and flat feet; but half of fragile X children do not exhibit any of these characteristics. Other symptoms are less obvious, including hyperactivity, attention deficits, severe anxiety, and even violent seizures, making diagnosis difficult.

Again, I think it was the gentleman from Texas (Mr. GREEN) who indicated that it is estimated that somewhere between 80 and 90 percent of children with fragile X are currently undiagnosed or misdiagnosed. So it is fitting that today we consider a resolution recognizing National Fragile X Research Day and the urgency of the need to increase funding for fragile X research.

Mr. Speaker, 2 years ago this week, Congress enacted another bill sponsored by the gentleman from Oklahoma (Mr. WATKINS) and myself; it was labeled the Fragile X Research Breakthrough Act as part of the Children's Health Act of 2000. This law directed an arm of the National Institutes of Health to expand and coordinate research of fragile X and authorize the establishment of at least three fragile X research centers. I am pleased to report significant progress towards implementing these provisions. Early this year, the institute began accepting applications for the fragile X research centers, which hopefully will be ready to open their doors this coming spring.

Thanks to this Federal commitment, many prominent scientists have undertaken fragile X research projects, rapidly accelerating the progress and leading to new breakthroughs about its cause. In a series of landmark discoveries, researchers have identified the set of genes which are normally regulated by the fragile X gene. Scientists are also now pursuing promising drug therapies for fragile X as new evidence has shown that this type of defect may be blocked by relatively simple medications. These new discoveries may not only lead to treatments for fragile X, but also have uncovered striking connections between fragile X and a whole litany of other neurological and psychiatric disorders. So all of this holds great promise for the development of safe and effective treatments. But as the gentleman from Oklahoma (Mr. WATKINS) has indicated, there is a great more still to be done.

So I encourage all of my colleagues to support this resolution. Again, I want to commend the gentleman from Oklahoma (Mr. WATKINS). His work in this particular endeavor is part of a wonderful legacy that he can take with him as he leaves this institution after some 20 years. So I want to extend my congratulations.

Mr. WATKINS of Oklahoma. Mr. Speaker, will the gentleman yield?

Mr. DELAHUNT. I yield to the gentleman from Oklahoma.

Mr. WATKINS of Oklahoma. Mr. Speaker, as the gentleman indicated, and the gentleman is my friend, and believe me, I truly feel that. The gentleman indicated that I am leaving. This is something I am very proud of in a humanitarian way, and I am going to be, hopefully, asking the gentleman to continue this work. I am going to be leaving the House. But I know that the gentleman will continue that effort.

Mr. Speaker, I would like to dedicate this day to a classmate that I had who had this when I was growing up. I used to sit next to him at this country school with a popsicle, and I always shared half that popsicle with him. So I dedicate this day to Herman Samples, that classmate of mine.

Mr. DELAHUNT. Mr. Speaker, reclaiming my time, I promise my friend and my colleague that I will take up this cause, and I will always remember this particular story that the gentleman concluded his remarks with. I too want to share in dedicating this day to him. Again, I thank the gentleman for everything that he has done for so many.

Mr. BILIRAKIS. Mr. Speaker, I rise today in support of H. Res. 398, which recognizes the devastating impact of Fragile X, the most common inherited cause of mental retardation.

Fragile X mental impairment may range from mild learning disabilities and hyperactivity to severe mental retardation. In addition to intellectual disabilities, some individuals with Fragile X display common physical traits and characteristic facial features. Children with Fragile X often appear normal in infancy but develop typical physical characteristics during their lifetimes. Because of scientific advances, improvements in genetic testing, and increased awareness, the number of children diagnosed with Fragile X has increased significantly over the last decade.

I was proud to have worked with my friend from Ohio, Mr. BROWN, to expand research on a number of disorders that disproportionately affect children, including Fragile X, through the Children's Health Act of 2000. The law urges the Director of the National Institutes of Health (NIH) to expand, intensify, and coordinate research on Fragile X at NIH.

Mr. Speaker, I urge my colleagues to support H. Res. 398, which recognizes the devastating impact of Fragile X on thousands of people in the United States and their families. Furthermore, this resolution calls for additional Fragile X research and supports National Fragile X Research Day.

Mr. BEREUTER. Mr. Speaker, as an original cosponsor of the resolution, this Member wishes to add his strong support for H. Res. 398, which would recognize the impact of Fragile X and would call upon the Federal Government to enhance and increase its efforts and commitments to Fragile X research.

