



## 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.***



### A BUSY FALL FOR THE AYJ FUND

Our journey with childhood cancer started ten years ago this Columbus Day weekend, when our daughter Anna suddenly had a seizure in our home. That day, after a call to 911, a quick local ED visit, and a medical airlift, we heard that Anna had a brain tumor. Our lives were changed forever. Every two minutes around the world a family hears that their child has cancer. Now, after ten years, we are committed more than ever to making a difference for children with cancer and to advancing research to find effective cures, so other families don't face this devastating news.



In this newsletter, you will see how we have been busy locally, regionally and internationally to raise awareness, advocate for change and advance this fight. You will meet some of the children we have supported and find easy ways you can help to make a difference and support these efforts, so we can reach even more children. You can sponsor a holiday backpack for a child in treatment this holiday season, select the AYJ Fund when you shop on Amazon, and pick up a reusable bag at Big Y to benefit the fund.

Thank you for all of your support over the past ten years, and, especially, for continuing to honor Anna by helping other children with cancer and being such an important part of advancing the work of the AYJ Fund.



*Kathy + Joe*

### 3rd INTERNATIONAL CONFERENCE ON GLIOMATOSIS CEREBRI

The AYJ Fund was proud to be a lead sponsor of the 3rd International Conference on Gliomatosis Cerebri held in Barcelona, Spain on September 22-23rd. This conference brought together over 30 of the leading pediatric neuro-oncologists from North America and Europe and families and family foundations like ours from all over the United States, South America and Europe.

Physicians and researchers presented current research. The physicians asked for financial support to sponsor a call for research



projects to advance research on gliomatosis cerebri. Four foundations, including the AYJ Fund, responded to this with a commitment of a combined total of \$100,000 for each of the next three years to fund a collaborative research project to advance the priorities identified by this conference.

The priorities of the conference included development of a clinical GC registry to make more tissue available for research, development of guidelines for surgical biopsy resection and an autopsy protocol, and advancement of cell lines and mouse models to drive research.



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Gliomatosis  
Cerebri

GC families and foundations worked to define the requirements of the research project, including that: researchers from more than one research institution must collaborate, advance the GC Global website, support communication between foundations, increase awareness of GC globally, and support additional families diagnosed with gliomatosis cerebri. It was exciting, educational, and inspiring and gave us hope that research is advancing and will one day identify effective treatments for children diagnosed with GC. It is essential to support and fund research to make this happen in the near future.

**A SPECIAL GIFT**

A most special part of the GC Conference we attended, was a beautiful art exhibition, “Estacion Esperanza,” which means “Hope Station.” Maria Muela Gallardo, a talented and lovely artist, created the largest installation of polymer clay in Spain. She created a house to honor each of our children worldwide who have died of gliomatosis cerebri. The exhibit emphasized hope in



research. Maria spent hundreds of hours creating each unique and beautiful house and involved her whole community to create the base of the exhibit, filled with houses, parks, roads, and bright and beautiful pieces. This is Anna’s house, titled “Disney,” complete inside with a figure sporting NYC and an iPhone in her hand. Just perfect!

**DOWNTOWN CELEBRATION**

Our princesses were popular on Main Street this August as they took part in the annual North Adams



Downtown Celebration, taking many photos and making kids smile as we spread the news of the upcoming concert and the AYJ Fund mission.

**FALL FOLIAGE PARADE FUN**

The Fall Foliage Parade is the Berkshires’ celebration of our wonderful Berkshire community, with the



backdrop of the beautiful foliage. This October 6th, the AYJ Fund was pleased to be a part of the celebration and thrilled to have our AYJ Fund princesses join us to spread the

word about our upcoming “Once Upon a Dream” Children’s Princess Concert. Pam and Mark Wilk created a beautiful crown and led the princesses with Disney music. We thank our banner carriers, Christa, Connor, and Paxton Wood! Our



beautiful princesses were a highlight, with little children calling out to them and running out to hug them as they walked by. Such a great job princesses!



**“ONCE UPON A DREAM” CHILDREN’S CONCERT**

As we go to print, we are finalizing details and fitting our princesses gowns for our now famous children’s princess concert being held on October 26th. This year, Berkshire’s popular music duo Samantha Talora and Ron Ramsay will return, student Jennie Collins and the MCLA’s Allegrettos, the talented a cappella and gospel group. This is such a fun event, with so many magical moments of children enjoying both the Disney princesses and the beautiful children’s music. We will share photos on our AYJ Fund Facebook page.

