



## 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 (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.***

### CHILDHOOD CANCER AWARENESS MONTH

We are so excited to share all that AYJ Fund has been involved in this summer: July 4<sup>th</sup> SMILES, a rainy golf tournament, our Brighton tasting event joined by ten Dana-Farber researchers, a trip to Weill Cornell Medicine, another to Dana-Farber's Filbin and Bandopadhyay's Labs, Octopus Garden's concert, and a sweltering BURCS race. We have been blessed.

We do not know how September comes so quickly each year, but it is Childhood Cancer Awareness Month and time for our AYJ GOLDEN SMILES CAMPAIGN. We are asking for your support for children facing a devastating cancer diagnosis that will forever change them.



Our North Adams Police Department is changing their patches gold for the kids, and you can purchase yours to show support for only \$10.

We will travel to London in September for our 5<sup>th</sup> International Gliomatosis Cerebri Conference, along with over 60 scientists and researchers. We are filled with gratitude that we have our AYJ Fund supporters helping to advance these research projects.



### AYJ's MCLA SUMMER INTERN



Hello readers! My name is Paige Dufur and I worked as Kathy's and Joe's intern for 11 weeks this summer. I am going into my senior year at the Massachusetts College of Liberal Arts (MCLA). I am incredibly thankful for all

that I have experienced, the people that I met, the work that I got to do. I am especially thankful for Kathy and Joe. I worked on tasks such as event advertisement, social media management, donation management, putting together SMILES, and more. I had the opportunity to increase my knowledge on pediatric brain cancer through various reading materials and videos that were provided to me, as well as the chance to attend a few webinars and board meetings. I think that the most rewarding part of my internship was seeing the smiles of the faces of children that received a SMILE that I put together (you can see some of them in the SMILES section on the next page!). Thank you, Kathy and Joe, for a great summer! ♥



**AYJ  
SMILES**



**AYJ  
CONNECTIONS**



**AYJ  
CURES**



## AYJ SMILES

### SANTIAGO



Santiago is local high school student and soccer star who was sidelined after being diagnosed with osteosarcoma. A huge Cristiano Ronaldo fan, we sent some Ronaldo swag, including a licensed shirt. His Dad said these brought big smiles to his face, and were greatly appreciated.

### ARIA GRACE



We love a birthday surprise, so when we heard Aria Grace was going to be traveling back to St. Jude's for her birthday, we helped to make it extra special with AYJ Birthday SMILES.

### PRESTON



Preston was on his way to a Ronald McDonald House when he received his AYJ SMILE. He will spend his days between there and the hospital for almost three months. Shhh! We are going to give him a surprise birthday party when he is done!

### AYJ SMILE LIGHTENING THE LOAD

*"A very special package arrived from you for Aubrey and we can't thank you enough! She has been having a really emotional week and the minute she opened the box, my sweet girl burst into tears... She wants me to tell you 'thank you so so much for my new PlayStation! I have been dreaming of having my own and I can't wait to share it with my friends at the hospital too!'"*

*"She has been in a deep depression and has been having panic attacks daily. You have given her something to focus on and escape with and it means the world. Thank you so much for bringing so much joy and happiness to Aubrey. Thank you for helping us not feel alone and for making the impossible possible for my girl. I never could have gotten that for her right now with all of the medical costs and surprise costs that occur being in the hospital."*

*Aubrey's Mom*

### EMILY & HER BROTHERS



Emily is 5 years old and very close to her older brother and her younger one too. We know cancer affects everyone in the family, so we included surprises for them too!

*"Thank you again so much. This really brightened our girl and her brothers' day!!"*

*Emily's Mom*

### CAMBRIA



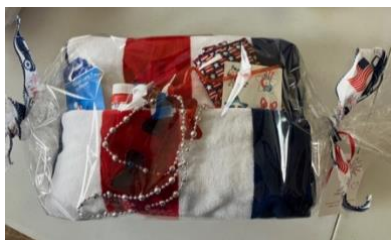
When 15-year-old Cambria was diagnosed with leukemia this spring, she knew that so many things would change. Time away from school and friends and so many hospital visits. But cancer can't change her great spirit, fun personality and her posing skills – she sent so many fun photos! This girl has it all!



