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**EXPRESSING SENSE OF CONGRESS REGARDING NEED FOR ADDITIONAL RESEARCH INTO HYDROCEPHALUS -- (House of Representatives - February 27, 2007)**

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Mr. PALLONE. Mr. Speaker, I move to suspend the rules and agree to the concurrent resolution (H. Con. Res. 74) expressing the sense of the Congress regarding the need for additional research into the chronic neurological condition hydrocephalus, and for other purposes.

The Clerk read as follows:

H. Con. Res. 74

Whereas hydrocephalus is a serious neurological condition, characterized by the abnormal buildup of cerebrospinal fluids in the ventricles of the brain;

Whereas there is no known cure for hydrocephalus;

Whereas hydrocephalus affects an estimated one million Americans;

Whereas 1 or 2 in every 1000 babies are born with hydrocephalus;

Whereas over 375,000 older Americans have hydrocephalus, which often goes undetected or is misdiagnosed as dementia, Alzheimer's disease, or Parkinson's disease;

Whereas with appropriate diagnosis and treatment, people with hydrocephalus are able to live full and productive lives;

Whereas the standard treatment for hydrocephalus was developed in 1952, and carries multiple risks including shunt failure, infection, and overdrainage;

Whereas there are fewer than 10 centers in the United States specializing in the treatment of adults with normal pressure hydrocephalus;

Whereas each year, the people of the United States spend in excess of \$1 billion to treat hydrocephalus;

Whereas a September 2005 conference sponsored by 7 institutes of the National Institutes of Health--`Hydrocephalus: Myths, New Facts, Clear Directions"--resulted in efforts to initiate new, collaborative research and treatment efforts; and

Whereas the Hydrocephalus Association is one of the Nation's oldest and largest patient and research advocacy and support networks for individuals suffering from hydrocephalus: Now, therefore, be it

*Resolved by the House of Representatives (the Senate concurring), That--*

(1) the Congress commends the Director of the National Institutes of Health for working with leading scientists and researchers to organize the first-ever National Institutes of Health conference on hydrocephalus; and

(2) it is the sense of the Congress that--

(A) the Director of the National Institutes of Health should continue the current collaboration with respect to hydrocephalus among the National Eye Institute; the National Human Genome Research Institute; the National Institute of Biomedical Imaging and Bioengineering; the National Institute of Child Health and Human Development; the National Institute of Neurological Disorders and Stroke; the National Institute on Aging; and the Office of Rare Diseases;

(B) further research into the epidemiology, pathophysiology, disease burden, and improved treatment of hydrocephalus should be conducted or supported; and

(C) public awareness and professional education regarding hydrocephalus should increase through partnerships between the Federal Government and patient advocacy organizations, such as the Hydrocephalus Association.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from New Jersey (Mr. *Pallone*) and the gentleman from Oklahoma (Mr. *Sullivan*) each will control 20 minutes.

The Chair recognizes the gentleman from New Jersey.

#### GENERAL LEAVE

Mr. PALLONE. Mr. Speaker, I ask unanimous consent that all Members may have 5 legislative days to revise and extend their remarks and include extraneous material on the bill that we are considering.

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

There was no objection.

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

I rise in support of H. Con. Res. 74, expressing the sense of the Congress regarding the need for additional research into the chronic neurological condition hydrocephalus.

Hydrocephalus simply means water on the brain. The term "hydrocephalus" defines a condition characterized by an excessive accumulation of fluid in the brain. This buildup of fluid inside the skull causes the brain to swell, infections of the nervous system, lesions or tumors of the brain or spinal cord, and decreased mental function among other symptoms.

The causes of hydrocephalus are not all well understood. It may result from genetic inheritance or developmental disorders. Other possible causes include complications of premature birth, diseases or infections caught before birth, and injury before, during or after childbirth.

Hydrocephalus is believed to affect approximately one in every 500 children. At present, most of these cases are diagnosed prenatally, at the time of delivery, or in early childhood. Advances in diagnostic imaging technology allow more accurate diagnoses in individuals with atypical presentations, including adults with conditions such as normal pressure hydrocephalus.

The National Institute of Neurological Disorders and Stroke, a part of the National Institutes of Health, is the leading support of research on hydrocephalus within the Federal Government. NINDS works collaboratively with other institutes at NIH to further research on the influence of hydrocephalus on development and on the more general issue of the effect of early brain injury. The knowledge gained from this research will foster hope for new methods to treat and prevent developmental brain disorders such as hydrocephalus.

