2018 Ependymoma Awareness Day & Butterfly Release

cernfoundation™
Collaborative Ependymoma Research Network

May 6, 2018

Ependymoma Awareness Day is May 6, 2018!

Thank you for your interest in the Ependymoma Awareness Day and the Collaborative Ependymoma Research Network (CERN) Foundation. Now in its seventh year, this campaign is an international effort from the CERN Foundation in partnership with medical professionals, patients and caregivers from around the world. Together, we have designated May 6, 2018, as *Ependymoma Awareness Day*!

The CERN Foundation is thrilled to announce that this year's *Ependymoma Awareness Day* will be held during the National Brain Tumor Society's "Head to the Hill" event in Washington, DC!

Head to the Hill

The CERN Foundation is honored to be a part of this three-day event, held on May 6-8, at which brain tumor advocates from across the country descend on our nation's capital to share their stories and advocate for public policy issues that are important to brain tumor patients, survivors and caregivers.

CERN encourages all those who support the ependymoma cause to attend the 2018 Head to the Hill event! Together we can drive the agenda forward for better treatments, stronger research, and ultimately a cure. Top find out how to participate, please visit braintumor.org/headtothehill.

National Brain Tumor Society

Purchase a Live Butterfly to be Released on Ependymoma Awareness Day!

The CERN Foundation will commemorate *Ependymoma Awareness Day* with a mass butterfly release that will take place on May 6 during the 2018 Head to the Hill activities. If you would like to attend the butterfly release, please RSVP to administrator@cern-foundation.org. The butterfly release will be video-taped and posted on the internet so that supporters unable to attend can participate and share in this moving occasion. We ask that you encourage those you know to donate to support our mission. For every $25 raised, a butterfly will be released during the awareness day ceremony! It's easy to do and only takes a couple of minutes. To donate, visit the CERN Foundation website at cern-foundation.org.

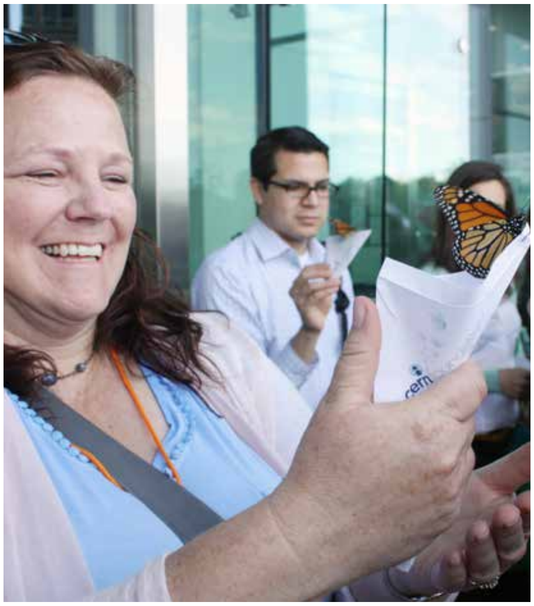
Create Awareness Where **You** Live!

On a **local level**, we urge you to participate in an awareness activity, helping to create a greater understanding of this disease.

You could support awareness in the following ways:

- Create your own Awareness Day event!
- Raise funds to help with research!
- Share information on ependymoma with another person who has never heard of it!
- Tell your doctor and healthcare providers about *Ependymoma Awareness Day*!
- Document your awareness efforts on your Facebook page, Twitter account or blog and use hashtag #CERNbutterfly!
- Share your story with your local media!
- Educate colleagues, co-workers, school groups and congregations!
- Order and wear an ependymoma awareness lapel pin or CERN hat!
- Display or release CERN awareness balloons!
- Seek recognition from your local government or ministry of health!

If you are interested in printing your own t-shirts, posters or banners for your awareness event, contact us - we have digital files available. You may also want to contact your local media including newspapers, radio stations and TV stations to let them know about your efforts. These media outlets are often interested in covering awareness events in their local area. Use our **sample press release** provided on the following pages.



Of course there may be other ways you can support the cause, including bake sales, charity runs, etc. Get creative! We would love to hear from you to see how we can help! Read about ways others around the world have commemorated *Ependymoma Awareness Day* on the following pages.

Show your support!

You can show your support of *Ependymoma Awareness Day* by donating, wearing an awareness support pin or hat, or even holding an awareness event of your own! We welcome your participation in this year's activities – together we can grow awareness of ependymoma!

Join us in making a difference!

The CERN Foundation is currently engaged in a range of community outreach programs and support efforts designed to have a positive impact on the lives of children and adults living with ependymoma, as well as their families and caregivers.