## JULY 4<sup>th</sup> SMILES

July 4<sup>th</sup> is Anna's Auntie Mary's birthday and always a special day in our family. We love to share the celebration by sending patriotic-themed AYJ SMILES packages to the Jimmy Fund Clinic. We are grateful to our volunteers, who had fun putting these cute packages of a beach towel and lots of other fun patriotic items together.

We heard from the Jimmy Fund Clinic that the packages were so popular that they kept refilling them for the teens and they didn't have time to take any pictures!



## MISS MASSACHUSETTS PAGEANT

We are so proud of Neveah Williams, Miss Freedom Trail, who competed in the Miss Massachusetts pageant. She selected the AYJ Fund as her Community Service Initiative, after being one of our volunteers and princesses in prior "Once Upon a Dream" concerts and parades. Her talent performance was a powerful original poem about her brother Shavie, who died of childhood cancer.



## DRURY CIVICS CLASS DONATION

We were so honored that the AYJ Fund was selected as one of two local non-profit organizations that the Drury High School Civics students selected for class presentation and donation. Students researched, learned the missions and impact of non-profits, and then advocated with other students to select and recognize our work.



## ONCE UPON A DREAM

Our change in location this year to Drury High School for our "Once Upon a Dream" children's concert gave us extra space for new beautiful props made by Pam and Mark Wilk, with artist touches by Erika Pecor. This year's addition of the Bibbidi Bobbidi Boutique, with costumes for any child who wanted a costume or just a crown or wand, was a wonderful addition that brought special moments to so many. We thank Michelle Palumbo for this wonderful idea and all of her work to make it such a success.



Popular sing-a-long tunes were sung by Mary Scanlon and her son Matt, with support from Paul Oleskiewicz on sound. She had the room singing and

dancing and loving every minute. Trish Denault returned with her popular treats table, which was enjoyed by all.

Our princes, princesses, and all of our characters did an outstanding job of dressing and playing the part for the children who were wide-eyed with amazement. We love how the little ones dress up and scan the room for their favorite characters and run to them with joy.

You will get to see our fabulous princesses, princes and characters again on October 5 in the Fall Foliage Parade.



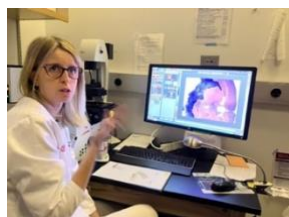




## AYJ CURES

### CBTP LAB FAMILY DAY

We visited Weill Cornell Medicine's Children's Brain Tumor Project (CBTP) Lab Family Day where Jeff Greenfield, MD, PhD, and Mark Soudwaine, MD,



presented research updates. One part we love is the tour of the lab, with the research scientists explaining their projects and answering lots of questions from the families. We viewed slides

that demonstrated the difference in how brain tumors grow, some concentrated in specific parts of the brain or brain cells, compared to gliomatosis cerebri (GC), which infiltrates many lobes of the brain even before diagnosis. Following the tour, we heard about exciting new projects focusing on advances in methods to get drugs into the brain, and new methods to analyze the components of each brain tumor cell.

Check out Anna's photo on the top row of the slide below.



### VISIT TO DANA-FARBER CANCER INSTITUTE BANDOPADHAYAY LAB

We visited Dr. Mimi Bandopadhayay, MBBS, PhD, and her staff of the Bandopadhayay Lab. Susan Chi, MD, Director of the Neuro-Oncology Program at Dana-Farber, joined us and shared with the lab how important it was to focus research on these rare tumors. We presented Dr. Mimi with



a donation of \$10,000 to support advancements in her brain cancer research.



### FILBIN LAB

During AYJ Fund's visit to Dana-Farber Cancer's Filbin Lab, we presented Mariella Filbin, MD, PhD, with the third and final payment of our \$1 million donation for GC research.

Dr. Filbin, along with Kuscha Tabatabai, who is focused on GC research, and Kevin Lu, who is working on a CAR T-Cell program, shared their research and insights.