**CHILDHOOD CANCER AWARENESS MONTH**

September was Childhood Cancer Awareness Month, a time to raise awareness of childhood cancer and its impact on families all over the world. Gold is the color of childhood cancer, as pink is the color of breast cancer. It is much more than gold ribbons, though. In raising awareness in our communities, we advocate to change legislation, which leads to increases in funding for childhood cancer research. This is why we go gold! We were very honored that Mayor Tom Bernard proclaimed September as Childhood Cancer Awareness Month in North Adams at a North Adams City



Council Meeting and recognized the work of the AYJ Fund. Additionally, MASS MoCA, the largest museum of contemporary art in the US, located in North Adams, went gold for September. They shone gold lights on their iconic upside-down trees at the museum entrance. They joined landmarks and sports teams

throughout the country and around the world that recognized Childhood Cancer Awareness Month. We are happy to live in a community that cares so much about our children.

**#LEGOJET #LEGOAYJFUND**

Kathy was more than honored that our friend Jake created a LEGO character of her. Jake first created #LEGOJET, which his classmates, friends, and supporters take on trips, They send photos back to Jake when he is in treatment and cannot join in their adventures. We took #LEGOJET to Barcelona with us



when we traveled for our research conference. We can't think of a more special recognition of the AYJ Fund!

**McCANN TECHNICAL HIGH SCHOOL AND CLARKSBURG ELEMENTARY SCHOOL CELEBRATE CHILDHOOD CANCER AWARENESS MONTH**

Jake's friends and family celebrated Childhood Cancer Awareness Month at both McCann Technical High School, where Jake is a freshman, and Clarksburg Elementary School, which his sister Lyla attends. Both schools raised awareness by sponsoring a "Hat Day" and encouraging students to wear yellow or gold. Lyla rocked it, as you can see in the photo and even brought extra gold swag to share with friends. Thanks to our #JETPACK friends, donations that came to the AYJ Fund and will be used to support children with cancer.



**BERKSHIRE FIGHTERS and ANGELS**

Our friend Christen, who is Mom to Cameron the Leukemia Warrior, created this wonderful poster, which was seen around the Berkshires to raise awareness during Childhood Cancer Awareness Month. She recognized not only her son, who has battled leukemia, but a number of children in our local Berkshire community. We celebrate Connor, Cameron, Jake, Samuel, Titus, Tony, and Anna, along with all of our Berkshire fighters and angels.

**September is Childhood Cancer Awareness Month**

- Everyday, 43 Children are diagnosed with Cancer.
- 5 Families will lose a child to Cancer today.
- 95% of Childhood Cancer Survivors will suffer Long-term effects from treatment.
- Childhood Cancer is the leading cause of death by disease in children 19 and under.



Wear Yellow or Gold to Show Support!

#ChildhoodCancerAwareness - #GoGold  
 #CameronTheLeukemiaWarrior - #Jetpack -  
 #TogetherWithTony - #Titus - #AYJ - #MomentsHouse

"Support the Fighters, Admire the Survivors, Honor the Taken."

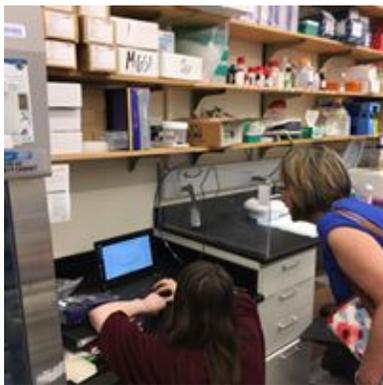
**VISIT TO DANA-FARBER'S LAB**

We had an exciting trip to Dana-Farber earlier this summer when we toured the research labs of Dr. Mimi Bandopadhyay and Dr. Mariella Filbin. Both labs shared their exciting research. We talked about the



great collaborations underway between these labs and other US and European labs whose researchers attended our GC Conferences. They were excited to show us one of their new toys, a microscope incubator where brain tumor cells are

grown. The microscope allows them to view and track cell changes. They are able to view multiple cells or individual cells from their computer without removing the samples from the incubator, which allows them to collect so much more information so much more efficiently.



**PHOTO SHOP**

After our friend Daisy had been going through a difficult time, her Mom posted that she was loving her photography class and was thrilled she found something she could pour her heart into. "Even when things were hard, this is what's saving her right now." The class had only two weeks to go, so we sent a special photo-themed SMILES pack. Her Mom wrote:

*"Oh, Kathy!! This was the best gift ever!!! Thank you and the AYJ Fund for the amazing thoughtful gift! She is loving the books and cannot wait to make her own photo book! 💕💕📷"*



**AYJ FUND'S CORN HOLE TOURNAMENT**

Our Corn Hole Tournament, held in September at the North Adams Armory, was a great success and lots of fun once again this year. We thank our Gold Sponsors: the Berkshire County Jimmy Fund, Berkshire Performance, Greylock Federal Credit Union, MountainOne, Smith Watson & Co., Southwestern Vermont Health Care and Kathy & Jim Whitney, along with over 45 Silver Sponsors and Friends.



