTY-FIFTH AMENDMENT TO REGULATION 62
(11 NYCRR 52)**

**MINIMUM STANDARDS FOR THE FORM, CONTENT AND SALE OF HEALTH
INSURANCE, INCLUDING STANDARDS OF FULL AND FAIR DISCLOSURE**

I, Neil D. Levin, Superintendent of Insurance of the State of New York, pursuant to the authority granted by Sections 201, 301, 3201, 3216, 3217, 3221, 4235 and 4237 and Article 43 of the Insurance Law, do hereby promulgate the following Twenty-fifth amendment to Part 52 of Title 11 of the Official Compilation of Codes, Rules and Regulations of the State of New York (Regulation 62) to take effect upon publication in the State Register.

(MATERIAL UNDERLINED IS NEW; MATERIAL IN BRACKETS IS DELETED)

Subsection (9) of subdivision (c) of Section 52.16 of Part 52 of Title 11 of the Official Compilation of Codes, Rules and Regulations is hereby amended to read as follows:

(9) dental care or treatment, except for such care or treatment due to accidental injury to sound natural teeth within 12 months of the accident [;] **and except for dental care or treatment necessary due to congenital disease or anomaly;**

I, Neil D. Levin, Superintendent of Insurance of the State of New York, do hereby certify that the foregoing Twenty-fifth Amendment to 11 NYCRR 52 (Regulation 62) was duly promulgated by me on this day pursuant to the authority granted by Sections 201, 301, 3201, 3216, 3217, 3221, 4235, 4237 and Article 43 of the Insurance Law to take effect upon publication in the State Register

Prior notice of this amendment was published in the State Register on July 21, 1999 as a Notice of Proposed Rule Making. No other publication or prior notice is required by statute.

Neil D. Levin
Superintendent of Insurance

Dated: November 18,
1999

Dear Friend of the NFED,

The National Foundation for Ectodermal Dysplasias has an exhaustive amount of data on the insurance industry's obligation to provide treatment for the dental aspects of the various ectodermal dysplasias. The data is based on the first hand experiences of families who have dealt with the insurance industry and technical information from scientific journals about the scope of such treatment.

All in all, a compelling case has been made over the years that the ectodermal dysplasias are genetically determined birth defects, there are inherent abnormalities of the teeth in individuals with ectodermal dysplasias, and treatment for the dental abnormalities must be covered as part and parcel of ordinary medical insurance. The dental treatment that might be necessary includes 1) orthodontics for the alignment of teeth that are not positioned properly in the jaws, 2) crowns to reshape malformed teeth, 3) root canals (endodontics) that are necessary to facilitate placement of crowns 4) full or partial dentures and bridges (removable and fixed prosthodontics) to replace missing teeth, 5) dental implants, 6) oral surgery to remove impacted teeth (if any) and to place dental implants, and 7) gum surgery (periodontics) that may be necessary for any of the treatments mentioned above.

There is less evidence about how to treat routine restorative work (fillings) or surgery for routine gum disease (gingivitis and periodontitis). In fact, I do not consider routine cavities or routine gum disease as part of the ectodermal dysplasias. Any family applying to an insurance company for dental treatment under the auspices of medical insurance must be clear about this; the coverage the family asks for must be limited to the dental problems related to the ectodermal dysplasia. Then, the insurance company will more readily see the logic involved, and the decision it makes will be more clearly focused on the important issue; namely, the industry's obligation to cover all costs related to diagnosis, management, and treatment of birth defects.

Please feel free to refer to this letter in the course of your application or appeal to your insurance carrier, and do not hesitate to give my name to the carrier as a spokesperson on your behalf.

Sincerely yours,

Ronald J. Jorgenson DDS, PhD, FACMG
Chairman, NFED Scientific Advisory Board
Applied Genetics Inc.
1524 South I.H. 35
Suite 200
Austin, TX 78704
(512)443-4363

MEMO

TO: Insurance Carriers

RE: Insurance coverage for dental implants for individuals affected by ectodermal dysplasias

The Ectodermal Dysplasias are a group of genetic disorders involving more than one derivative of the embryonic ectoderm. In most ectodermal dysplasias abnormalities of the oral structures and dentition are an integral part of the multiple system effects. The teeth may be totally absent (anodontia), a few to most of the teeth may be absent (hypodontia), the teeth may be misshapen or small (microdontia), or there may be defects of the structures of the teeth. The lack of teeth results in improper development of the bones of the jaws.

The utilization of dental implants to support the replacement of missing teeth has been proven to be an important and well-accepted treatment modality in older children, adolescents and adults. There is no evidence to show that implants supported dental prosthesis affects growth and development of the craniofacial structures. The ideal replacement for natural teeth does not exist. However, after many years of basic and clinical research dental implants have been developed which can predictably be used to support restorations replacing natural teeth. The most frequently used implants are made of titanium in cylindrical form.

Potential benefits of dental implants supporting restorations include increased biting force, improved satisfaction with the dental prosthesis, increased self-esteem, and improved ability to eat some foods.

