



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.

MAY IS BRAIN CANCER AWARENESS MONTH

We have so much good news to share in this newsletter. We started the year off with great news that Dr. Kathy Warren, a great friend to the gliomatosis cerebri community, will be leading the team of brilliant pediatric neuro-oncologists at Dana-Farber.

We joined others at a national level to recognize the month of May as Brain Tumor Awareness Month. Kathy and AYJ Fund Board member Mary Costa joined the National Brain Tumor Society Head to the Hill days in Washington, D.C. We traveled to the offices of our US Senators and Representatives to advocate for the brain tumor community.

We had great fun and very successful Wine, Chocolate and Craft Beer Tastings this spring in both Brighton and North Adams. We are so grateful to all of our supporters who joined us, donated items, volunteered and sent donations. As pediatric neuro-oncologist Dr. Mimi Bandopadhyay of Dana-Farber said "You are changing the lives of kids".

The 3rd International Conference on Gliomatosis Cerebri, which the AYJ Fund will help sponsor, will be held in Barcelona and will bring together leading brain cancer researchers and physicians from around the world. This conference will be held in late September, so we plan to move our Cornhole Tournament into October this fall.



DR KATHY WARREN TO JOIN DANA-FARBER CANCER INSTITUTE

We are very excited to be able to share that Dr. Kathy Warren, who has led the Pediatric Neuro-Oncology program at the National Institutes of Health in Bethesda and hosted the 2nd International Conference on Gliomatosis Cerebri, has joined Dana-Farber Cancer Institute as Professor and Director of Pediatric Neuro-Oncology at Dana-Farber Cancer Institute. She succeeds Mark Kieran, who did so much for the advancement of research on gliomatosis cerebri.

We first met Dr. Warren at the Curie Institute in Paris in 2015 at the 1st International Conference on Gliomatosis Cerebri. She approached Kathy and asked if we were from North Adams! Dr. Warren is a 1982 graduate of North Adams State College (now Massachusetts College of Liberal Arts), where Joe worked for 36 years and graduated from in 2018.

Dr. Warren is known for her kind and compassionate care of her patients, and for her determination to find more effective treatments for rare brain tumors in children. She cares deeply for her patients and can be seen in this photo climbing Mount Kilimanjaro. She carried the names and memories of some of her patients with her, and posted "Done. With the help of a few angels."



GO GRAY IN MAY



BRAIN TUMOR AWARENESS



BRUINS FUN FOR THE JIMMY FUND CLINIC

As part of our SMILES program, the AYJ Fund purchased 30 tickets to the Boston Bruins Hockey game on March 2nd for kids being treated at the Jimmy Fund Clinic. We filled Bruins string backpacks with Bruins hats, gloves, cups, basketball hoops and more to add to the fun. We were also able to arrange with the



Bruins Foundation for Blades, the Bruins mascot, to visit the kids at their seats and give them each a signed hockey puck. We also got a welcome message to the AYJ Fund and Jimmy Fund Clinic up on the jumbotron! A special thanks to the Costa family for making this possible.

VALENTINE'S DAY LOVE

Valentine's Day is a special day for us, as it is Anna's "Angelversary." To turn this into a fun day for other kids battling cancer, each year we deliver Valentine's Day-themed items to be distributed in the Jimmy Fund Clinic on February 14th.

This year, for the teens who had to be in the clinic receiving treatment instead of having fun in school sharing Valentines, the AYJ Fund gave popcorn canisters with iTunes cards and stuffed gorillas to the teen boys, and pink heart-shaped pillows and canvas signs to the teen girls.



"The Valentine's Day gifts are already a huge hit, and have made the morning so so special for the teens who are here."

Jen Noonan, MSW

BEANIES FOR NAT

Love Your Melon is a company, founded by two friends in a college class, with a mission to improve the lives of children battling cancer. Love Your Melon has given over 160,000 hats to children with cancer, and has given over \$6.1 million in research and support. The AYJ Fund participated in an effort with the Love Your Melon organization to send mini beanies to Nathalia, who was diagnosed at 12 years old with osteosarcoma cancer, and was coming to the end of her journey. Nat had a close connection with Love Your Melon, and had made mini hats previously for LYM staff. Nat received over 37,000 of the mini handmade beanies during her last days; a few were from the AYJ Fund. Love Your Melon sent a Love Your Melon hat to everyone who mailed one to Nat. You will find the hats as part of our AYJ Fund auctions and SMILES programs.