This Member would like to commend the distinguished gentleman from Louisiana [Mr. TAUZIN], the Chairman of the House committee on Energy and Commerce, and the distinguished gentleman from Michigan [Mr. DINGELL], the ranking member of the House Committee on Energy and Commerce, for bringing this important resolution to the House Floor today. This Member would also like to commend the gentleman from Oklahoma [Mr. WATKINS] for sponsoring H. Res. 398 and for his personal interest in Fragile X.

Fragile X syndrome is a hereditary condition which causes a wide range of mental impairment, from mild learning disabilities to severe mental retardation. It is the most common cause of genetically-inherited mental impairment. In addition to mental impairment, Fragile X is associated with a number of physical and behavioral characteristics.

House Resolution 398 would recognize the devastating impact of Fragile X on thousands of people in the United States and their families. In addition, the resolution would call on the National Institutes of Health, the Centers for Disease Control and Prevention, and other sources of Federal and private research funds to enhance and increase their efforts and commitment to Fragile X research.

Furthermore, the resolution also would call upon medical schools and other health care educators, medical societies, and associations, and Federal, state, and local health care facilities to promote research that will lead to a treatment and cure for Fragile X. Finally, H. Res. 398 would comment the goals and ideas of a National Fragile X Research Day and would support interested groups in conducting appropriate ceremonies, activities, and programs to demonstrate support for such a day.

Mr. Speaker, in closing, this Member urges his colleagues to support H. Res. 398.

Mr. GREEN of Texas. Mr. Speaker, I yield back the balance of my time.

Mr. SHIMKUS. Mr. Speaker, I want to thank the gentleman from Oklahoma and the gentleman from Massachusetts for their fine work on this bill, and I yield back the balance of my time.

The SPEAKER pro tempore (Mr. BOOZMAN). The question is on the motion offered by the gentleman from Illinois (Mr. SHIMKUS) that the House suspend the rules and agree to the resolution, H. Res. 398.

The question was taken.

The SPEAKER pro tempore. In the opinion of the Chair, two-thirds of those present have voted in the affirmative.

Mr. GREEN of Texas. Mr. Speaker, I object to the vote on the ground that a quorum is not present and make the point of order that a quorum is not present.

The SPEAKER pro tempore. Pursuant to clause 8, rule XX and the Chair's prior announcement, further proceedings on this motion will be postponed.

The point of no quorum is considered withdrawn.

EXPRESSING THE SENSE OF THE CONGRESS WITH RESPECT TO THE DISEASE ENDOMETRIOSIS

Mr. SHIMKUS. Mr. Speaker, I move to suspend the rules and agree to the concurrent resolution, (H. Con. Res. 291) expressing the sense of the Congress with respect to the disease endometriosis.

The Clerk read as follows:

H. CON. RES. 291

Whereas endometriosis is a painful, chronic gynecologic disease;

Whereas, with such disease, tissue that is similar to the endometrium (the tissue lining the inside of the uterus) grows outside the uterus in the abdominal cavity and results in internal bleeding, inflammation, and

the development of scar tissue because the tissue has no means of leaving the body (unlike the monthly development and shedding of the endometrium through the menstruation process);

Whereas an estimated 10 to 20 percent of American women of childbearing age have endometriosis;

Whereas endometriosis is a poorly understood disease and can strike women of any socioeconomic class, age, or race;

Whereas the disease can affect a woman's ability to work, ability to reproduce, and relationships with her mate, children, and everyone around her;

Whereas infertility occurs in about 30 to 40 percent of women with endometriosis;

Whereas the cause of endometriosis is unknown;

Whereas the disease can only be definitively diagnosed through gynecologic surgery;

Whereas studies have shown that the average delay in actual diagnosis is more than nine years; and

Whereas there is no definitive cure for endometriosis: Now, therefore, be it

Resolved by the House of Representatives (the Senate concurring), That the Congress—

(1) strongly supports efforts to raise public awareness of endometriosis throughout the medical and lay communities; and

(2) recognizes the need for better support of patients with endometriosis, the need for physicians to better understand the disease, the need for more effective treatments, and ultimately, the need for a cure.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from Illinois (Mr. SHIMKUS) and the gentleman from Texas (Mr. GREEN) each will control 20 minutes.

The Chair recognizes the gentleman from Illinois (Mr. SHIMKUS).

GENERAL LEAVE

Mr. SHIMKUS. Mr. Speaker, I ask unanimous consent that all Members may have 5 legislative days within which to revise and extend their remarks on this legislation and to insert extraneous material.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from Illinois?

