



The AYJ Fund smiles ... connections ... cures

The AYJ Fund was created in honor of Anna Yan Ji Arabia, who was diagnosed at age 13 with gliomatosis cerebri, a rare brain tumor. At the time of Anna's diagnosis, there was no research being done on this type of cancer. We are committed to supporting new research now being conducted to find effective treatments and a cure for this devastating disease.

The mission of the AYJ Fund is to bring smiles to kids with cancer, to keep them connected to friends and school through technology, and to support the research of gliomatosis cerebri and other brain cancers to find a cure.



2022 MOVING FORWARD!

We have so much to be grateful for as we start to emerge from the COVID-19 pandemic, which has impacted all of our lives over the last two years. The impact on children with cancer has been so much more than what we have endured. The fear of having an immunocompromised child contract COVID, being hospitalized and not able to have more than one person visit; the initial hold on many clinical trials; and the lack of blood supply, which has delayed some procedures and treatments, is more than what these families should have to deal with. For them, we will continue to move forward safely in all we do.



We are so excited for our first in-person fundraising event in 2022! Pam the Berkshire Medium has generously offered to support the AYJ Fund with this very special event on Saturday, March 12th. Pam Ellis shares her special gift as a spirit medium to celebrate loved ones who have passed. Tickets are limited and vaccinations and masks are required to assure this is a safe experience for all who attend. Get your tickets at AYJfund.org

MOMENTS HOUSE LOVE

Our friends Alice Trumbull and her daughter Danielle Garrison started the Moments House in Pittsfield MA as a cancer support center in honor of their friend Linda. We first connected when Anna was sick and they supported us and shared their love, support, handmade jewelry and Christmas smiles.



Moments House was a very special place which provided so much more than cancer information and financial support to so many that entered their doors. They were a space for love, health, wellness and cancer information and whatever was needed most by someone with cancer. They shared music, art journaling, tears, memory bears, grief counseling, new friends and so much more. Although they closed their doors during the pandemic, they will continue to spread their love and impact on everyone they touched and supported through their cancer journey.

AYJ Fund was once again recently touched by their special love with a wonderful \$16,000 donation as they closed their final accounts of Moments House. Yes, Alice and Danielle – we will proudly carry on your dreams of making a cancer diagnosis a bit easier for others, “so no one faces cancer alone.”

AYJ Fund
PAM the BERKSHIRE MEDIUM
 Sat March 12th
 12 - 2pm
 Freight Yard Pub
 North Adams
AYJ FUND BENEFIT
 supporting children with cancer
 TICKETS \$45 at AYJfund.org
for COVID safety vaccines and masks required



Moments house
 comfort • information • support
www.momentshouse.org
NEIGHBORS HELPING NEIGHBORS SO NO ONE FACES CANCER ALONE

HOLIDAY SMILES PROJECT

This holiday season many hospitals continued COVID pandemic restrictions, but we shared more AYJ Fund Holiday SMILES this year than ever before. We are so grateful for our ever-increasing number of supporters of this great project! We sponsored over 200 gift cards that were sent to Dana-Farber’s Jimmy Fund Clinic in Boston, MA, Baystate Health’s Pediatric Clinic in Springfield, MA, Children’s Hospital at Dartmouth-Hitchcock in Lebanon, NH, The Children’s Brain Tumor Project at Weill Cornell in NY, NY, and Children’s Hospital of Los Angeles, CA.



In addition, we purchased over \$2,500 in gifts from the Jimmy Fund Clinic’s and Dartmouth-Hitchcock’s Amazon Wish Lists and had them sent directly to the clinics.

The AYJ Fund also sent gift boxes filled with lots of fun items directly to over 15 children. We heard from so many of them who loved their holiday surprises.



“Just a quick thank you to the AYJ Fund for the Christmas gift! Happy to share the pics of my cats that I never knew I needed with this post that your gift allowed me to take 😊”
Sarah



Mikey has gliomatosis cerebri and has been undergoing treatment. He was very excited to get an Amazon gift card in the box! Maybe more Legos?

“Thank you so much!”
Josele – Mikey’s Mom

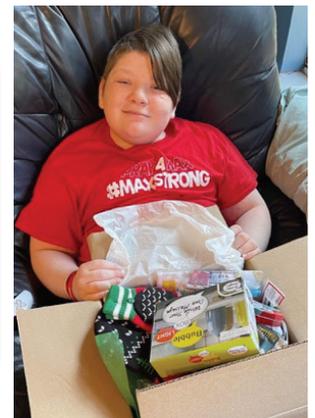


“Thank you to our friend Kathy Prince Arabia from the AYJ Foundation for sending Silas such a thoughtful Christmas box full of activities and fun things. He was so happy while he was opening it. I was trying to film a bit of the unboxing and he was so goofy and silly...”

