



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.



BIRTHDAY CAMPAIGN: THANK YOU!

Thank you for all of the contributions to Anna's 25th Birthday Campaign. We exceeded all of our expectations, with a final total of \$16,495.

What a wonderful celebration of our beautiful angel!



Although all of our in-person indoor events were canceled this year, you will see that it has been a busy year of supporting children and advancing research. We have been blessed with many new events, planned by old and new friends of the AYJ Fund. This newsletter is filled with lots of information on these fun times.

This summer and fall have been filled with so much emotion, with more local children receiving a cancer diagnosis, and heartache, as children we know who fought their battles so bravely became angels. This makes us more committed than ever to continue our work, with your support, to make a difference, and find effective treatments for children with cancer.

We are very grateful to *iBerkshires* and *The Berkshire Eagle*, which published articles on the AYJ Fund and helped us spread the word about childhood cancer and the need for more funding for research.



As we look toward the holidays, with hospitals still under many COVID restrictions, we will continue our AYJ Holiday Program, not with backpacks, but with gift cards, Amazon Wish Lists and more! Please contribute if you are able, so we can send more AYJ Holiday SMILES than ever!

Kathy + Joe

RESEARCH FUNDING

Diffuse Intrinsic Pontine Glioma (DIPG) is a type of brain cancer which is closely related to Gliomatosis Cerebri (GC), the brain tumor which Anna was diagnosed with. DIPG also shares a devastating survival rate of less than 5%. Dr. Michelle Monje of Stanford CA is one of a few researchers with exciting trials using Cart T Cells. Kathy met Dr. Michelle Monje at a nanocourse she attended in 2013 at her Monje Lab. Dr. Monje has since presented at our GC International Conferences. We believe research being conducted in her lab will help lead to advances in treatment of both DIPG and GC.



Dr. Michelle Monje

We are happy to share that the AYJ Fund is now supporting this research by joining other foundations in a collaborative grant to fund a nurse practitioner position which allows this clinical trial to expand to more brain cancer patients. This is a trial our friend and now angel Jace participated in and his family still strongly supports.

We are also pleased that The Brain Tumor Charity, a foundation we are working with in the UK, recently awarded Rameen Beroukhim, MD, PhD, a grant of more than \$1.5 million to lead an international collaboration to examine the drivers of glioma brain tumors. We are excited that this project is being carried out by a team of researchers at Dana-Farber, in Europe, and in the UK The researchers at Dana-Farber include our friends and brilliant researchers Dr. Mimi Bandopadhyay and Dr. Mariella Filbin.

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<https://www.berkshireeagle.com/news>

AFTER A NORTH ADAMS COUPLE LOST THEIR DAUGHTER TO A RARE CHILDHOOD CANCER, THEY PUSH FOR MORE RESEARCH

By Greta Jochem, *The Berkshire Eagle*

Kathy and Joe Arabia's daughter, Anna Yan Ji Arabia, was diagnosed with gliomatosis cerebri, a brain tumor, at age 13. When the North Adams parents learned that there were no promising treatment options, "I was shocked," Kathy Arabia said.

"I had worked in health care for 30 years. [I] grew up in Boston, where there are so many major medical institutions that are known worldwide," she said. "I just expected they would have some treatment



available. I knew it was serious, but not that they really didn't have something they knew would be effective."

The overall survival rate for gliomatosis cerebri is about [5 percent](#), according to St. Jude Children's Research Hospital.

Anna, a Drury High School student, died in 2013, several years after the tumor was discovered.

"Anna faced her rare brain tumor gliomatosis cerebri with amazing strength and never let it touch her spirit," her [obituary](#) reads.

"She was treated at Dana-Farber and received the best care that was available, but there were no treatments," Kathy Arabia said. "To us, that was unacceptable. After she passed, we wanted to start a fund to help the research."

The Arabias started the AYJ Fund, a volunteer-run [organization](#) that supports kids with cancer and fundraises for research. Recently, AYJ teamed with several other foundations around the world to fund a research grant.

Dr. Mariella Filbin, a neuro-oncologist at the Dana-Farber Cancer Institute and Boston Children's Hospital and an assistant professor of pediatrics at Harvard

Medical School, is one of the researchers leading the grant-funded project.

Gliomatosis cerebri is "vicious," Filbin said. The tumor cells grow in between brain cells and not in a single mass.

"There's not an apple or orange in your brain that you can cut out," Filbin explained. "They don't destroy the structures that are there.

They go in every single space that is available."

The research focuses on gliomatosis cerebri in those younger than 20, and it seeks to better understand the tumor cells and develop new therapies, Filbin explained.