We encourage you to create your own online fundraising campaign or event to help us improve the care and outcome of people with ependymoma.

Donations

You can donate online at cern-foundation.org or mail:
CERN Foundation
PO Box 217
Zionsville, IN 46077

Organize Your Own Event

Interested in holding an *Ependymoma Awareness Day* event where you live? No problem! You can order your own Awareness Day kit!

Included in the $25 kit, that is available for purchase on our website, cern-foundation.org, is this Awareness Day packet of information, an Ependymoma Guide, 5 buttons, 2 temporary tattoos, 10 butterfly balloons, and 5 stickers!

Interested in holding a butterfly or balloon release where you live? Our suppliers will express mail live butterflies, wind-up butterflies or balloons *directly to you!*

Live Butterflies: Butterflies will be delivered to you or your event location along with any displays and accessories. Complete instructions accompany your order. A minimum order applies so please call Kathy at Vibrant Wings (vibrantwings.com) for details at 832-671-4755.

Wind-up Butterflies: Wind-up butterflies will be delivered to you and instructions on how to use. For more information, contact Steve at Flying Butterfly (flyingbutterfly.com) for specific details at 321-258-8132.

Butterfly Balloons: Another easy way to participate is to release CERN awareness balloons. You can order these balloons in bulk as part of your own fundraiser, or simply to release on *Ependymoma Awareness Day* to remember a loved one or to show your support.

Let Us Hear From You!

Share your experiences with us. Notify us if your event is open to the public and we can help promote! You can also submit information and pictures of your activities so that we may include them in future events and on our website, giving inspiration to others as they get involved in *Ependymoma Awareness Day*.

Awareness Day events held throughout the world!

In a groundswell of international support, patients, caregivers, professionals and advocates have participated in a variety of *Ependymoma Awareness Day* events.

Here a few of the Ependymoma Awareness Day activities that were held around the world in 2017!

Memorial Walk and Balloon Release

Brenda and her family held a memorial walk after her older daughter's graduation party. They honored her younger daughter, Carly, who passed two years earlier after a two-year battle with ependymoma. Her older daughter graduated nursing school and was inspired to become an oncology nurse after witnessing the cancer journey first hand. They also held a balloon release of monarch butterflies where love notes were attached.

Featured Article in Alabama

(Pell City, Alabama) For Lori, the past three years were filled with challenges, fear and uncertainties after she was diagnosed with an anaplastic ependymoma. Lori advocated for more funding for research and better treatments at National Brain Tumor Society's Head to the Hill. We are also honored she joined us at CERN Foundation's butterfly release!

To read Lori's article, search: *Local brain tumor survivor will travel to Washington to speak with lawmakers about need for more research, treatment,* by St. Clair Times or visit our website.

Awareness Day in South Africa

(Lonehill Johannesburg, South Africa) Ependy Angels held a picnic and butterfly release as a symbol of hope as community members and friends gathered to honour Ependymoma Awareness Day on May 6. This annual event was created in support of Layla, who has been suffering from an ependymoma for the past four years and to honour the other fallen angels as well as the children still living with ependymoma. Community members gathered for a day of family-fun with activities that included: arts and crafts, a play area, tea garden and multiple beautifully decorated cakes!

Featured News Article in Kansas

(Kansas) Allie, diagnosed with a grade III anaplastic ependymoma in 2016 at the age of 24, was featured on a local news station in Topeka, KS where she shared her story in hopes to raise more awareness of ependymoma and how knowledge is power. "I tell people don't sit on the sidelines. Even if you feel it's not going to go your way – you never know. Miracles happen." - Allie.

To read Allie's article, search: *25-year-old Topeka native battles Ependymoma brain cancer,* by KSNT or visit our website.

Follow our Twitter EAD hashtag #CERNbutterfly

Worldwide events!

Butterfly Release and Penny War in Michigan

(Michigan) Keenan was diagnosed in October 2013 with an ependymoma in the posterior fossa covering his brain stem. He went through chemo and photon radiation and was re-diagnosed with an ependymoma tumor in his L4 area of his spinal canal in June 2015. He underwent surgery, followed by photon radiation. In January 2016, he underwent surgery to remove two ependymoma tumors in the frontal lobe of his brain. He then underwent proton radiation followed by oral chemotherapy. He just completed his Freshman year of high school while completing his chemotherapy. Because of his perseverance, his school, Gladwin High School in Michigan, celebrated with a penny war and butterfly release. Each class was tasked with collecting pennies to donate to the CERN Foundation in honor of Keenan's Kampaign against Cancer. The pennies were worth 1 point and any other currency meant points away. For instance, $1.00 in the Freshman bucket meant a negative 100 points. The Freshman class raised the most money but had the least points. The senior class ended up with the most points. In total, the school collected approximately $300!

