



The AYJ Fund was created in honor of Anna Yan Ji Arabia, who was diagnosed at age 13 with gliomatosis cerebri (GC), 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.***

**AN EXCITING 2024**

2024 is moving fast and so is the AYJ Fund. We started the year with a fabulous celebration of our 10<sup>th</sup> Anniversary as a 501(c)(3) nonprofit foundation supporting children with cancer.

In looking back over the past 10 years, we were overwhelmed with our wonderful supporters, so many special moments with our AYJ Kids, and four international research conferences that have led to advances in research, which move us closer to an effective treatment, and, one day, a cure.

This year, we also celebrated in Boston with a fabulous Wine, Chocolate and Craft Beer Tasting, our “Once Upon a Dream” children’s concert in North Adams, Superhero Week at the Jimmy Fund Clinic at Dana-Farber Cancer Institute, and so much more.

This newsletter is filled with photos and stories of very special children and of many friends who are helping us make a difference for too many children with cancer.

*Kathy + Joe*



**IN THE FIGHT OF HER LIFE**

Throughout the past ten years, we have connected with hundreds of children with cancer and their families. We have heard exciting results of stable MRI scans and have helped fund End-of-Treatment celebrations. We have also experienced, along with many parents, the devastation of being told their strong and beautiful child has a diagnosis of cancer. Throughout this time, we have met the most courageous, kind, brilliant and fun children and young adults who bring us joy by meeting and getting to know them.



One of these very special people we feel blessed to have connected with is Carrigan Nelson. We met Carrigan at the Strong Little Souls Gala in Pittsfield in May. Carrigan had received an AYJ Fund SMILES pack, and we were excited to meet in person. Although



Carrigan has had five long years of treatment for osteosarcoma, including radiation, chemotherapy and multiple surgeries, including an above-the-knee amputation, the tumors in both lungs are now growing again. Carrigan has no further local treatments available, and has been approved for a clinical trial using a new CAR T-cell therapy. Carrigan faced additional heartbreak when

her insurance was not accepted by the hospital. She was told she needed to pay out-of-pocket \$54,000 for the trial, plus the costs of the hospital admission, travel and additional expenses. Her care was delayed, but luckily after a difficult process they accepted her insurance and she will be starting the trial. The remainder of expenses are still her responsibility. Our AYJ Fund is happy to provide some support. If you are able to support her also by sharing her story, saying a prayer, making an additional donation, or support in any way you can, we have included a link below. In spite of previous lung surgeries, and now active tumors in both lungs, Carrigan continues to sing with her most beautiful voice, and spread joy and love wherever she goes.

<https://www.facebook.com/profile.php?id=100007771185291>

<https://gofund.me/d9f82af8>

### SUPERHERO WEEK

Each year, the Jimmy Fund holds a weeklong event to celebrate the superheroes that are treated at the clinic each day. This year the AYJ Fund took on the planning and decorations for this special celebration.



We planned daily gift bags, activity sheets, superhero snacks, craft activities, and we packed capes and masks, balloons, photo props, etc..

For the kids and the staff alike, it is one of the favorite weeks of the year at the clinic. We cannot think of anyone stronger and with more super powers than these children fighting cancer. Thank you to our supporters, packers and drivers who made this possible. Special thanks to Michelle Dion/Gimme Some Sugar, and Lisa Boyer for amazing superhero cookies.



AYJ Volunteers packing AYJ Superhero SMILES packs



Grammy-nominated musician Noah Kahan stopped in to the Jimmy Fund Clinic and played with the kids on our AYJ gaming Go Karts with one boy still sporting his superhero beanie.



*"Their most recent theme has been 'superheroes' which feels right because to me that is the only way to truly describe what they do, what they go through, and the strength they possess. I'll think about everyone I met yesterday for the rest of my life. Thank you for having me."* Noah Kahan, musician





**MORE AYJ SMILES**

**Princess Isabella**

Isabella is fighting leukemia and we heard she loved Princess Jasmine and unicorns. Her Mom shared she was so excited she “shrieked” as she opened her AYJ SMILES package. *“It made her day.”*



*“What perfect timing!!! Dirk had his 3<sup>rd</sup> brain surgery Monday and he was not feeling the best today. Boy O Boy did you guys brighten up this kid’s day!!! THANK YOU SO VERY MUCH”*  
Dirk’s Mom

**A Needed Getaway**

Kota has been fighting leukemia since July 2021. After long periods of time in the hospital, he was feeling better and his Mom wanted to surprise him and his siblings with a getaway to their favorite indoor water park.



