



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

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.

Gliomatosis cerebri is the rare type of brain tumor that Anna Yan Ji Arabia was diagnosed with at age 13. At the time of Anna's diagnosis, there was no research being done. We are committed to supporting new research now being conducted to find effective treatments and a cure for this devastating disease.



CHILDHOOD CANCER AWARENESS MONTH

September is Childhood Cancer Awareness Month. It is important that we share the facts about Childhood Cancer to raise awareness. Awareness is the first step that leads to increased funding for research. More funding for research is the only way to find effective treatments and, one day, a cure for these beautiful kids. Please Go Gold this month and check out the article on page 7 of this newsletter to learn more.



JIMMY FUND WALK - ANNA'S ARMY

Our team, Anna's Army, will walk again this year in the Boston Marathon Jimmy Fund Walk on Sept 24th.

Anna's family and friends join 9,000 walkers along a portion of the Boston Marathon route. This year, our team will honor not only Anna, but also our team member Brice Flowers, Jack's Dad, who walked with us last year and recently joined Anna in heaven. Please support our team by donating to Anna's Army at



http://jimmyfundwalk.org/goto/Annas_Army

AYJ FUND CORNHOLE TOURNAMENT SATURDAY, SEPT 29th

Please join us for a great day of fun on Saturday of Fall Foliage Weekend, Sept 29th, at the Armory in North Adams. The winning team will win a \$100 prize!



All ages and all levels of skill are welcome, from beginners to expert players. Two-person teams can register for only \$20. Registration is open online at AYJfund.org or through the AYJ Fund event on Facebook.

Stop by for our great Chinese Auction and raffles, even if you don't plan on playing. It is not to be missed! We thank all of our fabulous sponsors of this event.

With the support of so many community businesses and individuals, we will reach our goal of \$10,000 to help support local kids with cancer and research now being done at Dana-Farber Cancer Institute. Sponsorships are still available, and donations for the Chinese Auction are welcome also.

CHILDREN'S PRINCESS CONCERT OCT 27th

Last year's Children's Princess Concert was such a special and fun event, that we have invited the princesses back on Saturday, Oct 27th, at the MCLA Church



Street Center. Please join us this year as the MCLA Allegrettos and Jess Renee perform Disney and children's music and create special moments.

The princesses will be available before and after the concert to take pictures and spend time with the guests. Children can dress in their Disney or other costumes and join in the fun.

PAINT PARTY IN AYER

The AYJ Fund is so grateful to our friends in Ayer who held the most fun painting party! Thanks to Anna’s Aunt Linda and cousin Elise, who made sure all the details were in place for a great evening; Pastor Susan Gaeta for inviting us to us the new space for the Shepherd of the Valley Lutheran Church; and all the “artists” who came and supported the AYJ Fund. Thanks also to Thrivent Insurance for supporting the event with a grant for food and supplies and even T-shirts for all the guests! We had a great time.



CONNECTIONS PROGRAM IAN

Ian graduated from high school last year and had to return his laptop back to the school. He has been through some tough treatments for gliomatosis cerebri, the same type of cancer Anna had, and not able to attend college due to the difficult side effects of treatment. He would like to take some college classes online. The AYJ Fund knew he needed a laptop to stay connected with school and friends, and sent him an “Anna-approved” laptop. We surprised him when he got home from his stay at St. Jude’s Hospital, and we think it was a hit! Ian sent us a wonderful message:



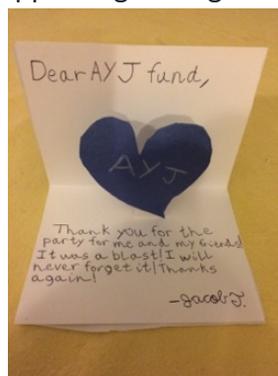
“Hey, I just wanted to say thank you for the computer and headphones. I think I’m in love with them haha”.

SMILES PROGRAMS JACOB’S ADVENTURE

When we heard that Jacob’s tumors needed to be removed and he was scheduled for hip surgery this summer, we knew that Jacob needed a day full of adventure and fun with his friends before his hospital stay in Boston. No better place than Bousquet Water Slide and Adventure Park to enjoy a fun summer day! It looks like they had quite the adventure!



Jacob has a long road ahead, as he has Li-Fraumeni Syndrome, which puts him at great risk of cancers appearing throughout his lifetime. He undergoes frequent screenings – but more importantly is a typical bright, energetic kid who is off to school this fall! As busy as he is, he made us one of our favorite, and only pop-up, thank you cards ever!



We had a great time when he visited and Joe was able to show him his Legos, and we gave him a Lego set to work on. He mastered this quickly too!



His Mom writes:

“A big thank you to the AYJ Fund for bringing a huge SMILE to Jacob. Legos are the BEST distraction for this guy. His favorite. He’s so excited to be heading back to school soon – 8th Grade!”