There was no objection.

Mr. SHIMKUS. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, today the House is considering House Concurrent Resolution 291, a resolution expressing the sense of the Congress with respect to endometriosis.

Reported unanimously by the Committee on Energy and Commerce, this resolution will help raise awareness about a common disease that can unfortunately lead to devastating consequences for many women.

Endometriosis is a painful, chronic gynecologic disease affecting approximately 10 to 20 percent of American women of childbearing age. Of those affected, about 30 to 40 percent will experience infertility.

Unfortunately, the cause of endometriosis is unknown, and there is still no cure. Diagnosis can be difficult to confirm without surgery, and it is typically delayed by an average of 9 years. The National Institutes of Health is currently conducting several studies that may lead to other treatment options. Hormone treatments may show some success so that women affected by endometriosis may still be able to bear children.

The resolution before us today recognizes the need for improved patient support, improved physician awareness, and more effective treatments, including a cure. I would like to thank the gentleman from California (Mr. MCKEON) for his leadership in helping to raise awareness of endometriosis.

Mr. Speaker, I encourage my colleagues to adopt the resolution.

Mr. Speaker, I reserve the balance of my time.

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Mr. GREEN of Texas. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, I rise in support of House Concurrent Resolution 291. This legislation will bring recognition and hope to those who suffer endometriosis.

Endometriosis is a serious affliction that affects between 10 percent and 20 percent of American women of childbearing age, more than 26 million women. Endometriosis is a disease where tissue similar to the lining of a woman's uterus grows outside the uterus and into the abdominal cavity. This growth leads to internal bleeding, inflammation and scar tissue.

This disease, which is such a mystery to the medical community, has no known cause or cure. It can strike women of any age, race, income level, and it can hamper a woman's ability to work and start a family. For 30 to 40 percent of those afflicted, this disease causes infertility.

House Concurrent Resolution 291 will help raise the awareness of this devastating disorder not just to the public, but to the medical community as well. It is my hope that this resolution will lead to better support for patients who suffer from this disease, a better understanding by physicians of the needs of those who have endometriosis, and more research for treatments, and ultimately a cure for all women with this disease.

I would like to thank my colleague and good friend, the gentleman from California (Mr. MCKEON), for introducing this resolution and bringing it to our attention. I urge passage. The sooner we educate ourselves about this disease, the sooner a cure will be found. I urge my colleagues to support it.

Mr. Speaker, I reserve the balance of my time.

Mr. SHIMKUS. Mr. Speaker, I yield such time as he may consume to the gentleman from California (Mr. MCKEON), the author of the legislation.

Mr. MCKEON. Mr. Speaker, I thank the gentleman for yielding time to me.

Mr. Speaker, I rise in strong support of this resolution. I introduced House Concurrent Resolution 291 to bring awareness of a serious yet obscure disease from which many American women of childbearing age suffer. Endometriosis is a disease in which tissue similar to the tissue inside of the uterus grows outside of the uterus in the abdominal cavity. Because the tissue has no natural way to leave the body, the result is internal bleeding, inflation, scar tissue, and pain.

I had never heard of endometriosis until a constituent, Mary Prenger, brought it to my attention. Since then I have come to learn that 10 to 20 percent of all women suffer from the disease, and infertility occurs in about 30 to 40 percent of all women who suffer from it.

Endometriosis is a nondiscriminating disease. It affects women from all walks of life. Socioeconomic background and race have no bearing. Because such a large percentage of women who have the disease become infertile, endometriosis has the potential to be not only a great physical disability, but also the emotional and psychological burden is great.

Mr. Speaker, it is my hope that by passing this resolution, both the medical and the lay communities will become more aware of endometriosis. It is only through awareness of the disease that we will be able to grow closer to a cure.

Mr. DINGELL. Mr. Speaker, I rise in support of H. Con. Res. 291, raising public awareness on the disease endometriosis.

Endometriosis is a painful, chronic gynecologic disease affecting 10 to 20 percent of American women of childbearing age and causing infertility in an estimated 30 to 40 percent of those afflicted. Studies have shown that the average delay in actual diagnosis of endometriosis is in excess of nine years. It is time we work together to find a cure for this life-altering, devastating disease.

H. Con. Res. 291 support efforts to raise public awareness of endometriosis throughout the medical and lay communities. It also recognizes the need for better support of patients with endometriosis, the need for physicians to better understand the disease, the need for more effective treatments, and ultimately, the need for a cure.