PHOTOS FOR EMMA and JACOB TOO!

We saw a Facebook post that Emma, a young girl who was being treated for brain cancer, loved getting pictures of dogs to brighten her day. So we put our Alaskan Klee Kai, Ayla, to work. She posed for a picture to send to Emma and brighten her day.



Knowing that our friend Jacob, from nearby Clarksburg loved Ayla also and was at Boston Children's Hospital having hip surgery, Ayla did double duty and posed again. Jacob's team of supporters go by the name #JETpack. You can check out Jacob and follow this amazing kid on Facebook!

JACK IS HONORED AS A YOUNG PACESETTER

Our friend Jack was honored in Boston in early March as a Young Pacesetter for his success in the Boston Marathon Jimmy Fund Walk. Jack was on our Anna's



Army team, along with his Mom Laura, sister Andrea, brother Tage and his friend. A Young Pacesetter is recognized for being under 12 and raising over \$500 for the Jimmy Fund Walk. Second year in a row!!

We are so proud of all Jack does for kids with cancer. Jack included Anna's Army's team picture and photos of Anna in the video they showed during the celebration. Go Jack!

SMILES FOR LANDON

Our friend Landon is 12 years old and has gliomatosis cerebri, the same brain cancer that our Anna was diagnosed with. Landon is not able to attend school these days, but we hear that getting mail brightens his day – a silly joke, a cute picture of an animal, or just a note to say hi.

Please join us in bringing Landon more SMILES. Mail can be sent to his school until the end of the school year to:

St Paul Lutheran School
Attn: Landon
18 S School St
Mt Prospect, IL 60056



SPRING SMILES IN THE JIMMY FUND CLINIC

To celebrate Anna's birthday on April 9th each year, we conduct a SMILES project so that teens being treated at the Jimmy Fund Clinic that day receive a little something special. This year, we were feeling extra ready for springtime and sunshine so we put together 50 beach towel packs for the teens in treatment that day. For the boys, we found Red Sox beach towels and added a Red Sox cup and hat. For the girls, we selected fun, bright and tropical beach

towels and added a tumbler and a pair of sunglasses. We loved hearing that our friend Jacob arrived in the JF Clinic that day in his AYJ Fund shirt and had a smile for us as he received his beach towel SMILE pack! His Mom wrote:

"It's been a tough two days and this was an amazing spirit lifter."



We also heard from Ryan Manning on our AYJ Fund Facebook page:



"Today I am celebrating 7 years cancer free!!! At my check up at the Jimmy Fund I received an AYJ Fund 7 year cancer free trophy, couldn't be more stoked and appreciative. Everytime I use this towel or cup or look at the little hat, I will remember the day I found out I was 7 years cancer free!! Thanks guys for everything you do."

AYJ FUND FLYING HIGH

Thanks so much to Emily Ranger and InFlyte Entertainment in Marlborough for honoring the AYJ Fund as the Fly for a Cure charity for the month of April. InFlyte is a fun aerial dance studio (think Cirque du Soleil). They have a wonderful program where they select a charity each month to which they donate a percentage of sales.

Check out their FB page and website for photos and videos of their great dancers, including Emily! Emily is the talented daughter of my friend Helen, originally from Brighton.



JAKE'S BUCKET LIST

Jake Silver was an 18-year-old patient at the Jimmy Fund Clinic after being diagnosed with osteosarcoma. His "bucket list" was shared on social media and Boston news stations, and the AYJ Fund supported



Jake to make sure as many adventures as possible could be crossed off Jake's bucket list. One of Jake's trips was to the Patriots Super Bowl Game in Atlanta. After a long train ride and enjoying some of the pregame festivities, Jake ended up in the Intensive Care Unit instead of at the Super Bowl game. He used his tickets to send the nurses who took care of him to the game. Jake did get a surprise voice message from Tom Brady, which certainly brightened his day. Jake is in heaven now, but we won't forget how Jake and his family fought to make every day special.

FACEBOOK BIRTHDAY FUNDRAISERS

We are so grateful to so many of our friends who chose to celebrate their birthdays by setting up a

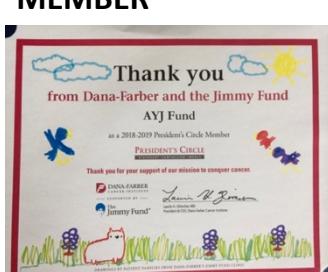
birthday fundraiser on Facebook.