Butterflies Released in Massachusetts

(Massachusetts) Pam held a butterfly release on May 7 for Ependymoma Awareness Day at her son's garden located at his elementary school. Aaron was diagnosed with an ependymoma 2 weeks after his first birthday in 2006 and recurred in November 2008, which was followed by treatment. "We always remember and hope to help raise awareness for other families. Our son, Aaron, may no longer be "here" with us, but he is here in our hearts." - Pam

Advocate Shares Her Story

(Arizona) Pati advocates each year at the National Brain Tumor Society's Head to the Hill representing the ependymoma community and we were honored she was able to join us at CERN's butterfly release! "YOU as an individual are the most effective advocate there is: someone who cares and makes a conscious decision to speak out for the ones who can't." - Pati.

To read Pati's article, search: *Head to the Hill: An Advocate's Perspective,* by NBTS or visit our website.

Sample Press Release To Local Media

Media Release Contact:
[Insert your name and contact info here]

CERN Foundation Media Contact:
Kristin Odom (844) 237-6674 kodom@cern-foundation.org
cern-foundation.org

Ependymoma Awareness Day

On May 6, 2018, we invite you to join patients, caregivers and medical professionals around the world in recognizing *Ependymoma Awareness Day*.

Ependymoma Awareness Day offers a rare opportunity to focus attention on this tumor which affects the brain and spine of all age groups - from infants to older adults.

[Insert how you have been affected by ependymoma]

[If you are holding an Awareness event, insert information about your event: when, where, event details]

Would you consider running a featured story to help us increase public awareness of this rare tumor? We are grateful for any media attention to help our cause.

Thank you for your consideration.

Sincerely,

[Signature and title]

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Let's epENDymoma this disease.

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What is ependymoma?

Ependymoma is a rare tumor of the brain or spinal cord. It occurs in both adults and children. Ependymoma is a primary tumor, which means that it starts in either the brain or spine. The brain and spine are part of the central nervous system (CNS). Primary brain and spinal cord tumors are typically grouped by where the cells start.

The most common types of cells in the central nervous system are neurons and glial cells. Tumors from neurons are rare. Glial cells are the cells that support the brain. Tumors that occur from these cells are called gliomas.

Glial cell subtypes of the CNS include:
- Astrocytes
- Oligodendrocytes
- Ependymal cells

CNS brain tumors associated with all three types of glial cells are recognized by the World Health Organization as astrocytomas, oligodendrogliomas and ependymomas.

How do ependymomas form?

Scientists believe they develop from precursor cells to the ependymal cells. These cells line the ventricles (fluid-filled spaces in the brain) and the central canal of the spinal cord.

Ependymomas can occur anywhere in the CNS, including the brain or the spinal cord. The cause of ependymoma is not known.

Do they spread?

Sometimes, ependymoma tumor cells can spread in the cerebrospinal fluid (CSF). They may spread to one or multiple areas in the brain, spine, or both. Although it is rare, ependymoma can spread to other parts of the body. In general, tumors form where the tumor cells originate, such as the base of the brain and the bottom of the spinal cord.

Who does ependymoma affect?

Ependymomas can occur in both children and adults. Overall, ependymomas occur in males slightly more often than females. It also occurs in white people more often than those of other ethnicities.

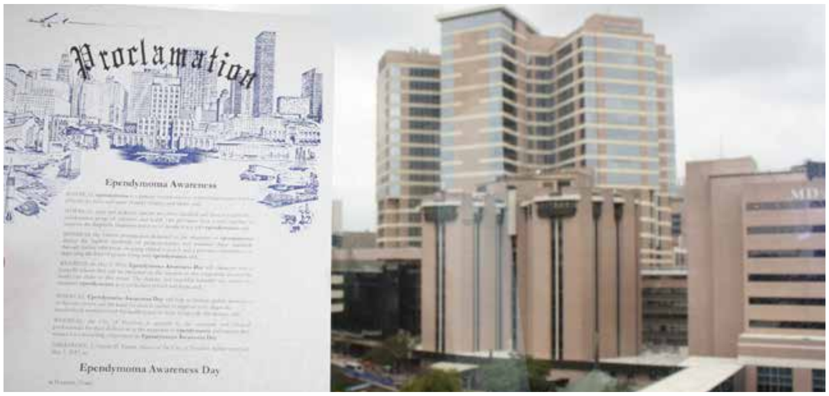
Approximately 1,340 people per year are diagnosed with ependymoma in the U.S.