Avery has been fighting rhabdomyosarcoma almost two years. She is finishing her chemo, but her treatment left her with devastating side effects on her intestinal system. Avery may be traveling soon to Boston for a special intestinal rehabilitation program to help her maintain her weight.



“Thank you so much for sending Max a Christmas Box! That was so thoughtful of you! You just don’t know how much the things you do for us means to me. You insert light in my darkness & I am forever grateful!”
Allyson – Max’s Mom



Thank you to all who sponsored a Holiday SMILE or helped in any way to make these smiles and so many more possible. We loved including the homemade

cards and beautiful pillowcases, which were generously donated by our crafty supporters. They made these gifts extra special!

SNOWFLAKE SMILES

Liam Steiner heard about the AYJ Fund, and as part of a school project he raised money and made snowflakes



and other Christmas ornaments to include in our Holiday SMILES Program gift boxes. Liam said: *“I decided to pick the AYJ Fund because I liked how it helps to remember Anna and you help other families who have someone with cancer that are going to Dana-Farber like my grandfather did.”*

We are so grateful to Liam and his teacher and family for this wonderful donation. We know that the children enjoyed receiving ornaments in their holiday gift boxes, knowing it was sent with the love of a special young man who was honoring both Anna and his grandfather.

SANTA NICK ARRIVES

Our friend Nick Murach arrived one day in December with armfuls of presents—blankets, trucks, books, crafts, dolls and more —ready to send out to some of our AYJ children. Thanks so much to Nick and all his friends who donated to make Christmas special for so many children who deserved an extra smile this holiday season.



PAWPRINTS DONATION

The Pawprints program at Boston Children’s Hospital has a team of over 20 therapy dogs available to visit patients and make their stay more comfortable and friendly. Pawprints provides patients and their families with a healthy diversion from the usual hospital

Dayton



routine and an opportunity for social interaction. Dogs visit both inpatient and outpatient areas, wherever patients need a visit most.

Ana



The AYJ Fund donated \$1,000 to support Pawprints and help the program spread even more smiles.

THANK YOU from the CLINICS

We heard from so many of the clinics we donated to with their thanks for all of our AYJ Fund donations:

“You and the AYJ Fund continue to amaze me with your love & generosity. You are all making such an impact in Anna’s memory. Cheers!”

Lisa / Jimmy Fund Clinic

“Just letting you know we received all the gift cards! Thank you again so much, very excited to deliver to all of our teenagers.”

Jon / Baystate Medical Center

“Oh, my goodness Kathy!!!! Your gift card donation itself is amazing. THIS is an extra (items from Amazon Wish List) OH MY GOODNESS!!!! Giving me a tear, thank you so very much.”

Amie / Dartmouth-Hitchcock

“We just got the stack of gift cards – which I know our pre-teen/teen patients will appreciate! And thanks for your note and the beautiful (heart-warming) newsletter. It is wonderful to hear from you. I am so glad that you are continuing this work, even in challenging times.”

Nathan (Anna’s neuro-oncologist)
Children’s Hospital of Los Angeles

“We also received the totally awesome (and thoroughly sanitized) Amazon gift cards! The clinic staff has already sent me a list of all tweens and teens who will be coming to the clinic ... and we will also be mailing them to the tweens and teens who have scheduled video visits. Crediting the AYJ Fund, of course, in memory of Anna. Thank you for all that you do.”

Cindy / Children’s Brain Tumor Project NYC

MEAL TRAIN FOR LUKE

Luke was diagnosed with gliomatosis cerebri at a young age and is developmentally disabled and unable to speak, but has a family full of love and faith. Luke was recently diagnosed with another brain tumor, ATRT, which required more treatment and comes with a difficult prognosis. His Dad was recently diagnosed with early Alzheimer’s Disease. The AYJ Fund helped with a meal train for the family and earlier helped support renovations to make life a bit easier.



REPLENISHING THE CRAFT CLOSET

When the Jimmy Fund Clinic reached out and let us know that their craft closet was running low after Christmas, we went shopping! We found items on Etsy that were perfect for keeping



teens/preteens busy and distracted from a long day of testing and cancer treatment in the clinic.