Thanks to all who donated, volunteered, attended, and helped in so many ways; without you this would not be possible. You helped us exceed our goal through one of our largest events to support children with cancer. It was a great day!

**FACEBOOK BIRTHDAY FUNDRAISERS**

Thank you again to all of our Facebook Friends who have chosen to celebrate their birthdays with a Facebook birthday fundraiser. Thank you to Krista Altman, Sharon Leary and Alison Meehan, our most recent Facebook fundraisers, for supporting the AYJ Fund. Happy Birthday!



**PRINCESS BIRTHDAY PARTY DONATION**

Our AYJ Fund princesses are so popular and great with children that a family reached out to us to see if any of our princesses could help them celebrate at their daughter's Disney princess-themed birthday party. Ana (Caroline Cellana) and Elsa (Jayden Tower) arrived at the party and celebrated with all the children. Caroline and Jayden donated a portion of their payment to the AYJ Fund to help support children with cancer. We know our AYJ Fund princesses are extra special, but this just melted our hearts!



**JULY 4th SMILES**

July 4th was always a special holiday for Anna and our family, so again this year we thought the best way to celebrate would be to help brighten the holiday for teens in treatment at the Jimmy Fund Clinic. Many of our supporters helped shop for lots of exceptionally cute and fun red, white, and blue and patriotic-themed items to fill 50 baskets.



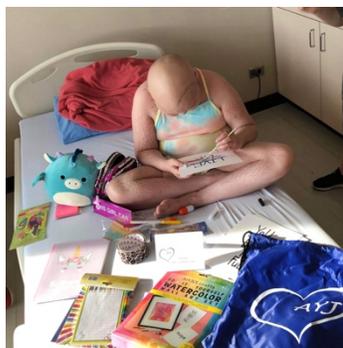
We heard from one of their Moms on our AYJ Fund Facebook page:



*"You all are amazing. My teen son is a patient and we appreciate everything." 🧡🧡*

**PERFECT TIMING**

Sometimes our SMILE packs arrive at just the right time, which was the case with a pack we sent to our friend Kailyn, who has a diagnosis of gliomatosis cerebri, the same brain cancer Anna had. Kailyn's Mom



picked up the package on her way to the hospital— certainly not a place Kailyn was looking to being at again— for Kailyn's recent admission. Kailyn's Mom shared that Kailyn hugged the box tight the whole way to the hospital. When she was admitted, Kailyn was distracted from what she was going through and not focused on being in the hospital and away from home and friends again. Her Mom shared:



*"I'm so happy I checked the mail before I brought her in. Thank you it made her day big time! PS couldn't get a photo of her smiling; she was too busy coloring."*

**FLY HIGH ANGELS**

Although our fighters go through more than any child and any family should ever face, childhood cancer continues to take the lives of way too many. We are heartbroken to share our newest angels:



Our friend Landon shared the same rare brain cancer as Anna. He had a very special connection with his Mom and we got to know and love them both.



Anthony bravely battled leukemia three times. He lived nearby in Pittsfield in our own Berkshire County.



Ian was also diagnosed with GC. Although we had been connected with Ian's family, we first met his Dad this year at the GC Conference in Barcelona, where he advocated for Ian's final wishes to make a difference to advance research.

**ADVOCACY**

It is critical to advocate at the national level to impact change for children with cancer, as there is so little federal funding. The AYJ Fund recently endorsed the reauthorization of the Creating Hope Act, which creates an incentive for companies to develop drugs for pediatric rare diseases through a voucher program. We are also following the shortage of the chemotherapy drug Vincristine. It's a crisis, following the decision of one company making this drug to stop production and a manufacturing problem at the only remaining drug company. We will be advocating for change with the FDA for children whose lives depend on this and other rare drugs.

**MEMORIAL DONATIONS**

The AYJ Fund is blessed to have our friends and loved ones select the AYJ Fund as the recipient of memorial donations:



Lucille Gagnon, our friend Mike Mongeon's Aunt, lived 92 years and now continues to do good through generous memorial gifts in her name.



Everett Unis, a well-known local tavern owner and mailman, was an avid supporter of local athletics and Dad to our friends Nancy and her husband Jay Meehan.

**AYJ SIGHTINGS**

We have lots of AYJ sightings to share. If you have a photo of our AYJ logo anywhere around the world, please share!