How often do ependymomas form in children?

- The third most common pediatric brain tumor
- The most common type of primary spinal cord tumor
- Approximately 250 children are diagnosed per year
- Most commonly occur in the brain

How often do ependymomas form in adults?

- Two percent of adult gliomas
- Approximately 1,100 adults are diagnosed per year
- Most commonly occur in the spinal cord

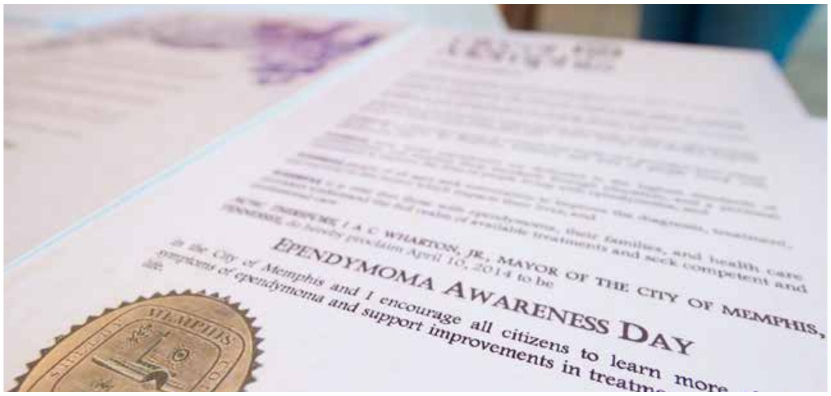


Contact Your Local Officials

The templates on the following two pages can be customized to help you spread the word about *Ependymoma Awareness Day*.

The first document is a **sample letter to an elected official**. Fill in the blanks and send this letter to your mayor, governor, minister of health, etc. You may want to personalize the letter so that it has more impact and tells your experience with ependymoma. Elected officials and other government representatives will be interested in how ependymoma has affected you, your family, or your friends.

The next document is a **sample proclamation** that you should send with the letter to your elected officials so that they can easily recognize *Ependymoma Awareness Day* where you live. This proclamation would be signed by your elected official.



I A C WHARTON, JR., MAYOR OF THE CITY OF MEMPHIS,
do hereby proclaim April 10, 2014 to be

EPENDYMOMA AWARENESS DAY

in the City of Memphis and I encourage all citizens to learn more
symptoms of ependymoma and support improvements in treatm

Make sure your town is included in 2018!

On a local level, you can create awareness of ependymoma where you live! In the past, *Ependymoma Awareness Day* has been officially recognized by numerous municipalities, including:

- State of Colorado
- State of Illinois
- State of Indiana
- State of Kansas
- State of Massachusetts
- State of Michigan
- State of Missouri
- State of New Hampshire
- State of New York
- State of North Carolina
- State of Ohio
- State of Oregon
- State of Pennsylvania
- State of Tennessee
- State of Texas
- State of Virginia
- State of Wisconsin
- Harford County (MD)
- Montgomery County (MD)
- Shelby County (TN)
- Trigg County (KY)
- Washington, DC
- City of Austin
- City of Chicago
- City of Cincinnati
- City of Columbus
- City of Dayton
- City of Detroit
- City of Eureka
- City of Happy Valley
- City of Houston
- City of Ithica
- City of Los Angeles
- City of Madison
- City of Memphis
- City of Palo Alto
- City of Pittsburgh
- City of San Diego
- City of Santa Barbara
- City of Seattle
- City of Sunnyvale
- City of Texarkana
- City of Toronto (Canada)
- Town of Chapel Hill
- Village of Schaumburg (IL)

Sample Letter To Elected Official

Dear Mayor/Governor____________:

On May 6, 2018, we invite you to join patients, caregivers and medical professionals round the world in recognizing *Ependymoma Awareness Day*.

Ependymoma is form of brain and spinal cancer. *Ependymoma Awareness Day* is designed to increase public awareness of this rare tumor and the need for clinical studies to improve early diagnosis, standardize treatment and improve the health status of those living with this disease.

Ependymoma Awareness Day offers a rare opportunity to focus attention on this tumor which affects the brain and spine of all age groups - from infants to older adults. *Ependymoma Awareness Day* will culminate with a butterfly release that will be streamed on the internet so that supporters around the world can share in this event. The delicate and beautiful butterfly was chosen to represent the spirit of the ependymoma community as it symbolizes hope through change.

In recognition of the adults and children who have the diagnosis of ependymoma, we ask that the city/state of ____________ issue a proclamation for *Ependymoma Awareness Day*, on May 6, 2018.