We selected a variety of paint by numbers, embroidery, painted rocks and string art. We are grateful to so many of these small business owners, who discounted and donated craft kits when they

heard we were purchasing them for children at the Jimmy Fund Clinic.



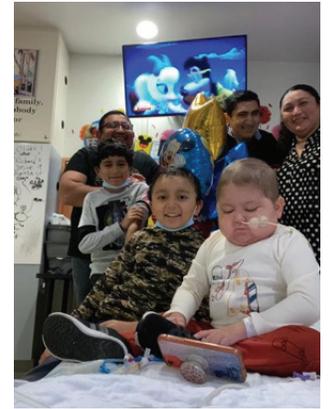
HAPPY 4th BIRTHDAY RICHARD

Our friend Richard had been at Children's Hospital Boston for over 8 months when we heard he was turning 4 years old! We knew he deserved a party, and wanted his family to be a big part of it. We provided a gift certificate to Richard's Dad so he could take Richard's brothers out to buy some fun birthday presents for him (Mom has been spending the whole time in Boston with Richard).



We knew he loved Mickey Mouse so we purchased Mickey Mouse-themed party decorations for his room.

We had arranged with our friends at the Princess Program Foundation for a Mickey character to visit, but unfortunately hospital infection control restrictions would not allow an outside visitor. We were so excited his whole family was allowed to be together and celebrate this big day for Richard. Even better news is that he was able to be discharged in late January and is now home with his family.



RESEARCH DONATIONS

We are proud that we were able to make two significant donations to two of the research facilities we work with who are conducting research to find effective treatments for children diagnosed with brain cancer.

The AYJ Fund donated \$10,000 to the research being done at Dana-Farber Cancer Institute through the programs of Dr. Kathy Warren and the lab of Dr. Mariella Filbin. This donation will be used to help continue the research on gliomatosis cerebri and related brain cancers.



You guys are amazing!!! Thank you so very much for all you do and I cannot wait for a time we can get together again.

Mariella Filbin

Thank you for sending this, and, importantly, thank you for your continued support for GC research and our patients. This is especially appreciated over the past 2 years when fundraising has been a bit more "challenging."

Kathy Warren

We also made a donation of \$10,000 to the Children's Brain Tumor Project at Weill Cornell Medicine in NYC.



Dr. Jeff Greenfield also conducts innovative research in his lab to advance the understanding of gliomatosis cerebri to help children with this most difficult diagnosis.

VALENTINE'S DAY SMILES



We love to celebrate Anna's Angelversary with a donation to the Jimmy Fund Clinic, so the children spending that special day undergoing testing and treatment have something fun to do. This year the tweens/teens spending

Valentine's Day in the clinic had fun making and painting Valentine gnomes that we sent to the clinic.



IMAGINE A WORLD WITHOUT CANCER

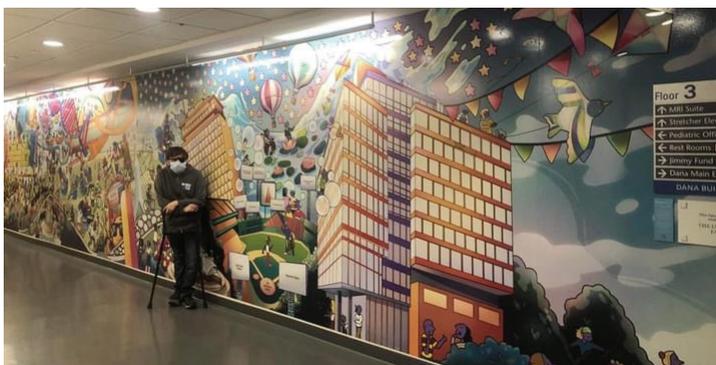
There is a new display outside the Jimmy Fund Clinic at



Dana-Farber, a whimsical representation of their unique research model, "bench to bedside," through the eyes of their young patients. It includes scientists speeding the translation of groundbreaking laboratory discoveries to children receiving these lifesaving treatments. It

highlights many Boston landmarks, including Fenway Park, the Swan Boats and the Boston Common's Make Way for Ducklings ducks. The Imagine Display celebrates the diverse Dana-Farber community - patients, families, caregivers and staff.

If you look closely, you will find a window in the Prudential Center building donated by Kathy and Joe that honors Anna and the AYJ Fund. We were thrilled when our friend Jake sent us pictures!