Mom said they had so much fun and *“Thank you again for this much needed getaway.”*

**Kitty Cat Love**

Penelope’s smile warmed our hearts. She is 10 years old and fighting leukemia. She loves cats, and she loved this little one we included in her AYJ SMILES pack. “Made by Marjorie” sent adorable cat cards when she heard Penelope loved cats.



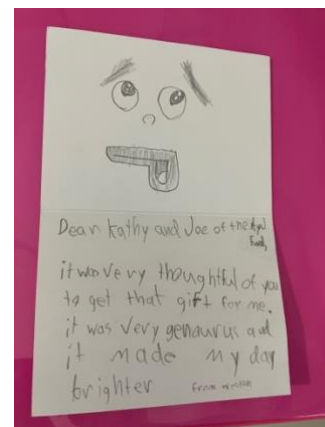
**Spring Smiles**

Each year, we celebrate Anna’s birthday by sending something fun to the children at the Jimmy Fund Clinic. This year we sent fifty “Warmies,” adorable stuffed animals which can be warmed in the microwave for a warm hug or chilled for cooling comfort. This photo of Liam shows how much the children loved them.



**Wesley**

Wesley lives in NH and is being treated at Dana-Farber. He is kind, strong and very creative. We love the thank you card he sent us!



**Carrigan**

We sent an AYJ SMILES package to Carrigan and included this fun princess crown. Although the package got delayed at the post office, she was thrilled to receive it at a time that she needed it most. Her special friend sported the pink princess crown for us!



**Perfect Timing**

Sebastian’s Mom shared that he had been having a rough couple of weeks battling his leukemia. She sent a note to say his AYJ SMILES pack *“Came at the perfect time. It definitely brightened up his day. Thank you so much.”*





## AYJ FUND'S 10<sup>th</sup> ANNIVERSARY CELEBRATION



We celebrated the end of our 10<sup>th</sup> year of the AYJ Fund supporting children with cancer. It was a very special evening as we gathered to thank all who have made this possible. We were amazed when we calculated that we have distributed 4,662 AYJ SMILES to children, and

thrilled to announce the total raised over ten years was over \$1.86 million, with \$1.39 million directed to funding brain cancer research to find effective treatments for these children who face such devastating diagnoses.

We played video messages from Jeff Greenfield, MD, PhD, of Weill Cornell Medicine and Mariella Filbin, MD, PhD, of Dana-Farber. The Massachusetts House of Representatives sent a proclamation of congratulations, thanks to Rep. John Barrett.

*"I really wish I could be with you in person to tell you about our latest gliomatosis cerebri research that has so wonderfully and amazingly been funded by all of you here...I wanted to extend my biggest thanks from all of us here in the laboratory, from all of my clinical colleagues, for your generous funds that help us push the envelope and move the needle for our patients."*  
 Mariella Filbin, MD, PhD

We thank all of our supporters who were able to join us, and all of those who were not with us, but helped us to reach these milestones. Special thanks to our generous sponsors Berkshire Catering, Moresi & Associates, Becks Printing and to friends West Package Store and Aladco Linen Services.

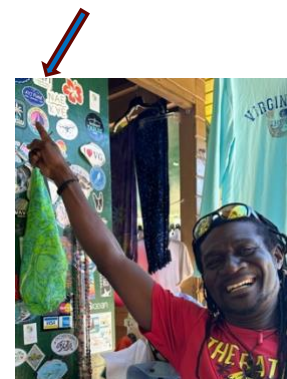


We showed a slideshow of many of our activities over the past 10 years. View it on our AYJ Fund YouTube page at: <https://www.youtube.com/@AYJfund>

### AYJ SIGHTINGS



Prof. Anthony Daly's MCLA class in Glendalough, County Wicklow, Ireland.



AYJ sticker in Virgin Gorda, British VI



Prince family in St. Croix



Kevin & Linda in Porta, Portugal

### PAM THE MEDIUM

Pam the Berkshire Medium hosted a session once again this spring to benefit AYJ Fund. We are grateful for her ongoing support and for sharing her special gift. The event sold out again. Watch for our 2025 date.

**PAM the BERKSHIRE MEDIUM**  
 Sunday March 10, 2024 12-2pm  
 Freight Yard Pub, North Adams  
**AYJ FUND BENEFIT**  
 AYJ Fund Smiles...Connections...Cures  
 Supporting children with cancer

**TICKETS \$50**  
at [AYJfund.org](http://AYJfund.org)



### KIDS HELPING KIDS

We met with the 7<sup>th</sup> grade Faith Formation Class of St. Elizabeth of Hungary Parish. They donated the proceeds of their Pancake Breakfast to the AYJ Fund, over \$500 to help support other children. Thank You!



