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Following the article you will find information on what you can do to keep these bills moving in Congress.

Schumer, Vitter, Lee Introduce Bill to Combat Brain Tumors in Children

*California Political Desk
January 24, 2009*

Washington, D.C. – U.S. Senators Charles E. Schumer (D-NY) and David Vitter (R-LA) joined with Congresswoman Barbara Lee (D-CA) to introduce legislation that would require the National Cancer Institute at the National Institutes of Health (NIH) to establish a National Childhood Brain Tumor Prevention Network. The new National Childhood Brain Tumor Prevention Network would be tasked with conducting and coordinating research, providing grants, and issuing guidance and recommendations with the ultimate goal of preventing and curing pediatric brain cancers. Senator Schumer and Senator Vitter introduced the bill in the Senate today. Rep. Lee reintroduced the legislation in the House.

"There is very little that we know about the causes of brain tumors in children. But what we do know is that this disease confounds researchers, inflicts heartache on families, and shortens the lives of far too many children," Senator Schumer said. "For kids enduring treatment, and family and friends watching them suffer, research provides a ray of hope. We must provide the National Cancer Institute with the mandate, and the resources, to study this terrible disease, because every kid should be afforded the opportunity to grow up healthy and happy."

"Brain tumors are the third most common type of cancer in children, and I believe it's important to provide real and necessary resources at the National Cancer Institute to fight childhood brain tumors. After speaking with Louisiana patients suffering from brain tumors and gaining a greater appreciation of their struggles with this disease, I'm looking forward to working with Sen. Schumer, Rep. Lee and my colleagues in the Senate to pass this legislation into law," said Senator Vitter.

"There are many young people in my district and across this country that suffer from these horrible, often fatal brain tumors," said Rep. Lee. "The establishment of this network will help us to discover the causes of these tumors and will ultimately improve our ability to prevent and treat them. Nothing is more important than the health of our children, that is why we must do all we can to ensure they live healthy lives."

According to the National Cancer Institute (NCI), brain tumors are the third most common type of childhood cancer, after leukemia and lymphoma. Unlike leukemia and lymphoma, childhood brain tumors do not have the same favorable prognosis. Each year, approximately 2,200 children and adolescents are diagnosed with malignant central nervous system tumors, over 90 percent of which are located within the brain. Children diagnosed with malignant brain tumors have only a 60 percent survival rate. Those that do survive have long-term health problems due to the invasiveness of brain tumors and treatment.

Childhood brain tumors present a unique challenge for doctors and researchers, as treatment of brain tumors in children is different than treatment in adults. Compounding this challenge, the symptoms of childhood brain tumors vary greatly from child to child. The cause of childhood brain tumors remains largely unknown and the few risk factors that have been identified explain only a small fraction of all cases.

Despite the differences between brain cancers and other childhood cancers, and adult brain cancer and childhood brain cancer, NCI does not have a separate division dedicated to studying childhood brain tumors. The new National Childhood Brain Tumor Prevention Network would fill this gap in research and treatment, providing a much needed resource for experts and doctors, as well as grant funding for research.

The following information – on what you can do to help - is provided by the Brain Tumor Foundation for Children:

GRASSROOTS CAMPAIGN TO PASS THE NATIONAL CHILDHOOD BRAIN TUMOR PREVENTION NETWORK ACT OF 2009

Two identical bills were introduced in Congress recently that would create the “National Childhood Brain Tumor Prevention Network Act of 2009.” In order to keep these bills moving, everyone concerned about this issue needs to keep the attention on the desperate need for research by performing two important actions.

1. Contact your Congressional Representative and Senator in Washington D.C., representing your district, and ask them to support these bills and vote in favor of them.
2. Contact your State Representative and State Senator (at your state Capitol) and ask them to file or support a joint resolution urging Congress to pass these bills.

The language used in your communication is very important. Details on suggested letter format, legislative process, and definitions are included in the information below.

STEP 1.

Read the legislation that has been filed in Congress [Washington, D.C.] (links posted below this paragraph) so that you are somewhat familiar with its content. One bill was filed in the House, one in the Senate. These are called “companion bills:” identical bills filed in both chambers at the same time send a message of importance and can help the legislation move more quickly through the process. Bills must be approved in their own chamber and then the opposite chamber before they can be passed into law.

House Bill 653 link:

[http://thomas.loc.gov/cgi-bin/query/z?c111:H.R.653:](http://thomas.loc.gov/cgi-bin/query/z?c111:H.R.653)

Senate Bill 305 link:

[http://thomas.loc.gov/cgi-bin/query/z?c111:S.305:](http://thomas.loc.gov/cgi-bin/query/z?c111:S.305)

STEP 2.

Identify your Congressional House of Representatives Member and Senator by visiting www.congress.org. You will need your zip code + 4.

E-MAIL your Representative and Senator in Washington with a customized letter (a suggested format is provided below.) Regular mail must be irradiated because of the

2001 anthrax attacks and can take up to 3 months to arrive. All of Congress is set up to receive and prefers e-mail.

Tell them you will be e-mailing them to follow up on the status. Always end with an “ask.” Your ask = their action.

STEP 3.