Facebook makes it easy, and it really does make a great difference for the AYJ Fund and kids with cancer. Since the start of 2019 we have had FB birthday fundraisers created by Fran Maruco, Mary McLaughlin, Michele Haskins, Megan Costa and Cat Record! These fund-raisers have already raised more than \$ 850 for the AYJ Fund! Happy Birthday to these wonderfully thoughtful and generous AYJ Fund

friends, we love celebrating your special days with you.



DANA-FARBER JIMMY FUND PRESIDENT'S CIRCLE MEMBER



The AYJ Fund was recognized as a President's Circle Member due to our ongoing annual donations to "lead by example, help save lives, fund cancer research, and shape Dana-Farber's future."

EXCITING NEW RESEARCH AT DANA-FARBER

Dr. Mariella Filbin's Lab is working on exciting new research that has developed a process to test brain tumor cells in an environment that closely resembles the human brain.

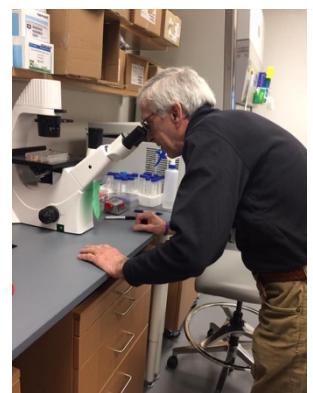
One of the challenges in brain tumor research is that many times drugs that work in the lab, when tested on tumor cells growing in dishes, and even in mouse



models, do not work once they are used in children or adults. Major challenges include that researchers have not been able to provide a more natural brain microenvironment to the tumor cells tested in the lab. Additionally, many drugs are blocked by what is known as the blood-brain barrier (BBB) which works in our bodies to

protect the brain from toxins. Therefore strategies to overcome the BBB in patients to deliver drugs to brain tumors are needed.

We had the pleasure of meeting Dr. Alexander Beck, who runs a lab at LMU of Munich, Germany, and is temporarily in Boston helping to set up a program in the lab at Dana-Farber to advance research in human brain microenvironment and preclinical tumor models. Dr. Beck has developed a process to grow stem cells into cells that simulate the healthy human brain more closely, and cells that simulate the blood-brain barrier. Through this process, actual brain tumor cells can be tested in this advanced microenvironment and researchers can learn more about brain tumor cells and can test a variety of drugs to more accurately see how a drug may react when used in children and adults.



We were able to see this research in the lab and able to view these tumor cells in this simulated brain microenvironment under the microscope. We are very excited about this research and its potential to find effective treatments for gliomatosis cerebri and other brain cancers.

PILLOWCASE SMILES

We are so grateful to our wonderful group of sewers who continue to create bright, colorful and fun pillowcases for the kids at the Jimmy Fund Clinic. On our last visit, the staff was telling us that the kids love

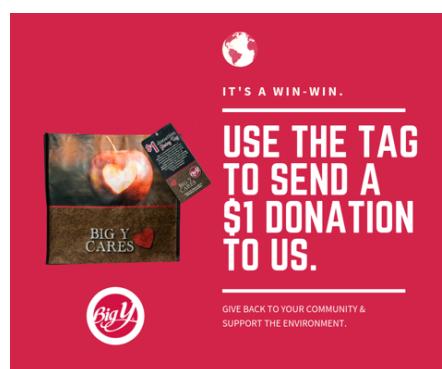
them because they not only give them out to cover the boring white pillowcases in the clinic, but also use them to cover the hot pack and ice packs for the kids when they need to get

more comfortable. The pillowcases brighten the kids' days and are a great distraction from their discomfort.

BIG Y GIVING TAG PROGRAM – ALL YEAR LONG

You can continue to help the AYJ Fund through the Big Y supermarkets Giving Tag program which continues all year long. Big Y will donate \$ 1.00 to the AYJ Fund for each bag you purchase. Three easy steps:

1. Purchase a bag for \$2.50 at any Big Y store and visit mybigycause.com within 7 days of purchase.
2. Remove the scratch-off layer on the Giving Tag to reveal the unique identifier.
3. Submit the identifier and select the AYJ Fund as the non-profit to direct the donation.



Thank you to everyone who participated in purchasing a bag during February, when the AYJ Fund was selected as the Community Bag recipient for all bags purchased that

month and not otherwise directed. We raised a total of almost \$ 100 during just that one month.

Whether you've bought a bag or helped spread the word, we couldn't have done this without you. The money generated through this program will help us to support more children with cancer.