**INSURANCE WOMEN AT WORK**

We were invited to speak about the AYJ Fund at a MA Association of Insurance Women meeting. We enjoyed sharing our story and the work we are doing to help children. They presented us with donations for the children that filled our car and our hearts.



**ABC CLOTHING GRANT**

ABC Clothing Shop on Spring Street in Williamstown is a popular stop for gently worn clothing. ABC stands for "A Better Community." With the support of Williams College and a

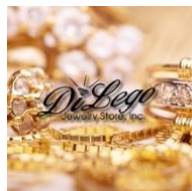
team of volunteers, this shop generates



proceeds which are donated to local non-profit organizations. This spring, the AYJ Fund received a \$2,500 grant. Stop by, check out their great items, and let them know you support the AYJ Fund.

**DiLEGO JEWELRY STORE**

We join our community in celebrating the retirement of the owners of DiLego Jewelry Store. In the last days of the store's 92-year history, they spread their love to the AYJ Fund again, with a \$500 donation to support our programs.



**ADAMS SNO-DRIFTERS**

The Adams Sno-Drifters, Berkshire County's first snowmobile club, is dedicated to keeping the sport of snowmobiling alive and active in Berkshire County. They are also dedicated to their community. They contacted us to hear our story and to make a donation to our AYJ Fund. Another wonderful local group.



**SERVICE ABOVE SELF**

We were so happy to hear that one of our princesses from our "Once Upon a Dream" children's concert and



Taconic High School Graduate Neveah Williams was chosen for the Pittsfield Rotary Club's Service Above Self Award.

Neveah received a \$200 award to be directed to a charity, and she selected the AYJ Fund as the recipient.

Neveah was first-runner-up in the Western MA Miss Teen contest. As part of the program, she selected the AYJ Fund as her Community Service Initiative, after volunteering with the AYJ Fund in the fall. Neveah honors her late brother Shavie, who we supported during his cancer journey. Neveah is off to Fitchburg State University next year and we wish her all the best.

**BRAIN CANCER AWARENESS MONTH, GC GLOBAL**

We recognized May as Brain Cancer Awareness Month, along with our partners around the world. The Franck un Rayon de Soleil Foundation created a social awareness campaign that we were happy to share to raise awareness about GC and other brain cancers. They adapted the campaign to different languages, foundation specifics and included photos of Anna and other children lost to GC. Global awareness is such an important part of increasing funding for GC research.



**WINE, CHOCOLATE & CRAFT BEER TASTING**



AYJ Fund was in Boston in May to host our popular Wine, Chocolate & Craft Beer Tasting. It was a great evening filled with family and friends, a great wine selection, a large assortment of craft beers donated by local breweries, and a great Silent Auction. We even had friends from Williamstown, the Wongs, surprise us, as their daughter Sarah works at the Presentation School Foundation location where the event was held. Thanks to all who joined us, donated items, bid and all who supported us.

Tim Chang, MD, and Kelly Cai of Dana-Farber's Bandopadhayay Lab of joined us and shared information on their current research on senescence in high-grade glioma brain cancers.



We enjoyed seeing Dolores and her twin sister Gabriella each week in church. They could also be seen having fun at the casino with her daughter Missy and Lollie.



Susan Zoltek was an avid walker who could be seen each morning with friends walking around North Adams. She retired from teaching in North Adams.



Jane Battersby was Treasurer of not only the City of North Adams, but also the North Adams Little League. She was active in MASS MoCA and a direct descendant of Susan B. Anthony.



Barbara Harpin was a CNA who retired to enjoy her family of 8 grandchildren, 17 grandchildren and 24 great grands. She lost a granddaughter to childhood cancer; we will always remember Sonya.

### ADAMS COMMUNITY BANK

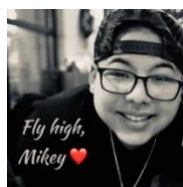


We are so grateful to Adams Community Bank and their amazing group of employees who continue throughout the year to support our community. Again this year, Adams Community Bank held dress down days, sold tags to post in their bank lobbies, and held Pace for a Purpose, and their annual Golf Tournament. Proceeds from all of these events



from January through June went to our AYJ Fund and to PopCares. During the second part of the year, we hope to attend their events that support Alzheimer's fighters.