I would like to thank Congressman **MIKE THOMPSON** of California for his work to bring this resolution before us today, and I would urge my colleagues to support H. Con. Res. 74.

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

Mr. SULLIVAN. Mr. Speaker, I yield myself as much time as I may consume.

I stand here today in support of this resolution, House Concurrent Resolution 74, addressing the need for additional research into the chronic neurological condition hydrocephalus.

This disease, for which there is no cure, affects an estimated 1 million Americans. Often the symptoms of hydrocephalus are confused with those of dementia, Alzheimer's disease or Parkinson's disease. When the disease is properly identified, people with hydrocephalus are able to live full and productive lives.

The National Institutes of Health has responded to the needs of the hydrocephalus community by working with scientists and researchers to organize a conference in September of 2005 called ``Hydrocephalus: Myths, New Facts, Clear Directions.''

Demonstrating the need for collaborative research at the National Institutes of Health, seven institutes were able to work together and initiate new research and treatment efforts for hydrocephalus.

I thank Representative **MIKE THOMPSON** for his work in bringing awareness to this issue.

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

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Mr. PALLONE. Mr. Speaker, I am pleased to yield 5 minutes to the gentleman from California (Mr. *Thompson*), the sponsor of the House concurrent resolution.

Mr. THOMPSON of California. Mr. Speaker, I thank the gentleman for yielding.

I am here today to ask all of my colleagues to support this resolution. Hydrocephalus is an abnormal buildup of fluid in the brain, and it affects nearly 1 million Americans. Without treatment, hydrocephalus is fatal, but when treated, most people with this condition can lead full and productive lives.

I became aware of this condition through a constituent and a friend of mine, Cynthia Solomon, who has a family member who suffers from this condition. Cynthia struggled to find information about hydrocephalus and wanted to connect with other affected families. So she cofounded the first patient advocacy organization for this condition, the Hydrocephalus Association.

As anyone who has been affected by this condition can tell you, the symptoms are many and they vary from person to person. Excess fluid in the brain can cause head enlargement, blurred vision, seizures, learning disabilities and impaired physical development. In older adults, symptoms can mimic dementia, Alzheimer's disease and Parkinson's disease, often leading to a misdiagnosis and a delay in receiving critical and proper treatment.

Doctors do not yet understand the specific causes of hydrocephalus. However, the current treatment was developed back in 1952 and involves surgically inserting a shunt into the brain. This carries serious risk of shunt failure, infection and obstructions. Overdrainage is also a threat. This can trigger a vertical collapse, causing blood vessels to tear and possibly resulting in a subdural hematoma.

Improvement in this treatment is long overdue, and with additional research, we can make it happen.

The National Institutes of Health recognizes this need and recently organized their first ever conference on hydrocephalus. This has resulted in efforts to initiate new collaborative research projects and an expansion of their focus on the development of new treatments.

This resolution commends the NIH for their action and encourages them to continue their collaborative efforts. It also calls for additional research into this serious condition.

However, we cannot depend solely on Federal efforts to expand awareness about hydrocephalus. I commend the Hydrocephalus Association and other groups for their commitment to patient advocacy and public education. Partnerships between these groups, health care providers and the government will bring us closer to our common goal: improved treatment of this condition.

I would like to say a special thanks to Dory Kranz, who is the current director of the Hydrocephalus Association, for her help in putting this resolution together and her ongoing work in this regard.

I ask my colleagues for their support of this resolution so we can further research into this very serious and important condition and we can bring about improved treatment to those individuals who are affected by this very, very serious and debilitating condition.

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Ms. PELOSI. Mr. Speaker, I rise in strong support of H. Con. Res. 74 which has been introduced by my colleague from California, Congressman *Mike Thompson*, and co-sponsored by Democratic and Republican Members alike.

H. Con. Res. 74 encourages additional support for research into the prevention and treatment of the neurological condition hydrocephalus. It is a chronic medical condition that, like other conditions affecting a relatively small number of people, receives inadequate attention and resources, which delays research that could achieve great breakthroughs. Passage of H. Con. Res. 74 will demonstrate the support of the Congress for aggressive research to find improved methods for detecting and treating hydrocephalus not only among children, but within the increasingly large number to adults who are affected by late onset of the condition.