"With state-of-the art technologies, we study GC tumors in extraordinary detail — from the genes they switch on, to the way their DNA is organized, to what the tumor cells look like inside the brain. Here's why that matters: although every cell in the body has the same DNA, cells can behave very differently depending on which genes they 'turn on.' This is what makes a nerve cell different from a muscle cell. Modern methods now allow us to read which genes are active. In the past, researchers could only measure this in bulk — that is, averaging signals across the whole analyzed tissue. But even tumors are made up of many different types of cells, and important details get lost when you only see the average.

"That's why we take a different approach: analyzing each tumor cell individually. This helps us identify which kinds of cells are present and what roles they might play; for example, which ones drive the tumor's spread or help it resist treatment. Using this approach, we discovered that GC tumors contain an unexpected mix of cell types normally found in the healthy brain. Some behave like nerve cells ("neurons"), while others mimic support cells ("glia"). Understanding this mix is essential to reveal weak spots that we can target with therapies.



"We are also exploring an innovative form of immunotherapy called CAR T-Cell therapy. We are working to determine the best ways to train these immune cells so they can detect and eliminate GC tumors effectively.

"Our goal is clear: to uncover the hidden rules behind GC's growth, identify its weaknesses, and translate that knowledge into targeted, effective treatments for children affected by this devastating disease."

## WINE AND RESEARCH UPDATES IN BRIGHTON

Our Wine Chocolate and Craft Beer Tasting event was held in Brighton (Boston) in April. The beer and wine were flowing and the assortment of chocolates divine, and we felt so much love in the room as we focused on honoring Anna and celebrating the work being done through the AYJ Fund to support so many children.

This event is always so informative and inspirational, as we are blessed to have scientists and researchers join us



and present their work. Joana Marques, PhD, a post doctorate fellow in the Filbin Lab shared, "For a long long time, people thought that cancer creates one cell and it multiplies and becomes more of the same, and this is a paradigm that has changed now. Now when we look at the cancer, we

see that actually it's made up of different cell types. These cell types have different functions which lead to some invading different parts of the brain, and others remaining apparently harmless until they are activated by other treatments."

Nico Poux, a PhD graduate student in the Bandopadhyay Lab shared "Finding ways to better treat cancer has been



my goal since childhood, starting when I was diagnosed with leukemia at age 6....Our dream as a lab is to be able to develop treatments so that every child with a brain cancer has a chance for a cure without any side effects." To the AYJ supporters, "Thank you all for everything

you have done to give hope and stand in solidarity with this community of patients, families, doctors, researchers and supporters."

Anna's cousin Megan Costa is a PhD candidate in the Silverbush Lab at UPenn in Philadelphia. Dana Silverbush, PhD, joined remotely to share their recent breakthrough on CAR T-Cell therapy.



"Normally when you think about therapy you think the drug itself is doing the work. But actually in the case of CAR T-Cell therapy in gliomas what we saw is that the

drug wakes up the immune cells that are already in the patient, but also can wake up non helpful immune cells...where the patient does much worse....What's really interesting is that you can help this mechanism. We are working on a combinational therapy to boost this result...to help wake up the good, the helpful immune cells and inhibit the non-helpful ones. This gives really important hope for this devastating disease."



Bandopadhyay and Filbin Lab researchers joined our AYJ event

## REFLECTIONS FROM OUR RESEARCHERS



APRIL

"This was my first year attending the event and it was wonderful. This event was an amazing mix of researchers and patient family and friends that are able to come together in a semi-intimate setting to

discuss science and celebrate the progress I research. But more importantly to remember the patients that inspired these events and the work that we do in the labs. These events are super important to inspire us in the lab to keep working hard even when things don't work because its much bigger than all of us. The chocolate and wine aspect were also a nice touch and a fun way to learn more about the community, since I have only lived in Boston for a few years. I look forward to attending the event again and hope that I can make any contribution to scientific research for children with brain tumors!"