ADAMS COMMUNITY BANK

We are grateful to the Adams Community Bank for selecting the AYJ Fund as the recipient of a recent "Dress Down Day for Charity."



On these days, staff donate money to wear jeans or other comfortable clothes. AYJ Fund received a donation of \$375. This program raised \$3,426 for local organizations in 2021.

We were also invited to meet with their team to talk about the AYJ Fund and the work we do throughout Berkshire County and beyond to help children with cancer. We are looking forward to working with them to help even more local children.



LEE POLICE BADGES



The Lee Police Department each year creates a limited number of authentic police badges with pink stitching to raise funds to support those in our area affected by cancer. We are so honored that this year they selected the AYJ

Fund as the recipient of this great fundraiser. We were excited to meet with Chief Craig DeSantis and thank the police department for their donation of \$351 to help children in our area fighting cancer.



PRESIDENT'S CIRCLE THANKS

Dana-Farber and the Jimmy Fund sent a nice thank you for AYJ Fund's support recognized us the Dana-Farber's President's Circle.



ANNA'S HEART COLLECTION

Our talented friend Cathleen King has generously shared her beautiful artisan jewelry as a wonderful fundraising program for the AYJ Fund.



Cathleen selected a variety of blue hearts and other beads, wires in both silver and bronze tones to create beautiful pieces of earrings and necklaces. Anna's Heart Collection launched before Christmas and has already raised over \$500 for the AYJ Fund.



You can find these beautiful pieces, other unique pieces of jewelry and warm cozy scarves on her Irish Girls Art Facebook page and also at IrishGirlsArt.com

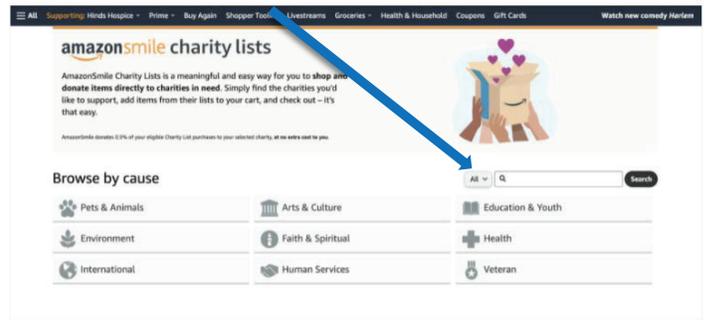


AYJ FUND LOGO WEAR

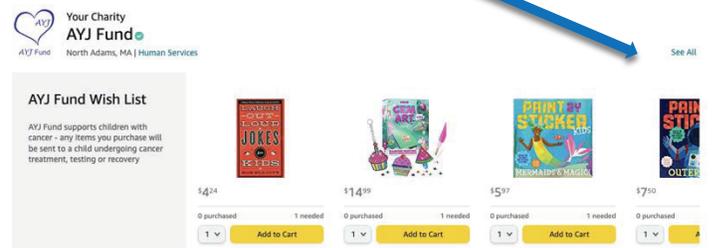
Our popular clothing line of AYJ Fund sweatshirts, T-shirts, vests and jackets is taking a hiatus for a few months, but will be back later this spring. These items are produced through Beck's Printing and have supported the AYJ Fund for over a year. We decided to launch the line every few months. We will announce through our social media channels when the logo wear will be open for purchase. Thanks to all who have been sporting our AYJ Fund clothing. We still to love to share your photos wearing AYJ Fund gear, so please continue to send them.

AYJ FUND'S NEW AMAZON CHARITY LIST

A new way to support the AYJ Fund and shop for items that we love to send children with cancer is now available through Amazon. When you sign into Amazon, look under Accounts and Lists on the left side. You'll find Amazon Charity List (not Wish List). If it does not pop up as your charity, search for AYJ Fund. Any items you purchase will be sent to AYJ Fund and we will forward them to our AYJ Kids.



Once you find our AYJ Fund list, expand the list to see all the items.



ADVOCATING FOR KIDS

Elyn Miller, mom to Gabriella who passed from DIPG at age 10, was successful in getting the Gabriella Miller Kids First Act passed through Congress in 2014. The original bill authorized \$12.6 million in annual funds for childhood research through Fiscal Year 2023. Kathy will now be advocating on calls alongside Elyn and others to pass the Gabriella Miller Kids First Research Act 2.0.

This new 2.0 version of the bill provides a new source of funding by redirecting penalties collected from pharmaceutical, cosmetic, supplement, and medical device companies that break the law, toward research. It is expected to be exponentially larger and without an end date. In recent years, hundreds of millions of dollars in penalties have been levied against these companies by the U.S. Securities and Exchange Commission.