As a young doctor, Filbin was hopeful that treatments would be coming. But, as she gets older, it becomes more painful, she said. "Every single patient is one too many. I want to give all of them the opportunity for a full life, and not being able to do that at this moment is incredibly, incredibly painful."

She added that the research "is not just interesting. This is urgent. This urgency is what I feel even more as I get older with each patient journey, and that's what makes it even more painful."

With the research, "I really hope we can find a new class of therapeutic drugs for GC," Filbin said. "How long it will take to get there, I don't know."



Dr. Mariella Filbin

Anna would have turned 25 in April, and the Arabias continue to raise money and work on programs to support children with cancer, like giving them technology to stay in touch with friends.

"Funding is a challenge, but we have had tremendous support from our local community," Joe Arabia said. This summer, the AYJ Fund held a concert at Balderdash Cellars in Richmond which, the Arabias said, raised more than \$10,000.

SPRING SMILES

The COVID 19 pandemic certainly has changed the way we bring smiles to children with cancer, but it doesn't stop us. To celebrate Anna's Birthday in April, we sent fun items directly from Etsy suppliers, as the clinics are not able



to accept direct donations from families or organizations.

We sent a number of activity kits to the Jimmy Fund Clinic to give the teens in the clinic something special to help keep them busy during their long day of testing, treatment, and appointments.



The girls kept busy creating felt flowers and making beautiful wreaths to take home. The boys put together STEM wooden kits — cars, airplanes, and more — including some that were solar- or battery-operated. We heard that they were quite a hit. Kate Nixon, Adolescent Specialist, created an AYJ Fund felt wreath for us!

JULY 4TH SMILES

*"Thanks again so much!!!
I ❤️ 4th of July with AYJ!
Kate – JF Clinic*

We can't stop the red, white, and blue celebration of our favorite family holiday, 4th of July! We were able to find special items



that could be sent directly to the Jimmy Fund Clinic for the teens to enjoy when they had to spend time around the holiday in the clinic while friends were out enjoying the summer.

It was a hands-on patriotic craft day for the teens as they created rainbow key chains, string star art and patriotic colored pourable art paintings.

The AYJ Fund also sent Lacey, who has spent too much time lately in the hospital, a July 4th SMILE package to brighten her day. Lacey had lots of fun with all the red, white, and blue gifts in her patriotic-themed backpack.



MAX STRONG'S BASEBALL TRIP

Max is fighting GC and just completed his 30-day cycle of daily radiation. His surprise was a trip to Atlanta, as he had been gifted with special box tickets for the Atlanta Braves game and more. AYJ Fund was happy to cover the cost of his hotel to help make this trip possible.



RICHARD IS ROCKING BCH



Richard is a local boy who has spent many months in Boston Children's Hospital. We were able to connect with his family and send a few different SMILES packages to the hospital to make his time more

fun, and send a donation home to his Dad and siblings. We also connected him with the local funds from the Jimmy Fund Council to help with travel to Boston.



STRANGER THINGS FOR MIKEY

We didn't quite know what "Stranger Things" was, but our friend and GC fighter Mikey sure did. He put together this 2,287 piece Lego set we sent him in record time! His smile says it all!



De'MONI SMILES



Sheena, De'Moni's Mom, summarizes what the last few months have been like since diagnosis, brain radiation, and all of the side effects of DIPG and cancer. It is not easy, but #MoniStrong is amazing each and every day and the AYJ Fund has been happy to be there to help this special little local warrior.

*"By any means life is not easy these days but we smile through everything just so the pain won't overbear our lives."
De'Moni's Mom*

Paw Patrol Hat: Thanks to The Magic Yarn



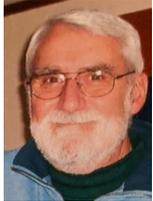
Ayva Loves Her American Girl Doll



MEMORIAL DONATIONS

We are so blessed to have been the recipient of donations in memory of Tom Bernard.

His family have been wonderful supporters of the AYJ Fund. We send our love and prayers to Tom's family. Tom was a veteran and NAPS teacher, and volunteered with the NA Veteran's Office. We are so grateful to his family and to so many who made donations in his honor.



TWO VERY SPECIAL ANGELS

JACE - Jace Ward was a very special DIPG fighter. His favorite saying was, "I am too busy to die." He faced his brain cancer bravely and continued to lead his life and fight for effective treatments and a better survival rate for himself and others. His fight inspired so many; his family continues his fight to increase funding and to advance research for childhood brain tumors.



TRISTAN - Tristan Lawson touched our hearts with his smile, his heart, and his fight. Also a DIPG fighter, and now beautiful angel, we cheered with every advance this 12-year-old local fighter made through the last 17 months. Tristan became an angel this month, and we are heartbroken. Tristan continues his stand against cancer through his tissue donation to "Gift From a Child." We will remember Tristan every time we have an ice cream or popcorn party! Tristan loved special moments with his family, which loved and supported him every step of the way.