It is the unanimous opinion of the Scientific Advisory Board and the Board of Directors of the NFED that the use of dental implants to support prosthesis to replace missing teeth in children, adolescents, and adults is a safe, effective and proper treatment for replacement of missing teeth in individuals affected with forms of ectodermal dysplasia.

Sincerely,

Ronald J. Jorgenson DDS, PhD, FACMG
Chairman, NFED Scientific Advisory Board
Applied Genetics Inc.
1524 South I.H. 35
Suite 200
Austin, TX 78704
(512)443-4363

MEMO

TO: Insurance Carriers

RE: Insurance coverage for individuals affected by birth defects

The Ectodermal Dysplasias are a group of genetic disorders involving more than one derivative of the embryonic ectoderm. In most ectodermal dysplasias abnormalities of the oral structures and dentition are an integral part of the multiple system effects. The teeth may be totally absent (anodontia), a few to most of the teeth may be absent (hypodontia), the teeth may be misshapen or small (microdontia), or there may be defects of the structures of the teeth. The lack of teeth results in improper development of the bones of the jaws.

What ever form the dental defects take, the dental problems are some of the most important features of the ectodermal dysplasias. Management of these conditions is essential to the total treatment of the medical disorder. The defective teeth affect nutrition, speech, oral function and self-image. Treatment of the dental conditions must be provided for the affected child to develop normally.

It is the unanimous opinion of the Scientific Advisory Board and the Board of Directors of the NFED that all treatment required by these individuals belongs under medical insurance coverage. This necessary treatment may include complete dentures, removable partial dentures, fixed bridges, crowns, orthodontic braces, and dental implants.

Sincerely,



Timothy J. Richert, M.D.
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Medical Insurance and Dental Claims
Suggested guidelines for NFED families

Any NFED member (nationwide) who has submitted *dental* claims to their *health insurance carrier* has undoubtedly been denied payment of benefits. If you are interested in learning about your rights under the health insurance laws and regulations in your state, try these suggested steps:

Contact your State Insurance Department. Ask to speak with someone in the Life, Accident & Health Bureau. You want to speak with someone who is qualified to speak about the health insurance *laws* and *regulations* in your state. (A senior attorney is the optimum person to speak with.) Whoever you speak with, get their name, title, address and phone/fax and e-mail numbers.

Tell them the nature of your call. Most people have never heard of ED. Explain to them clearly and succinctly what ED is. Make it clear that ED is a *congenital anomaly, a genetic disorder, a medical condition*. The focus of your conversation should be the dental problems associated with ED, (how dental insurance provides insufficient benefits if you have it) and that *medical insurance* will not pay benefits for “dental care and treatment”, a direct result of this medical condition.

Ask the Department to tell you what the *insurance laws and regulations* are in your state regarding the following *medical insurance* questions:

1. Does your state provide medical coverage for “dental care and treatment” under any circumstances? Ask for the citation, and if it is a law or a regulation. (Insurance regulations are not laws. They are promulgated from law.) Have a copy sent to you.
2. Does your state require that medical coverage be extended to children from the moment of birth for “congenital anomaly” (birth/genetic disorders)? Ask for the citation, and if it is a law or a regulation. Have copies sent to you.
3. If your state denies medical coverage for “dental care and treatment”, ask the Department for their *written opinion* on the matter and if the intent of existing insurance laws and regulations, when written, were to *willfully exclude* children born with ED for their oral health care problems for life?

Note: *If the insurance situation is bleak in your state, consider that when these laws and regulations were written, the people writing them probably never heard of ED. Was this their intent? Are they even aware of the problem? Probably not.*

4. If there is nothing for you to hang your hat on, based on *current insurance laws and regulations*, ask the Department for their advice on what they are going to *do* about it. Specifically find out if the problem a regulation that’s in the way? (The Department has the authority to amend regulations.) If that is the case, ask/demand that it be amended. Also, ask specifically what the process is and how long the process will take.

Note: Regulations are not laws. They do *not* supercede the law.

If you have nothing to hang your hat on, the Department may very well tell you that in order to require *health insurance carriers* to pay “*benefits*” for “dental care and treatment due to congenital anomaly” that **you** will need to do it legislatively. This is the longer road but may be the only road.

In the meantime, ask your insurance department to call your health insurance carrier on your behalf. Have them explain the situation you're in. They can be extremely successful in reasoning with your carrier and getting them to *agree* to pay dental benefits!

Find out how to get a "Bill" passed in your state. A quick way to find this information is on your state's senate and assembly web pages on the Internet.

Approach your *district* state senator and assemblyman. *You* are their constituent! *You* have voting power. Use it! That's the beauty of a democracy. The *people* have the *power*, if we choose to *exercise* it. Get the chair of the insurance and health committees in your state legislature on your side.

You can make a difference and change things in *your* state. Don't wait for someone else to do it. That person is **you**. Good luck!

Written by Susan M. Barbey, an ED Advocate in New York, NY