GIRL POWER

When we heard that Courtney was in the hospital and receiving both chemotherapy treatment and radiation, we knew she deserved a SMILES package to brighten up her day!



We picked out a soft fleece blanket, an Echo Dot, some warrior gear and a few more fun items and sent them off.

Her Dad wrote:

"Thank you so much for the care package. Courtney was stuck in bed and it really brightened up her mood"

Courtney faces a long period of treatment and recovery, and we send her our best along this road.

JULY 4th BASKETS

We celebrated the 4th of July by filling 50 patriotic hats with fun red, white and blue items for the teens in treatment at the Jimmy Fund Clinic.

We had great support with donations for this project, and we found lots of Red Sox items, red and blue nail polish, flip flops, string lights and so much more!



Thanks to our friend Julie who made patriotic earrings for all the girls! These baskets are some of our most fun creations, and we love seeing the kids so excited and smiling when they receive these great baskets.



We made sure our friend Cam was able to get one. As his Mom shared:

"Cam wasn't having it today!!!"

"Thank you AYJ Fund for the great festive 4th of July basket (they made sure they found Cam)."



He loves it!!!"

JOE'S GRADUATION

We celebrated Joe's graduation from Massachusetts College of Liberal Arts (MCLA) with an outpouring of gifts to the AYJ Fund. We are so proud of Joe's accomplishment, graduating cum laude with a degree in Sociology, and his graduation cap honored Anna and the AYJ Fund.



When Joe went back to take classes after retiring from MCLA, his goal was always to graduate with Anna in 2018. We know she was there with us as we celebrated, and we thank all of those who celebrated with us and recognized this special day with donations to the AYJ Fund.

CLAIRE'S BIRTHDAY FUNDRAISER

Thanks so much to our friend Claire Costello, who asked for donations to the AYJ Fund for her birthday instead of gifts. Claire wrote "I've chosen this nonprofit because their mission means a lot to me, and I hope you'll consider contributing as a way to celebrate with me." And they did! Claire's friends exceeded her goal, raising \$ 450 to help the AYJ Fund support kids with cancer. Thanks so much to everyone who made this possible!



DOWNTOWN CELEBRATION

AYJ Fund joined other local businesses and organizations to celebrate North Adams at the 2018 Downtown Celebration.

We were able to meet many local friends and share information about how the AYJ Fund is impacting kids with cancer



locally and beyond. A few tried out our corn hole boards to get ready for our tournament on Sept 29th!

MEET MARIELLA FILBIN, MD, PhD AYJ FUND'S \$20,000 DONATION

We had the pleasure of meeting with Mariella Filbin, MD, PhD, and talking with her about her research as we visited Dana-Farber this spring.

Dr. Filbin, a pediatric neuro-oncologist, leads the high grade glioma research lab at Dana-Farber Cancer Institute. A current focus of this research is to use single-cell RNA-sequencing to sift through the many different cellular types found within high grade brain tumors including gliomatosis cerebri. Single-cell RNA-

sequencing provides a vastly more precise view of each tumor's complex landscapes than the historical sequencing approach used to interpret a tumor's genomic profile, which involved pulverizing a tissue sample into a homogenous liquid and subsequently losing all context of the individual cells and their relationships to one another. It was identified at our 2nd International Conference on Gliomatosis Cerebri as an area of focus.



Dr. Filbin's recent published research, in collaboration with Massachusetts General Hospital and the Broad Institute of MIT and Harvard, revealed new discoveries in DIPG tumor cells with the H3K27M mutation. Her research lab is using single-cell RNA-sequencing to work to identify if these new discoveries are also relevant in gliomatosis cerebri tumor cells. We are excited that the AYJ Fund is supporting this research and are eagerly awaiting new information to help find effective treatments for these kids.

We presented a check for \$ 20,000 from the AYJ Fund to support this important research.

BERKSHIRE COUNTY JIMMY FUND

Upcoming local Jimmy Fund event:

Putt-a-Thon – Friday, Sept 14th, Baker's Golf in Lanesboro. 36 holes of Mini Golf



AYJ FUND SIGHTINGS



Megan at "the bean" in Chicago



Emma's Graduation Cap



Jack & Audree at the Westover Air Show



We salute you! AYJ at Westover



Joe's Graduation Cap



AYJ Bunny at Jack's Bake Sale

OTHER LOCAL EVENTS SUPPORTING CANCER PATIENTS IN OUR COMMUNITY

Polenta Supper – Tues, Oct 23rd, 6:30 pm, Berkshire Hills Country Club

Zip Stohr Comedy Show – Sat, Nov 17th, 8 pm, Berkshire Plaza Hotel (formerly Crowne Plaza)

Pop Cares Chicken Dinner and Live Auction – Sat, Oct 13th, 5pm, Greylock WORKS

Moment's House Hoedown for Hope – Sat, Oct 20th 3-10pm, Proprietor's Lodge (formerly the ITAM)

WELCOME BAGS FOR TEENS

The AYJ Fund received a wonderful donation directed to doing something special for the teens receiving care through the Jimmy Fund Clinic. After a discussion with Dana-Farber's Jimmy Fund Clinic's Adolescent Program Manager Jen Noonan, we agreed to support the funding of "Teen Bags" for new teen patients.