FALL FOLIAGE PARADE PRINCESSES

Although we have had to postpone our AYJ Fund's Children's Princess Concert until Spring 2022 due to COVID, our princesses walked in the North Adams Fall Foliage Parade. They spread smiles to so many children all along the route through the city of North Adams.



Many thanks to our AYJ Fund Board member Pam Wilk. Only three princesses returned from last year, as most of our princesses graduated and were off at college. Still, Pam was able to put together our largest group of princesses for parade day.



We cannot wait until spring, when we will be able to hold our Children's Princess Concert in person. These princesses are sweet, caring, and so excited to share more joy with children at the spring concert.



AYJ FUND SIGHTINGS



Addie in Montauk, NY



Nassau, Bahamas



Ron at Balderdash

NICK'S BOTTLE DRIVE

Our friend Nick Murach hosted our first post-pandemic AYJ Fund fundraiser. Donning masks and gloves, Nick and his



friends drove throughout the area collecting bottles and cans to support the AYJ Fund. Many other AYJ Fund supporters

dropped off all they had collected throughout the pandemic at the BFAIR Bottle & Can Redemption Center.

We are so grateful to all who participated and helped Nick raise over \$1,000 to help children with cancer.



DANCING FOR A CURE

This started with a challenge to do something special for Childhood Cancer Awareness Month. Jake, a local cancer fighter, and his mom Kate wanted to do something fun and creative. Jake posted a challenge on Facebook: If people donated \$500, he would dance. The "Dance for a Cure" Challenge met that goal in 20 minutes! Not to be one not to exceed every challenge he faced, he upped the challenge to \$2,000, and added he would sing.



In true Jake form, he exceeded that goal. Dance and sing Jake did, on Facebook Live on his

#JETPACK's page. Breathless and "one-hip-less," Jake dropped his crutches and danced his heart out, sang beautifully, and raised over \$3,000! The AYJ Fund will direct all proceeds to support brain cancer research at Dr. Mimi.

*"Jake is so amazing"
"I think he is so awesome"
Dr. Mimi Bandopadhayay*

Bandopadhayay's Lab at Dana-Farber. Thanks also to his backup crew for helping out!

BALDERDASH CELLARS SPECTACULAR!

The AYJ Fund was blessed to meet Donna and Christian Hanson years ago, when Balderdash Cellars was first located under the Subway in Pittsfield. We followed them through a number of popups as they outgrew their original location and celebrated when they purchased land in Richmond, MA.



Balderdash Cellars has supported all of our Wine and Chocolate events in North Adams, and so much more. They approached us during one of our visits with an offer to hold a fundraising event at their beautiful winery in June. This very special evening brought out so many friends

and supporters. We were excited that local musician and now Nashville star Michael Fabrizio, pictured with us below, came home to share his beautiful music with the crowd on this special evening.

Two local business owners, who prefer to remain anonymous, presented an on-the-spot challenge to the crowd that generated thousands of additional dollars in donations. We are grateful to these business owners.

This fabulous event raised \$10,500 which will help so many children who have been diagnosed with cancer.

Thanks also to iBerkshires for covering this very special and successful event.



STOCKBRIDGE GOLF

June 19th was a beautiful day for golf! AYJ Fund was blessed to be the beneficiary of the Women's Open



Scramble at the Stockbridge Golf Club in memory of Linda Palivoda. Linda was the inspiration behind Moments House, the special cancer support center that was in

Pittsfield. We enjoyed meeting these great golfers and generous ladies.

BURCS SWELTERING SUMMER RUN FOR AYJ



The Berkshire Ultra Running Community for Service held its annual "Sweltering Summer Ultra" on August 14 at Clapp Park in Pittsfield. This is an ultra-marathon race in which runners run for up to 8 hours, with an additional option of a 5K race.

The BURCS crew is composed of runners of all ages who seek to use their passion for sport and activism to spread awareness about important social, civic, and environmental issues.

In previous years, the race benefited Moments House, which closed this year. Our friends at Moments House suggested they reach out to us, and they chose the AYJ Fund to receive the proceeds of the race. We were honored to work with this wonderful organization.



We were amazed by their endurance, their strength their fun, and their hearts, as all proceeds of all of their events are donated to community organizations. An additional challenge at the event raised more dollars for the AYJ Fund. The athletes, lap after lap, ran as they carried a watermelon, named Wally. Wally's tracker recorded that he completed over a full marathon. This event raised \$6,539.02!!