### HONORING SPECIAL ANGELS



Our friend Mikey bravely fought gliomatosis cerebri for four years. Mikey's spirit will be in our hearts as we continue his battle against GC for all of these kids



Our friend Mason was a big brother, hockey player, chef and strong leukemia fighter. He used the laptop AYJ Fund sent to continue school remotely when he was not able to attend in person. We will remember his big smile and big heart.

### PODCAST

We had the pleasure of talking with Mark Levine about Anna and the AYJ Fund on his podcast "Help and Hope Happen Here" listen to our conversation here:



<https://www.buzzsprout.com/1218635/14291503>

And check out some of his other interesting podcasts about childhood cancer.

### MEMORIAL DONATIONS

Mary Hiser was a lover of animals and a great supporter of the AYJ Fund. She was active in our church, St. Elizabeth of Hungary in North

### COMMUNITY BAG PROGRAM



Thanks to all of our AYJ shoppers who picked up a bag at Stop & Shop during May. AYJ received \$1 for each of the 98 bags sold. Thanks to Stop & Shop for supporting the AYJ Fund.

### BIRTHDAY THANK YOU



Thank you to Allyson Moulds Dodge, Max's Mom and Benn Griffin, our BURCS friend, who asked for donations to the AYJ Fund on Facebook for their birthdays.

## ONCE UPON A DREAM

We moved our “Once Upon a Dream” children’s concert back to a spring schedule and it was bigger than ever. 35 high school students participated as princesses and other Disney characters to bring joy to all the children who attended. Thanks to our fabulous singers, Mary Scanlon and Serena Johnson; Pam and Mark Wilk for all of their work to make this possible; our wonderful students; and hard-working volunteers, MaryAnn King, who managed the ticket auction, and Trish Denault, who managed the bake sale.



## VISIT TO FILBIN LAB

Kevin, Linda and Keara Prince joined us for a visit to the Filbin Lab at Dana-Farber and a meeting with Mariella Filbin, MD, PhD, to receive an update on the GC research project that we are funding. We met two lab members working on the project, Rebecca Poetchke and Henrika Schaefer. They shared that one focus is to investigate the relationship between tumor cells and other normal cells throughout the brain.



## EXCITING GC RESEARCH PROGRESS

We met with our GC International research group in Boston when Mariella Filbin, MD, PhD, hosted Chris Jones, PhD, and Shauna Crampsie of ICR, London, David Castel, MD, of Paris, and Ilon Liu, PhD, of Berlin, to write up their GC research findings from the international GC research grant the AYJ Fund supported. We also discussed the GC research published by the SIOPE European group (link below) We are confident we are on the right research path. <https://www.icr.ac.uk/news-archive/scientists-uncover-new-treatment-pathway-for-rare-spider-web-childhood-brain-tumours>



Scientists uncover new treatment pathway for rare ‘spider web’ childhood brain tumours

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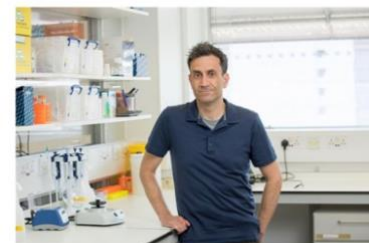


Image: Professor Chris Jones, Professor of Childhood Brain Tumour Biology at The ICR

## BFAIR SUPPORT FOR JULY 4<sup>th</sup> AYJ SMILES

Berkshire Family and Individual Resources (BFAIR) is a Berkshire-based agency dedicated to meeting the needs of people with disabilities. They reached out to support the AYJ Fund, and worked with us to put together our 50 patriotic AYJ SMILES packs we sent to the Jimmy Fund Clinic for distribution.





### ARE YOU RECEIVING OUR AYJ FUND MONTHLY UPDATE?



### AYJ Fund on VENMO

Did you know you can find AYJ Fund on Venmo for an easy way to make your donation?



### AYJ FUND CALENDAR



#### July

- ♥ 4 - Patriotic Smiles at Jimmy Fund Clinic

#### August

- ♥ 10 - BURCS Sweltering Summer Run - Pittsfield

#### September/Childhood Cancer Awareness Month

- ♥ Childhood Cancer Awareness Campaign
- ♥ 19-20 – BrainStorm Summit Washington D.C.

#### October

- ♥ 6 – Fall Foliage Parade

#### November

- ♥ LUMINAMA – Holiday window on Main Street, North Adams

#### December

- ♥ Holiday SMILES Project – sponsor a holiday gift for a child with cancer