CHILDREN'S BRAIN TUMOR PROJECT – POWERED BY FAMILIES

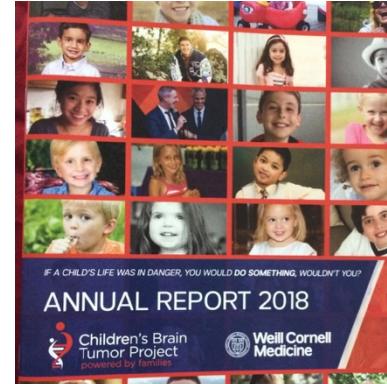
Kathy and Joe were pleased to be able to travel to New York City's Weill Cornell Medical College to participate in the Children's Brain Tumor Project's Family Council Meeting. Support for the Children's Brain Tumor Project comes from individuals and parent-founded organizations, like the AYJ Fund, with a desire to advance research into pediatric brain tumors and to help address the unmet needs of each and every child faced with these life-threatening diagnoses. Dr.

Jeffrey Greenfield and Dr. Mark Souweidane are doing exceptional research on gliomatosis cerebri and DIPG brain tumors, both of which have survival rates less than 1%, as well as other rare brain tumors.

The Children's Brain Tumor Project is "powered by families."

"Without the support of our families, we wouldn't be able to keep the lights on, keep the machines running, keep up with the technology, keep our scientists energized, keep moving toward advancing more treatment options."

Dr. Jeffrey Greenfield



Anna's picture was on the front cover of the Annual Report distributed at the Family Council Day, and her picture hangs in the lab along with those of other children and adult brain tumor warriors. The photos recognize the donations of the AYJ Fund and other families and foundations and inspire the researchers who work in the lab every day.

Dr. Jeffrey Greenfield was recently awarded \$1.08 million as a gift made in memory of Patrick Baylay Marsano, who lost his life to gliomatosis cerebri. Patrick's Mom attended the 2nd International Conference on Gliomatosis Cerebri with us at NIH. We are so grateful for this most generous gift, which will advance research and make a difference in the fight against these brain tumors.

MEMORIAL DONATIONS

The AYJ Fund is grateful for so many who made donations in memory of their loved ones, including these two special Arabia siblings:



Anthony Arabia, Joe's Dad and Anna's Nonno, was 98 years old when he passed on February 13th. We toasted him with red wine and hot cherry peppers, just as he told us to do. Salute Nonno!



Gloria Arabia Rougeau, Anthony's sister, passed not two weeks later at the age of 92. Gloria was the grandmother to Tracy Rougeau McConnell, one of our AYJ Fund board members.

COACHES VS. CANCER

Alie Mendel was diagnosed at age 17 with papillary thyroid cancer just six days before receiving the Female Athlete of the Year Award at the Hoosac Valley High School in Cheshire. Following surgery and treatment at Boston's Children's Hospital, Alie returned to the Berkshires, and to basketball. Earlier this year she played in the Coaches vs Cancer tournament to raise money for thyroid cancer research, and the AYJ Fund contributed to honor Alie and support cancer research.



AYJ SIGHTINGS



AYJ in Washington D.C.

AYJ sighting above the cruise ship in Nassau, Bahamas ❤️❤️



Our favorite cookies by Gimme Some Sugar



AYJ FUND WINE CHOCOLATE AND CRAFT BEER TASTING SUCCESS

Thank you to all who volunteered, donated, attended, bid, and all of you who celebrated with us in both Brighton in March and North Adams in April for our AYJ Fund Wine Chocolate and Craft Beer Tastings. These were fun, inspiring and very successful fundraisers for us. It was wonderful to see so many friends join us for these special events.

We were so pleased to have Dr. Mimi Bandopadhyay and Dr. Andy Hong of Dana-Farber join us in Brighton. Dr. Mimi spoke to our guests and shared the research and collaborative work that is being done and how important each of our supporters is:

"You're helping children and spearheading research. You are changing the lives of kids!"



A SPECIAL MESSAGE

We received a beautiful message from Kathy Ford-Droney to the AYJ Fund we wanted to share. So many of the small acts we do are so important to those we touch. We reached out to Kathy after hearing she had been diagnosed with gliomatois cerebri.

Thank you so much to AYJ for reaching out to me when I was diagnosed. I had never heard of this cancer. I'm so sorry you lost your sweet girl to it.