I urge my colleagues to join me in supporting H. Con. Res. 291.

Mr. BILIRAKIS. Mr. Speaker, today I rise in support of H. Con. Res. 291, which expresses the sense of the Congress with respect to the disease endometriosis.

Endometriosis is a painful, chronic gynecologic disease where the lining of the uterus grows in other parts of the abdominal cavity and results in internal bleeding, inflammation, and the development of scar tissue. Endometriosis affects an estimated 10 percent of reproductive age women and may cause infertility in 30 to 40 percent of all women who suffer from this disease. Roughly 99 percent of women state that they experienced pelvic pain for about 10 years before they were diagnosed with endometriosis.

The cause of the disease is unknown but researchers have found that family members of women with endometriosis more commonly suffered from the disease. Diagnosis can be difficult to confirm without surgery.

This resolution strongly supports efforts to raise public awareness of endometriosis and

recognizes the need for improved patient support, improved physician awareness and understanding, and more effective treatment, including finding a cure. Mr. Speaker, I urge my colleagues to support H. Con. Res. 291.

Mr. GREEN of Texas. Mr. Speaker, I yield back the balance of my time.

Mr. SHIMKUS. Mr. Speaker, I yield back the balance of my time.

The SPEAKER pro tempore (Mr. BOOZMAN). The question is on the motion offered by the gentleman from Illinois (Mr. SHIMKUS) that the House suspend the rules and agree to the concurrent resolution, House Concurrent Resolution 291.

The question was taken.

The SPEAKER pro tempore. In the opinion of the Chair, two-thirds of those present have voted in the affirmative.

Mr. GREEN of Texas. Mr. Speaker, I object to the vote on the ground that a quorum is not present and make the point of order that a quorum is not present.

The SPEAKER pro tempore. Pursuant to clause 8 of rule XX and the Chair's prior announcement, further proceedings on this motion will be postponed.

The point of no quorum is considered withdrawn.

RARE DISEASES ACT OF 2002

Mr. SHIMKUS. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 4013) to amend the Public Health Service Act to establish an Office of Rare Diseases at the National Institutes of Health, and for other purposes.

The Clerk read as follows:

H.R. 4013

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Rare Diseases Act of 2002''.

SEC. 2. FINDINGS AND PURPOSES.

(a) FINDINGS.—Congress makes the following findings:

(1) Rare diseases and disorders are those which affect small patient populations, typically populations smaller than 200,000 individuals in the United States. Such diseases and conditions include Huntington's disease, amyotrophic lateral sclerosis (Lou Gehrig's disease), Tourette syndrome, Crohn's disease, cystic fibrosis, cystinosis, and Duchenne muscular dystrophy.

(2) For many years, the 25,000,000 Americans suffering from the over 6,000 rare diseases and disorders were denied access to effective medicines because prescription drug manufacturers could rarely make a profit from marketing drugs for such small groups of patients. The prescription drug industry did not adequately fund research into such treatments. Despite the urgent health need for these medicines, they came to be known as ''orphan drugs'' because no companies would commercialize them.

(3) During the 1970s, an organization called the National Organization for Rare Disorders (NORD) was founded to provide services and to lobby on behalf of patients with rare diseases and disorders. NORD was instrumental in pressing Congress for legislation to encourage the development of orphan drugs.

(4) The Orphan Drug Act created financial incentives for the research and production of such orphan drugs. New Federal programs at the National Institutes of Health and the Food and Drug Administration encouraged clinical research and commercial product development for products that target rare diseases. An Orphan Products Board was established to promote the development of drugs and devices for rare diseases or disorders.

(5) Before 1983, some 38 orphan drugs had been developed. Since the enactment of the Orphan Drug Act, more than 220 new orphan drugs have been approved and marketed in the United States and more than 800 additional drugs are in the research pipeline.

(6) Despite the tremendous success of the Orphan Drug Act, rare diseases and disorders deserve greater emphasis in the national biomedical research enterprise. The Office of Rare Diseases at the National Institutes of Health was created in 1993, but lacks a statutory authorization.

(7) The National Institutes of Health has received a substantial increase in research funding from Congress for the purpose of expanding the national investment of the United States in behavioral and biomedical research.

(8) Notwithstanding such increases, funding for rare diseases and disorders at the National Institutes of Health has not increased appreciably.

(9) To redress this oversight, the Department of Health and Human Services has proposed the establishment of a network of regional centers of excellence for research on rare diseases.