Identify your State House of Representatives Member and Senator (who serve your local state Capitol) by visiting your state’s legislative website. You may have to Google “[state name] general assembly.” For example, Georgia’s web site is <http://www.legis.state.ga.us/>. You will need your zip code + 4. Again, you should send an e-mail (suggested format is included below as well.)

However, the goal of reaching the State Senator and Representative is a different “ask.”

Here, you are asking the legislators to pass a joint resolution (meaning the House and Senate both sign it) urging Congress to pass HR 653 and S 305. This carries a lot of weight and tells Congress that this issue is very important to the constituents in their states. A suggested format with the applicable language is included below.

Tell them you will be e-mailing them to follow up on the status. End with an “ask;” your ask = their action.

STEP 4.

Ask your friends, family, helper network, medical professionals, church, community, school, teachers, and anyone else you can think of to do the same. The more noise, the better. In legislative affairs, it is very true that the squeaky wheel gets the grease, so to speak.

STEP 5.

If Congress passes these bills, and if your state passes a joint resolution, make sure to thank your Representatives and Senators.

To track the Congressional Legislation (S/H), <http://thomas.loc.gov/>

SUGGESTIONS FOR DRAFT LETTERS

If you can e-mail your letter, that is the preferred method of communication. The next is via fax. Regular mail can take up to 3 months, as it has to be irradiated due to the anthrax attacks of 2001. It is likely your Congressional representatives will never see your letter that way.

Please customize your letter. Form letters that all say the same thing are extremely ineffective. But if you follow a general format, include personal testimony and clinical statistics, and “ask” for a specific action, your e-mail or faxed letter will be VERY, VERY impactful.

LETTER TO CONGRESSIONAL REPRESENTATIVE AND SENATOR

Your Name
Your Address
City, State, Zip

Today's Date

Representative/Senator Jones
VIA E-MAIL/FAX (as applicable)

Dear Representative _____(last name) or
Dear Senator _____(last name):

I am writing today to urge you to co-sign and pass companion bills HR 653 and S 305, which creates the "National Childhood Brain Tumor Prevention Network Act of 2009." This vital legislation amends a portion of the Public Health Service Act and provides grants and coordinates research with respect to the causes and risk factors associated with childhood brain tumors.

As the proposed legislation cites, tumors kill more children than any other disease, and brain tumors are the second most common type of cancer in children. Childhood brain tumors are the leading cause of death from solid tumors in children. The causes of the overwhelming majority of childhood brain tumors are unknown. Brain tumors have substantial costs for affected children, the families of such children, and society. Because of the relatively low overall incidence of childhood brain tumors, such tumors frequently do not receive sufficient attention and research funding.

No single institution has a sufficient number of patients to independently conduct research that will adequately address the causes of childhood brain tumors. There has been no comprehensive study analyzing all relevant clinical, biological, and epidemiological aspects of childhood brain tumors to identify potential risk factors and determine the cause of such tumors. A significant majority of children with brain tumors are first treated by neurosurgeons and not by oncologists typically involved in such groups.

[INSERT HERE, IN YOUR OWN WORDS, YOUR PERSONAL EXPERIENCE WITH A PEDIATRIC BRAIN TUMOR.]

Thank you for your leadership in the House (or Senate as applicable) and your consideration of this request. I would appreciate it if you would advise me of your actions on this extremely important and groundbreaking issue. My e-mail address is _____. I look forward to hearing from you soon. (include your phone number if you wish.)

Sincerely,

your name
your address

LETTER TO STATE REPRESENTATIVE AND SENATOR

Your Name
Your Address
City, State, Zip

Today's Date

Representative/Senator Jones
VIA E-MAIL/FAX (as applicable)

Dear Representative _____ (last name) or
Dear Senator _____ (last name):

I am writing today to urge you to sponsor a joint resolution in the state assembly urging Congress to pass HR 653 and S 305, which creates the "National Childhood Brain Tumor Prevention Network Act of 2009." This vital legislation amends a portion of the Public Health Service Act and provides grants and coordinates research with respect to the causes and risk factors associated with childhood brain tumors.

As the proposed legislation cites, tumors kill more children than any other disease, and brain tumors are the second most common type of cancer in children. Childhood brain tumors are the leading cause of death from solid tumors in children. The causes of the overwhelming majority of childhood brain tumors are unknown. Brain tumors have substantial costs for affected children, the families of such children, and society. Because of the relatively low overall incidence of childhood brain tumors, such tumors frequently do not receive sufficient attention and research funding.

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[INSERT HERE, IN YOUR OWN WORDS, YOUR PERSONAL EXPERIENCE WITH A PEDIATRIC BRAIN TUMOR.]

Thank you for your leadership in the House (or Senate as applicable) and your consideration of this request. I would appreciate it if you would advise me of your actions on this extremely important and groundbreaking issue. My e-mail address is

_____. I look forward to hearing from you soon. (Include your phone number if you wish.)

Sincerely,

your name
your address

Thank you for your part in helping to ensure these bills are passed in Congress. If you have any questions, please contact Marsi Thrash of the Brain Tumor Foundation for Children at mthrash@braintumorkids.org.