

115TH CONGRESS
1ST SESSION

H. RES. 464

Designating the week of July 17 through July 21, 2017, as “National Ectodermal Dysplasias Week” and supporting the goals and ideals of National Ectodermal Dysplasias Week to raise awareness and understanding of ectodermal dysplasias.

IN THE HOUSE OF REPRESENTATIVES

JULY 20, 2017

Ms. SPEIER (for herself, Mr. SCHIFF, and Mr. KHANNA) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Designating the week of July 17 through July 21, 2017, as “National Ectodermal Dysplasias Week” and supporting the goals and ideals of National Ectodermal Dysplasias Week to raise awareness and understanding of ectodermal dysplasias.

Whereas ectodermal dysplasias is a congenital disorder that causes defects to the skin, hair, nails, teeth, and glands of an individual and can also cause harm to other body parts of an individual, such as the eyes, ears, and throat;

Whereas ectodermal dysplasias is a genetic disorder that is passed from parent to child;

Whereas a child may be the first individual in a family to be affected by ectodermal dysplasias and can then pass the condition on to the next generation;

Whereas ectodermal dysplasias is a rare disorder that affects fewer than 200,000 people in the United States;

Whereas symptoms of ectodermal dysplasias in an individual can include—

- (1) the inability to perspire;
- (2) lack of tears in the eyes;
- (3) cleft lip and palate;
- (4) sparse saliva;
- (5) missing fingers or toes; and
- (6) absence or malformation of some or all teeth, known as anodontia and hypodontia, respectively;

Whereas there are more than 180 different types of ectodermal dysplasias and a specific diagnosis depends on the combination of symptoms that an individual experiences;

Whereas there is no cure for ectodermal dysplasias;

Whereas the treatment for ectodermal dysplasias varies depending on the severity of the disease, which can range from mild symptoms to extensive health issues that require advanced care;

Whereas many types of ectodermal dysplasias affect the teeth and the nature of dental and oral symptoms—

- (1) are specific to each syndrome; and
- (2) can include severe hypodontia and anodontia that require complex care;

Whereas an individual who suffers from ectodermal dysplasias can expect to spend approximately \$150,000 on dental care alone during the lifetime of the individual;

Whereas most insurance companies provide coverage for the treatment of a congenital disease or anomaly;

Whereas most States require coverage for any repair or restoration of body parts for a congenital disease like ectodermal dysplasias;

Whereas coverage for complex and medically necessary dental procedures that are required because of ectodermal dysplasias, including prosthetic teeth and bone grafts, is routinely denied;

Whereas access to health insurance coverage for medically necessary dental services relating to ectodermal dysplasias varies across the United States;

Whereas gaps in ectodermal dysplasias coverage have serious consequences for patients and their families and may lead to severe limits on proper oral function and the ability to eat or speak;

Whereas scientists across the United States are conducting research projects and clinical trials and are hopeful that breakthroughs in ectodermal dysplasias research and treatment are forthcoming; and

Whereas the House of Representatives is an institution that can raise awareness about ectodermal dysplasias to the general public and the medical community: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) expresses support for the designation of

3 “National Ectodermal Dysplasias Week”;

1 (2) supports the goals and ideals of National
2 Ectodermal Dysplasias Week to raise awareness and
3 understanding of ectodermal dysplasias;

4 (3) encourages the people of the United States
5 to become more informed about—

6 (A) ectodermal dysplasias; and

7 (B) the role of comprehensive treatment
8 for all symptoms of ectodermal dysplasias, in-
9 cluding dental manifestations, in improving
10 quality of life; and

11 (4) respectfully requests that the Secretary of
12 the House of Representatives transmit an enrolled
13 copy of this resolution to the National Foundation
14 for Ectodermal Dysplasias, a nonprofit organization
15 dedicated to improving the lives of individuals af-
16 fected by ectodermal dysplasias.

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