Recognizing that a pediatric hospital/clinic may at times feel "too young" for a teenager's unique challenges, this welcome kit would help introduce a number of teen-focused programs and opportunities of the "Just For Teens" program at the clinic.

Jen shared her message to the teens:

"You may be shocked, afraid, confused, sad, and feel like no one in the world can possibly understand what you are going through. Whatever you are feeling is normal and there is a whole community here at Dana-Farber/Boston Children's to support you. Additionally, there are other teens with similar experiences, so remember, you are not alone. You might find that learning more about what we have to offer you and connecting with other teens can help."

We agreed this would be a great way to help create awareness and enhance current support programs, which ultimately strive to ease the burden of diagnosis and treatment for this age group. It's hard to be a teenager these days ... and even harder to be a teen with cancer!

OUR ANGEL AIDAN

Our hearts are broken as we share that our friend Aidan has now joined Anna and so many other childhood cancer fighters in heaven. Aidan also had GC and he and his family fought hard throughout his journey. Aidan was tough and strong and will always be in our hearts.



JACK'S BAKE SALE

Our friend Jack and his family were busy this Memorial Day weekend raising money for the Jimmy Fund and for our AYJ Fund. Jack used his artistic and planning skills, and engaged his whole family, and friends too, in baking and sewing. Jack sold baked goods, stuffed AYJ Fund bunnies, soaps, candies and more on a beautiful day in Granby.



Jack created a poster sharing the stories of Anna and other kids diagnosed with cancer, and included childhood cancer facts to help raise awareness.



He also wrote an information sheet for customers to take away with them so they understood Jack's important message of helping children with cancer.

All proceeds from the Bake Sale were split between the AYJ Fund and to support Jack's Boston Marathon Jimmy Fund Walk on our Anna's Army team.

A ROOM FOR LUKE

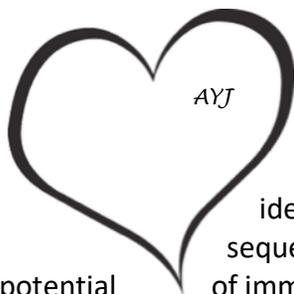
Luke is a very happy child who was born with an inoperable brain tumor diagnosed as GC. He was told he would not live more than two months to two years, and 15 years later he has a good quality of life, but needs constant care and attention. His home has become somewhat of an obstacle in caring for him, so a family friend started a GoFundMe page and the AYJ Fund contributed directly to his family to help open up a play space for Luke and add a handicap accessible bathroom. Keep smiling and keep playing Luke!



**JOURNAL OF NEURO-ONCOLOGY
ARTICLE**

We were thrilled when we saw that the Journal of Neuro-Oncology published an article on the International Gliomatosis Cerebri Conference we attended last June. "Gliomatosis cerebri: a consensus summary report from the Second International Gliomatosis cerebri Group Meeting, June 22-23, 2017, Bethesda, USA" was written by Dr Andres Morales La Madrid, Surabhi Ranjan MD and Kathy Warren MD, leaders and presenters of this important conference.

The article summarized the research that was presented at the conference, reviewed the challenges in diagnosis and treatment, identified relevant clinical trials for GC at the National Institutes of Health, and included the three provocative projects specific to GC that came out of the conference. It defined gliomatosis cerebri (GC) as an extremely infiltrative pattern of diffuse gliomas spread, rather than a discrete histologic or molecular subtype of glioma. This was important as there has been controversy based on research which has been done since the first GC Conference in Paris, over whether this is a distinctly separate disease, and how it is diagnosed.



A goal of the conference was to develop meaningful collaborative projects to be implemented within the next two years. The projects identified were (1) further tissue sequencing, (2) evaluating the potential of immunotherapy, using single cell sequencing to identify targets, and (3) clinical studies focused on tumor invasiveness and developing trials based on new research discoveries.

This journal article is important as a way to educate neuro-oncologists and other physicians who were not in attendance to understand the outcomes of this conference and the current understanding of this complicated disease and how it is diagnosed, as well as a general understanding of treatment options. Publication in this well-respected journal demonstrates the importance of this conference. The AYJ Fund is proud to have been a lead sponsor of this conference, and to be mentioned along with other sponsors in the article.