(b) PURPOSES.—The purposes of this Act are to—

(1) amend the Public Health Service Act to establish an Office of Rare Diseases at the National Institutes of Health; and

(2) increase the national investment in the development of diagnostics and treatments for patients with rare diseases and disorders.

SEC. 3. NIH OFFICE OF RARE DISEASES AT NATIONAL INSTITUTES OF HEALTH.

Title IV of the Public Health Service Act (42 U.S.C. 281 et seq.), as amended by Public Law 107–84, is amended by inserting after section 404E the following:

''OFFICE OF RARE DISEASES

''SEC. 404F. (a) ESTABLISHMENT.—There is established within the Office of the Director of NIH an office to be known as the Office of Rare Diseases (in this section referred to as the 'Office'), which shall be headed by a Director (in this section referred to as the 'Director'), appointed by the Director of NIH.

''(b) DUTIES.—

''(1) IN GENERAL.—The Director of the Office shall carry out the following:

''(A) The Director shall recommend an agenda for conducting and supporting research on rare diseases through the national research institutes and centers. The agenda shall provide for a broad range of research and education activities, including scientific workshops and symposia to identify research opportunities for rare diseases.

''(B) The Director shall, with respect to rare diseases, promote coordination and cooperation among the national research institutes and centers and entities whose research is supported by such institutes.

''(C) The Director, in collaboration with the directors of the other relevant institutes and centers of the National Institutes of Health, may enter into cooperative agreements with and make grants for regional centers of excellence on rare diseases in accordance with section 404G.

''(D) The Director shall promote the sufficient allocation of the resources of the National Institutes of Health for conducting and supporting research on rare diseases.

''(E) The Director shall promote and encourage the establishment of a centralized clearinghouse for rare and genetic disease information that will provide understandable information about these diseases to the public, medical professionals, patients and families.

''(F) The Director shall biennially prepare a report that describes the research and education activities on rare diseases being conducted or supported through the national research institutes and centers, and that identifies particular projects or types of projects that should in the future be conducted or supported by the national research institutes and centers or other entities in the field of research on rare diseases.

''(G) The Director shall prepare the NIH Director's annual report to Congress on rare disease research conducted by or supported through the national research institutes and centers.

''(2) PRINCIPAL ADVISOR REGARDING ORPHAN DISEASES.—With respect to rare diseases, the Director shall serve as the principal advisor to the Director of NIH and shall provide advice to other relevant agencies. The Director shall provide liaison with national and international patient, health and scientific organizations concerned with rare diseases.

''(c) DEFINITION.—For purposes of this section, the term 'rare disease' means any disease or condition that affects less than 200,000 persons in the United States.

''(d) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as already have been appropriated for fiscal year 2002, and $4,000,000 for each of the fiscal years 2003 through 2006.''.

SEC. 4. RARE DISEASE REGIONAL CENTERS OF EXCELLENCE.

Title IV of the Public Health Service Act (42 U.S.C. 281 et seq.), as amended by section 3, is further amended by inserting after section 404F the following:

''RARE DISEASE REGIONAL CENTERS OF EXCELLENCE

''SEC. 404G. (a) COOPERATIVE AGREEMENTS AND GRANTS.—

''(1) IN GENERAL.—The Director of the Office of Rare Diseases (in this section referred to as the 'Director'), in collaboration with the directors of the other relevant institutes and centers of the National Institutes of Health, may enter into cooperative agreements with and make grants to public or private nonprofit entities to pay all or part of the cost of planning, establishing, or strengthening, and providing basic operating support for regional centers of excellence for clinical research into, training in, and demonstration of diagnostic, prevention, control, and treatment methods for rare diseases.

''(2) POLICIES.—A cooperative agreement or grant under paragraph (1) shall be entered into in accordance with policies established by the Director of NIH.

''(b) COORDINATION WITH OTHER INSTITUTES.—The Director shall coordinate the activities under this section with similar activities conducted by other national research institutes, centers and agencies of the National Institutes of Health and by the Food and Drug Administration to the extent that such institutes, centers and agencies have responsibilities that are related to rare diseases.

''(c) USES FOR FEDERAL PAYMENTS UNDER COOPERATIVE AGREEMENTS OR GRANTS.—Federal payments made under a cooperative agreement or grant under subsection (a) may be used for—

''(1) staffing, administrative, and other basic operating costs, including such patient care costs as are required for research;

''(2) clinical training, including training for allied health professionals, continuing