*Our friends Nancy & Jay are off on their RV adventure and took the AYJ Fund along! Looking forward to more sightings!*

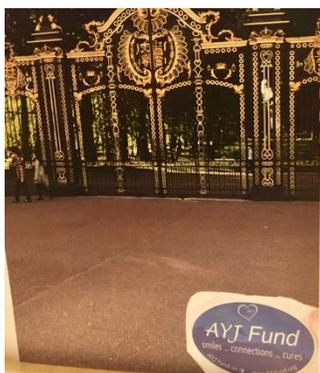


*AYJ Fund at the Mediterranean Sea in Barcelona*

*Connor and Paxton Wood, our AYJ Fund banner carriers in the Fall Foliage Parade*



*AYJ Fund at Buckingham Palace in London, thanks to Jake's DF nurse Annie*



*AYJ Fund in Dr. Mimi's lab at Dana-Farber*



*We left our AYJ Fund mark in Burlington Vermont during sisters' weekend*



**JAKE'S FRIEND ANTHONY**

When we heard that Anthony was more than a friend to Jake and was also being treated at Dana-Farber's Jimmy Fund Clinic, we were happy to send him a sports-themed SMILE pack. Anthony helped Jake learn all about baseball stats and the Red Sox, as they both attended a baseball game and teen weekend, compliments of the Jimmy Fund Clinic. So when Anthony was admitted to the hospital for emergency surgery, we knew just what would make him smile when he got through it. Anthony later texted Jake to tell him "it's awesome!"



**A SPECIAL MESSAGE**

The AYJ Fund received a beautiful message from Christen Simmons, Cameron the Leukemia Warrior's Mom:

*Thank you for what you do and all the smiles you have brought to Cam's face the last almost 3 years, and also the kiddos faces I've personally seen in clinic, and the things you have done to help my family. It's meant so much!!!*

*Christen*



**BRIELLE BRAVE**

Although they say that brain cancer is rare, when it hit once again in our Berkshire community, it made us wonder why it is considered so rare. Every child is one too many. Brielle is a beautiful teen who was recently diagnosed with brain cancer and we knew she deserved a "Girl Boss" SMILE pack. She is currently undergoing treatment, and has the support of her school, friends and community as she bravely faces this battle.



**WINTER WISHES BALL AT ANNA MARIA COLLEGE**

We are very excited that the AYJ Fund will partner with Anna Maria College's Campus Princess Program and Anna Maria's Program and Activities Council (PAC) to present a Winter Wishes Ball at Anna Maria College in Paxton, MA, on Saturday, December 7th.

All proceeds from the event will be directed through the AYJ Fund to support the children at Dana-Farber's Jimmy Fund Clinic. The evening will include a great night of music, dancing and fun for all ages. Tickets will be available on the AYJ Fund website on November 1st.

We are proud to be working with this wonderful group of young adults to bring smiles to children with cancer, and are impressed by the work they do all year.

**SPONSOR A BACKPACK FOR A CHILD WITH CANCER THIS HOLIDAY SEASON**

You can bring a smile to a child undergoing cancer treatment this holiday season by supporting our Holiday Backpack Program. The AYJ Fund will be filling 200 string backpacks and distributing them to a number of children's cancer centers to be given to teens undergoing cancer treatment.



You, your family, your co-workers or a group of friends can sponsor one or more backpacks and make a difference for children who are not able to fully enjoy the holiday season.

If you have a talent, such as knitting, sewing or making crafts, jewelry or other fun items, we would also welcome those items to fill our backpacks.

**DONATE or SHOP for items:**

If you enjoy shopping, you could also pick up items for us to include in the backpacks. A list of items can be found on our website and also on our AYJ Fund Facebook page.

All holiday backpack sponsorships and donated items will be needed by November 19th.

**Complete the sponsorship form below and mail it, or sponsor directly on our website at [www.AYJfund.org](http://www.AYJfund.org)**



**SPONSOR A HOLIDAY BACKPACK**



Make checks payable to **AYJ Fund**

I would like to sponsor \_\_\_\_\_ backpacks at \$25.00 each. Total donation: \$ \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Mail to AYJ Fund, 201 Eagle St., North Adams, MA 01247



[www.AYJfund.org](http://www.AYJfund.org)

All donations are tax deductible

### AMAZON SMILE for AYJ FUND

The AYJ Fund is now on Amazon Smile. Simply select the AYJ Fund as your charity and every time you shop, you help the AYJ Fund! When shopping on Amazon, go first to [www.amazon.com](http://www.amazon.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 school supplies, 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!



### SUPPORT AYJ FUND AT BIG Y in NOVEMBER

We are so happy that the AYJ Fund has been selected once again for the Community Bag Program for the month of November at the Big Y in North Adams. For every reusable community bag purchased, Big Y will donate \$ 1 to the AYJ Fund. It's a great bag to carry home your turkey!

At Big Y stores in other towns, you can purchase a community bag any time of the year and follow the directions on the Giving Tag to direct your donation to the AYJ Fund.