You have helped me so much through your support. I honestly thought I'd be dead in weeks. You all helped me be so positive. Thank you so much!! You are angels. Wish I had met Anna. ❤️❤️



OUR FAVORITE TYPE OF SMILE PROJECT

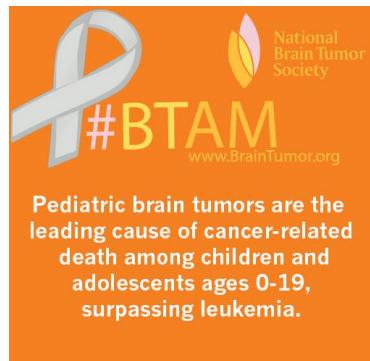
We were thrilled to be able to support Cam's "End-of-Treatment" Party in March. After three long and difficult years of intense treatment for mixed phenotype acute leukemia, a rare form of leukemia, Cam was able to celebrate with our favorite type of party – EOT!! Cam still has a tough road ahead and shows his strength every day as he struggles with the side effects of treatment, but this day was worthy of a great celebration!



MAY IS NATIONAL BRAIN TUMOR AWARENESS MONTH

BRAIN TUMOR FACTS:

- Brain tumors are the leading cause of cancer-related deaths in children and young adults age 19 and under in the US.
- Brain and CNS (Central Nervous System) tumors are the most prevalent form of pediatric cancer in kids under 19.
- There has never been a treatment developed and approved specifically for pediatric brain tumors.
- Nearly 700,000 Americans are living with a primary brain tumor – including 28,000 children.
- More than 87,000 Americans will be diagnosed with a brain tumor in 2019.
- The survival rate for some pediatric brain tumors, including gliomatosis cerebri and DIPG, is less than 1%.
- The average survival rate for all malignant brain tumor patients is only 35%.
- More than any other cancer, brain tumors can have lasting and life-altering physical, cognitive, and psychological impacts on a patient's life.
- Even benign brain tumors can be deadly if they interfere with portions of the brain responsible for vital bodily functions.
- There are more than 130 different types of brain tumors, many with their own multitude of subtypes.
- Despite the amount of brain tumors and their devastating prognosis, there have only been four FDA approved drugs – and one device – to treat brain tumors in the past 30 years.



ONLY 18% of those diagnosed with a BRAIN TUMOUR live beyond 5 years

AYJ FUND PARTICIPATES IN NATIONAL BRAIN TUMOR SOCIETY'S HEAD TO THE HILL

Mary Costa and Kathy traveled to Washington, D.C., to participate in this year's National Brain Tumor Society's (NBTS) Head to the Hill event, along with over 300 other brain tumor advocates. It was a busy two days on Capitol Hill, as we met to learn about the legislation and funding requests. On the second day, we met with the legislative aides in our Senators' and Representatives' offices to share our stories and advocate for change.



We asked our legislators to:

1. Prioritize medical research by providing robust funding for National Institutes of Health (NIH) at \$41.6 billion and the National Cancer Institute (NCI) at \$6.522 billion.
2. Provide \$30 million in funding to continue advancing the programs created by the new Childhood Cancer STAR Act, which we had advocated for in previous years.
3. Appropriate \$120 million for the Cancer Research Program within the Department of Defense (DOD) and to continue to include brain tumors as eligible topics for funding.
4. Support the Palliative Care and Hospice Education and Training Act to help bring access to patients across the country.

It was a very inspiring two days as we told our stories along side other brain tumor survivors, and daughters, sons and Moms and Dads of others diagnosed with brain tumors, many of whom had also lost loved ones.



SHOP AMAZON SMILE for AYJ FUND

You can shop and help the AYJ Fund! The AYJ Fund is now on Amazon Smile. When shopping on Amazon, go first to www.amazonsmile.com and select AYJ Fund as your charity option. From then on, every time you shop, a percentage of your purchases will go to the AYJ Fund. No cost to you! This works for all of your Amazon purchases, including back-to-school supplies, student books, food shopping, and all those other essentials you find on Amazon. If you own a business, you can help even more by signing up now!



YOU CAN HELP with JULY 4th SMILES

We'll be sending more SMILES to the Jimmy Fund Clinic for teens being treated over the Fourth of July holiday. If you'd like to donate any red, white and blue items, we'll include them in our baskets. If you'd like to donate money, we'll do the shopping! We'll be putting together 50 baskets for teens!



We include both patriotic-themed fun items and any red, white and/or blue items. Some suggestions include balls, sports items, jewelry, nail polish or cosmetics, pens and markers, games or puzzles, water bottles: anything fun that teens would like!