I am especially proud that the Hydrocephalus Association is headquartered in my congressional district in San Francisco, and that the couple whose pioneering efforts have encouraged and supported so many people with hydrocephalus and their families are San Franciscans--Emily and Russell Fudge, as is the Association's Executive Director, Dory Kranz.

Under their leadership, together with the board composed of leading physicians and researchers, parents and people with hydrocephalus, the Hydrocephalus Association has raised public awareness of this condition and the enormous impact it has on over one million Americans. Because of the medical advances and the advocacy efforts promoted by the Association, most of these children and adults are able to lead full and productive lives and make enormous contributions to our society.

These successes have inadvertently complicated the efforts to advance research, diagnosis and treatment. The typical surgical treatment--the insertion of a shunt to carry away excessive cerebral fluid from the brain--was developed over 50 years ago. Because shunting has alleviated many of the more grave aspects of pre-shunt hydrocephalus, many believe it represents a cure. But it does not. Shunt surgery and the frequent repairs, which are well known to those with hydrocephalus and their families, are not only serious operations, but cost a billion dollars a year, much of which might well be averted with development of advanced treatment strategies.

Promoting additional research through increased federal support is the goal of this resolution. Those advances will benefit not only those with hydrocephalus, but will help to reduce excessive costs in our health care system, and allow hundreds of thousands of people with hydrocephalus to live even fuller lives freed from the anxieties and costs associated with shunt failure and related complications.

Seven of the institutes of the National Institutes of Health--including the Office of Rare Diseases--sponsored a major national conference in September 2005 on ``Hydrocephalus: Myths, New Facts, Clear Directions'' which has encouraged aggressive action in the areas of research and treatment. Now it is time for the Congress to join the campaign to expand our understanding of the causes and modernize the treatment of hydrocephalus. I call upon my colleagues to support H. Con. Res. 74 to encourage our nation's leading medical institutions and researchers to expand their focus on achieving breakthrough research in the diagnosis and treatment of hydrocephalus.

Mr. WAXMAN. Mr. Speaker, I rise in strong support of H. Con. Res. 74. This resolution will encourage research into Hydrocephalus, a chronic and often devastating neurological condition.

Hydrocephalus affects an estimated one million Americans--which classifies it as a rare disease. And, unfortunately, like so many other rare diseases, insufficient resources have been directed toward it. Individuals with this disease are forced to undergo ``shunting,'' a highly invasive surgical procedure that carries with it serious safety risks. This procedure also takes a heavy toll on our entire health-care system, costing an average of \$35,000 per procedure.

We can avoid paying this price. With more research and focus on this disease, better treatment--and perhaps even a cure--is within our reach. Patients can be spared the trauma of brain surgery and American citizens can avoid paying more than a billion dollars each year for this treatment.

The NIH has already taken some positive steps toward this goal. By initiating a collaborative effort among 7 NIH institutes and sponsoring a major national conference, the NIH has begun the work that must be done. Now we need to send a strong statement that we want this work to continue.

Cures for rare diseases like Hydrocephalus will never be found unless we increase our effort and follow the scientific promise. We can start with this vote today.

Mr. GEORGE MILLER of California. Mr. Speaker, I rise today to express my support for H. Con. Res. 74 sponsored by Congressman **MIKE THOMPSON**. Passage of this bill will express federal support for Hydrocephalus research.

Hydrocephalus, a chronic neurological condition that causes cerebrospinal fluid to build up in the brain cavity instead of being reabsorbed into the body, is a disease that affects over one million Americans. This disease can cause head enlargement and blurred vision, learning disabilities and impaired physical development and is fatal if untreated.

Like many other diseases that affect a relatively small portion of our population, Hydrocephalus research lacks proper funding. It is deplorable that the current standard treatment, which requires the insertion of a shunt into the brain to drain out the fluid, was designed in 1952. Shunts are extremely prone to infections and frequently require repair through major surgery.

Modern medicine can do better. I am certain that with federal support for additional research we can develop a better treatment, if not a cure, for those suffering from Hydrocephalus and help them live healthier, fuller lives.

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I applaud my colleague, Mr. **THOMPSON**, for his efforts in this area and I encourage my colleagues to support this resolution.

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Mr. PALLONE. Mr. Speaker, I have no additional requests for time, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from New Jersey (Mr. *Pallone*) that the House suspend the rules and agree to the concurrent resolution, H. Con. Res. 74.

The question was taken; and (two-thirds being in the affirmative) the rules were suspended and the concurrent resolution was agreed to.

A motion to reconsider was laid on the table.

*END*