ANNA'S COUSIN: A RESEARCHER CLOSE TO OUR HEARTS

This article is written by Anna's cousin Megan Costa who is working in the Verhaak brain cancer research lab at The Jackson Laboratory in CT.

Since graduating from Boston University in May 2021, I have had the immense honor and privilege of performing brain tumor research at the Jackson Laboratory for Genomic Medicine in Farmington, CT. I work under the direction of Dr. Roel Verhaak, one of the top-cited brain tumor researchers in the world, and I am trained by accomplished scientists who have already completed doctoral programs in biomedical research. Our lab, which consists of twelve individuals with a mix of computational, clinical, and experimental research backgrounds, is a lab with a highly



translational (“bench to bedside”) focus. We study the upregulation of

extrachromosomal DNA (ecDNA) in brain cancer and are divided into two parts; the first is a computational (“dry lab”) group that uses software programs to characterize genetic changes in brain tumors along the trajectory from diagnosis to recurrence, and the second is a bench research (“wet lab”) group that uses genetic engineering and cell culture techniques to develop novel imaging techniques for ecDNA in tumor samples. One of my coworkers described our lab as a “gearbox” with each individual unit working independently, yet collaborating with others to create a coherent whole which is greater than the sum of its parts. I am part of the wet lab research group, and I am currently beginning work on an independent project which consists of culturing brain tumor cells and brain immune cells in a single dish to study ecDNA transfer between different cell types. It is quite encouraging and inspiring to be surrounded by some of the most hardworking and compassionate people I know, and it has been a lifelong dream of mine to put my intellectual skills towards helping those who are most vulnerable. I will be working in the lab

“I think of Anna so often when I work.”

Megan

through May of 2023 prior to (hopefully) matriculating into a PhD program in the fall.



Megan is third from the left in the photo

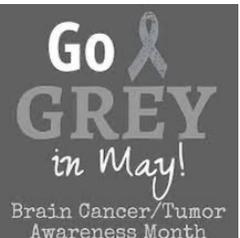
Our experiments almost always require generous funding from outside sources, some of which is not met due to the competitive nature of obtaining grant money. Funding from nonprofit organizations like the AYJ Fund can help drive important research forward by minimizing the steep cost of lab equipment and acquisition of patient samples.

Please check out some of our published work at <https://verhaaklab.com>

Megan Costa, The Jackson Laboratory

MAY IS BRAIN CANCER AWARENESS MONTH BRAIN CANCER FACTS:

- ♥ Pediatric brain tumors are the leading cause of cancer-related death among children and adolescents.
- ♥ In spite of all the advances in cancer, there are still brain tumors with no known effective treatments and five year survival rates less than 1%, including DIPG and GC.
- ♥ Children who survive brain cancer treatment are often left with lifelong deficits from the side effects of harsh treatments such as chemotherapy and radiation.
- ♥ 13 children are diagnosed in the US with a brain tumor each day.
- ♥ There are over 100 types of childhood brain tumors, complicating research and treatment.
- ♥ Pediatric brain tumors are different from those in adults and are often treated differently.
- ♥ Because brain tumors are located in the control center for thought, emotion and movement, their effects on a child's physical and cognitive abilities can be devastating.





A NEW WAY TO SHOP

The AYJ Fund always likes to have a variety of fun items available on hand to include in our AYJ SMILES gift packages we send to children. Many times, people will ask us how they can help or what they can shop for. We created an AYJ Fund Charity List on Amazon; see the story on page 6 for how to find us on amazon.com. We include a variety of toys and activities that we send to children to enjoy when they are in the hospital or home between treatments. This is certainly not an exclusive list; we love receiving any items that you think that children and teens would enjoy.



WAYS TO SPREAD SMILES

- ♥ Follow the AYJ Fund on Facebook, Instagram, and Twitter, and share our posts.
- ♥ Share this newsletter with a friend.
- ♥ Make a donation to the AYJ Fund as a birthday or memorial gift for someone special. We'll create a card you can give to let them know of this special gift.
- ♥ Select an item from our AYJ Fund Amazon Charity List next time you place an order from Amazon.
- ♥ Join us in advocating for children with cancer when we post about legislative initiatives that need your support.
- ♥ Sign up for AYJ Fund on Amazon Smile – AYJ Fund will receive a percentage of all your Amazon purchases all year long.