MCLA FOUNDATION SUMMIT

Kathy and Joe participated in the MCLA Foundation Inaugural Endowment Summit, which was held virtually in March. They were able to share information on the Anna Yan Ji Arabia Scholarship that is now administered by the MCLA Foundation, as well as the mission of the AYJ Fund and work we are doing both locally and internationally to support children with cancer and fund research projects.



NAMAZING EAGLE STREET PARKLET

The NAMAZing (North Adams, MA) Eagle Street Parklet Friday Coffee Dates were back this summer, and so was the AYJ Fund. We sponsored a morning event to raise awareness of childhood cancer and the AYJ Fund and to share coffee and pastries with our Northern Berkshire community.



SPIRIT OF CARING AWARD

Kathy and Joe received the Northern Berkshire United Way's (NBUW) Spirit of Caring Award for their work in the Northern Berkshire community through the AYJ Fund. We were so honored to receive this award, named after Al Nelson, who led the NBUW when Kathy started as a NBUW Board Member years ago. We were recognized during a virtual celebration and surprised with our photos on local billboards.



JIMMY FUND WALK

Team Anna's Army once again participated in the Jimmy Fund Walk. It was again a virtual event this year. Instead of walking the



Boston Marathon route, we had Mary Costa walking in Plymouth with Dan, Linda Prince walking in NH with Kevin, and Joe and Kathy walking in North Adams. Kathy and Joe ran into one of our favorite Jimmy Fund patients, Jake Tullo, along the way.



Anna's Army has raised over \$27,000 over a total of ten years walking in the Jimmy Fund Walk for Dana-Farber! We are happy to have helped this great event raise over \$6 million.



CHILDHOOD CANCER AWARENESS MONTH

September— Childhood Cancer Awareness Month — began with Kathy and Joe honored to have North Adams Mayor Tom Bernard present the AYJ Fund with a proclamation for Childhood Cancer Awareness Month at the North Adams City Council meeting.



We spread awareness in new ways this year. We participated in a “Childhood Cancer Awareness Rally” at Pittsfield Park Square, an event that honored so many local childhood cancer fighters, survivors, and angels. Thanks to

Christen Simmons and Stephanie Maschino, who planned this event. This was the first time local family and friends impacted by childhood cancer gathered for this type of rally, and we hope to spread this event to North County next year!



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Another new and impactful event was held at the National Memorial in Washington DC, where Anna’s sneakers were included in a display of 1,800 children’s shoes representing the 1,800 children who pass away from cancer each year. It meant the world to us that Anna was represented in this display created as part of CureFest for Children.



HOLIDAY SMILE CAMPAIGN

With COVID impacting many more children this year and the high risk to children who are immunocompromised, we needed to once again rethink how we did our annual AYJ Fund Holiday Backpack Program. Many hospitals, especially children’s hospitals, continue to restrict donations sent or brought in from homes and organizations throughout the holiday season. But that won’t stop our holiday spirit and AYJ Fund Holiday SMILES!



We will once again be providing \$25 gift cards to all of the hospitals and cancer centers that we previously have sent backpacks to: Dana-Farber Cancer Institute in Boston, Baystate Children’s Pediatric Cancer Center in Springfield, Weill Cornell at Sloan Kettering in NYC, Dartmouth-Hitchcock in NH, and Children’s Hospital of Los Angeles. In addition, we will order through Amazon’s Wish List program to send additional gifts to the Jimmy Fund Clinic and potentially other centers. We will also continue to send additional gifts to individual children we are connected with who are able to be home through the holidays.



Every day is a challenge for these children, and we love being able to help them celebrate the holidays and give them an extra reason to smile. We know how much this means to these children and to the staff of the clinics. We ask you to join us this holiday season.



SPONSOR A HOLIDAY SMILE



Make checks payable to **AYJ Fund**

I would like to sponsor _____ HOLIDAY SMILES at \$25.00 each.

Total donation: \$ _____

Name _____

Address _____

Mail to AYJ Fund 201 Eagle Street North Adams, MA 01247

Or make donation on www.AYJfund.org



All donations are tax deductible

AYJ FUND CLOTHING LINE

Find our AYJ clothing line at www.AYJfund.org or scan this code below.

AYJ FUND CLOTHING LINE

We're launching our AYJ Fund Clothing line available through our AYJ Fund website. We are excited to work with Becks Printing in North Adams to make this possible. Orders can be placed at any time.

All of these items and more are available for purchase



WAYS TO SPREAD SMILES THIS HOLIDAY SEASON

- ♥ Make a donation to our Holiday SMILES Campaign and brighten a child's holiday.
- ♥ Purchase an AYJ Fund clothing item for a holiday gift.
- ♥ 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 holiday gift for someone special. We'll create a card you can give to let them know of this special gift.
- ♥ 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.