SUPPORTING BEN'S WALK

Ben is a student at the Manville School in Boston, and is currently fighting AT/RT, a rare and aggressive form of brain cancer. Ben's school friends held an event at



the school to show their support and were able to raise funds by walking laps around the school's soccer field. Ben was feeling well enough to stop by for a short time to see the outpouring of support of his friends. The AYJ Fund was pleased to have been able to show our support of Ben and his fight with a donation to his walk.

Ben has endured two brain surgeries, radiation and chemotherapy and strives to get back to school, friends and his daily routine which are all so important to him.

The family has set up a GoFundMe account at www.GoFundMe.com/Benvestin

LEGISLATIVE ACTION - STAR ACT

The Senate Appropriations Committee approved a spending bill for FY 2019 that included the language necessary to fund the Childhood Cancer STAR Act. The full house has not yet taken up the bill for consideration, and they must also conference their bill with the Senate later this fall to reach agreement on a final funding bill to send to the President.

You can help by reaching out to your House of Representatives members to support this action. Rep. Katherine Clark of Massachusetts is on the House Labor/HHS Appropriations Subcommittee, if you are one of her constituents please reach out at (202) 225-2836 and urge that the Childhood Cancer STAR Act be fully funded.



**Childhood Cancer
STAR ACT**
Survivorship Treatment Access and Research
H.R. 820 · S.292

SEPTEMBER IS CHILDHOOD CANCER AWARENESS MONTH

DID YOU KNOW ...

Childhood cancer is the leading cause of disease-related death in children.

- 43 children are diagnosed with cancer every day in the US.
- Because of the treatments they had as kids, more than 95% of childhood cancer survivors will develop a chronic health problem and 80% will have severe or life-threatening conditions.
- More than 40,000 children undergo treatment for cancer each year.
- Although the overall five-year survival rate is now over 80%, there are still some childhood brain cancers where the survival rate is less than 1%.
- Every day 5 children will die of childhood cancer in this country.
- Worldwide, a child is diagnosed with cancer every two minutes.
- Despite these statistics, childhood cancer receives only 4% of federal funding for cancer, and is consistently underfunded by pharmaceutical companies.
- Gold is the color of Childhood Cancer Awareness.
- September is the month to commit to raising awareness of Childhood Cancer.



LOCAL GOLD!

North Adams Proclamation

We are excited and grateful that North Adams Mayor Thomas W. Bernard will present a proclamation at the North Adams City Council Meeting on Sept 11th, marking September Childhood Cancer Awareness Month in the City of North Adams. The AYJ Fund is honored to receive the proclamation and is grateful

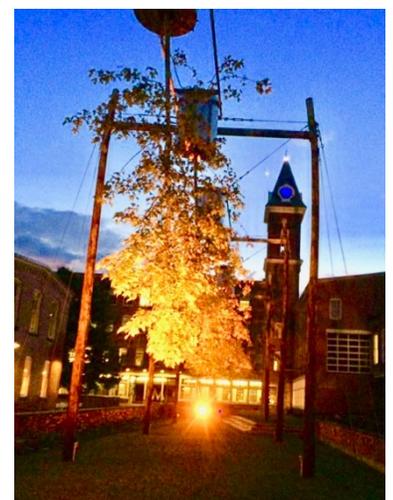


to Mayor Bernard and the City of North Adams for this ongoing support of the AYJ Fund and of the fight against Childhood Cancer.

GO GOLD with Mass MoCA

MASS MoCA is once again joining landmarks across the country and around the world, going gold this September to raise awareness for childhood cancer. In alighting its iconic entrance in gold, the North Adams museum joins Times Square, the Prudential Center, the Zakim Bridge, the TD Garden in Boston, Niagara Falls, the Eiffel Tower and other famous landmarks around the world to raise awareness of the battle children fight in this disease and the critical need for increased funding for research.

Major league sports teams are also recognizing and honoring children with cancer this month. Major League Soccer and all 30 Major League Baseball teams, including the Boston Red Sox at Fenway Park, have tributes in September.



SHOP AMAZON SMILE

You can shop and help the AYJ Fund! The AYJ Fund is now on Amazon Smile. When shopping on Amazon, go first to www.amazonmile.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!



HOW YOU CAN HELP

Check our Website at www.AYJfund.org. We have printable pages of ideas of how you can help kids through the AYJ Fund at home, business, or at school.

Donate – We are always grateful for donations in any amount to continue our mission of smiles ... connections ... cures.

Volunteer - Contact us at Kathy@AYJfund.org and let us know you're available to help in any way.

Support our programs - Ask what our next Smiles project is, or send along your ideas on what we can do to raise funds, help research, and make more smiles.

Stay connected - Follow us on Facebook at AYJ Fund and online at www.AYJfund.org.

Spread the word – Share information with family and friends on how critical increased funding for research is for childhood cancer and all brain cancers.