Background material about *Ependymoma Awareness Day*, as well as sample language that might be helpful in drafting a proclamation, is attached. We look forward to working with your office on this important endeavor and in representing ____________ in this major international campaign.

Thank you for your consideration.

Sincerely,

[Signature and title]

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Sample Proclamation

WHEREAS adult and pediatric cancers are often thought of and treated separately, a collaborative group of scientists and health care providers have joined together to improve the diagnosis, treatment and lives of people living with ependymoma.

WHEREAS these varied practitioners are dedicated to the highest standards of professionalism and maintain these standards through education, and ongoing clinical research and a personal commitment to improve the lives of people living with ependymoma; and

WHEREAS people of all ages seek information to improve the diagnosis, treatment, and survival of this tumor which impacts their lives; and

WHEREAS it is vital that those with ependymoma, their families, and health care providers understand the full realm of available treatments and seek competent and professional care;

THEREFORE BE IT RESOLVED that I, ____________ (Governor/Mayor/Municipal leader) of ____________ (State or City), do hereby proclaim May 6, 2018, to be *Ependymoma Awareness Day*, and I encourage all citizens to learn more about the symptoms of ependymoma and support improvements in treatment and quality of life.

____________ (Signature of Governor/Mayor/Municipal leader)

IN WITNESS WHEREOF, I have hereunto set my hand and have caused the seal of the ____________ of ____________ to be hereto affixed this sixth day of May, 2017.

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There is help!

The CERN Foundation is a non-profit organization dedicated to improving the lives of children and adults worldwide diagnosed with ependymoma. CERN strives to bring awareness to the rare disease and improve the outcomes and care of patients through supported and affiliated research efforts. CERN is comprised of medical professionals from around the globe who are committed to sharing research findings.

The CERN Foundation is committed to improving the care and outcome of people with ependymoma every day. But the efforts of the CERN Foundation are made possible only by another group dedicated to fighting ependymoma: the patients, caregivers and primary healthcare providers who are on the front line of treatment.

Questions?

(844) 237-6674
administrator@cern-foundation.org
cern-foundation.org

The CERN Foundation is committed to improving the care and outcome of people with ependymoma through community support and research efforts.

Ependymoma Outcomes and Risk Project

With the ultimate goal of ensuring a uniformly high standard of care for adults and children and improving our understanding of the issues faced by patients with this rare tumor, the CERN Foundation has initiated the Ependymoma Outcomes Projects. These are important initiatives that provide the opportunity to learn about the health status of those diagnosed with ependymoma and to use this information to improve patient care.

CERN is expanding the work of our successful Ependymoma Outcomes Surveys to improve our understanding of risk factors associated with the occurrence of ependymoma. Research has shown that certain risk factors, such as exposures to chemicals or other substances and genetic changes may increase a person's chances of developing some cancers. This hasn't been previously evaluated in patients diagnosed with ependymoma. Visit the CERN website to learn more and sign up to participate.

We are here for you!

In addition to our various research initiatives, the CERN Foundation is also a resource for patients, families and caregivers dealing with ependymoma. We have assembled a variety of useful information on ependymoma, treatment options, and caring for yourself or your loved one and more.

If you or a loved one has just been diagnosed or have been living with the disease for many years, you probably have lots of questions. We can help you get the facts on ependymoma.

FREE Ependymoma Guide!

The CERN Foundation has developed an ependymoma guide as a resource for patients, caregivers and advocates. The goal of this guide is to provide you with the basic facts surrounding ependymoma, its diagnosis and treatment. If you would like a copy of the guide mailed to you, please e-mail administrator@cern-foundation.org or simply visit the CERN Foundation website to download a pdf copy.
Supported by the Robert Connor Dawes Foundation.

Website Resources

The CERN Foundation's website, cern-foundation.org, is a comprehensive resource on the subject of ependymoma for patients and caregivers, as well as medical professionals.

The site contains a wide range of information on ependymoma including:

- Ependymoma Basics
- Diagnosis
- Treatment Options
- Recurrence
- Symptom Management and Support
- Resources

Please visit the website often as it is regularly updated with important information on new research, symptom management and the latest news from the CERN Foundation.

Ependymoma Inspiration Stories

We have created a special section of the CERN website where visitors can read about patients and caregivers' experiences with ependymoma diagnosis, treatment and survival. Visitors can submit their own stories, poems, and articles – anything that would be inspirational or impactful about a personal journey with brain cancer.

We encourage you to join our mailing list to receive our monthly newsletter for the latest news and research from the CERN Foundation as well as new inspiration stories.

Ependymoma Awareness Day

May 6, 2018

Print this out and display!