JENNA

"I have been deeply moved by all the families who continue to work so hard to support research into pediatric cancers, even those who have tragically lost their own children. It is commonly

said that 99% of science is failure and, in the lab, we are constantly faced with experiments that don't work for a million possible reasons, mistakes, setbacks and troubleshooting sessions that can go on for days, weeks or even years. But when struggling with the inevitable frustrations of research, I'm reminded of the resilience and determination shown by the patients and families I have had the pleasure of interacting with. That is why organizations such as the AYJ Fund are so important to all of us in the lab — they give us a constant reminder of what we're striving for. And despite all the challenges, we really are starting to understand these tumors better and pinpoint their vulnerabilities. Progress is being made and I and the rest of Bando lab will not stop working until we have new and effective treatments for all children."



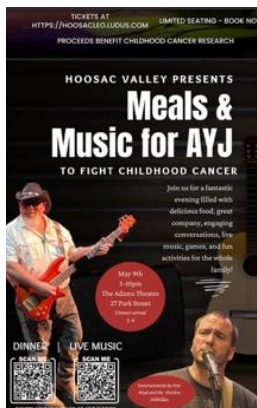
## ADAMS COMMUNITY BANK GOLF TOURNAMENT

The pouring rain did not deter the spirit of the golfers who showed up for the Adams Community Bank's Golf Tournament, which raised funds for the AYJ Fund, PopCares, and Strong Little Souls, all supporting those with cancer in our Berkshire Community.



## MEALS AND MUSIC FOR AYJ HOOSAC VALLEY LEO CLUB

A number of our AYJ Fund princesses from our Once Upon a Dream concert are also active in the Hoosac Valley High School Leo Club, a student club of the International Lions Club. They held an event at the Adams Theatre which included not only dinner, but also two different music programs. They outdid themselves, putting so much work into this program, selling tickets, marketing, preparing food, and serving dinners, all to support the AYJ Fund. What a wonderful evening.



## SWELTERING SUMMER ULTRA

The BURCS (Berkshire Ultra Running Community for Service) are a very special group of athletes who each year hold a Sweltering Summer Ultra Marathon race at Clapp Park in Pittsfield. This year again they donated the proceeds to the AYJ Fund, over \$6,000! This year certainly was sweltering, as they ran lap after lap for 8 hours, a number running over 40 miles! Wally the Watermelon is always a hit as runners alternately carry the watermelon to raise even more funding for childhood cancer. This year six racers carried two special watermelon beads as part of the Beads of Courage program. One bead is then sent to a child in treatment to add to their Beads of Courage. So much love, so many friends, such a special day, and so much sweat! We love you all!



## MCCANN TECHNICAL SCHOOL

AYJ Fund was honored as the school year ended with a donation from the newly formed SWARM student life committee at McCann Technical High School. This new student group chose to support us through the Dress Down drive as part of Spirit Week. We are proud of these students and their efforts to support the AYJ Fund.



## AYJ SIGHTINGS



Jake Fishing in North Adams



Jim and Kevin Prince at a Golf Tournament



Joe relaxing in Provincetown



Aidan settling in Seattle, WA



## OCTOPUS GARDEN

If you were lucky enough to join our Octopus Garden event at Bounti-Fare in August, you are likely still singing Beatles tunes, like we are.

When our friend Bob Balawender contacted us and offered to do a fundraising event to support the AYJ Fund, we were honored. When he told us he was getting local musicians together and forming the band "Octopus Garden" and they would be playing all Beatles Music, we were all in!



Local musicians Jay Fruet, Dan Hamilton, Mike Parsons, Wayne Tremblay, and Jim Stankiewicz joined Bob to complete the band, with Chuck Poulton on sound. They brought out the baby boomers and more, and we sang and danced the night away. We heard so many tell us that we should do this again, because it was so much fun!



## CHILDHOOD CANCER AWARENESS MONTH GOLDEN SMILES CAMPAIGN

The Mom of a child with cancer who recently received one of our AYJ SMILE packages shared that, "This journey has been so heartbreaking and unpredictable, but it's the support and love from this community that keeps us going."

September is Childhood Cancer Awareness Month, and AYJ Fund is launching our AYJ Fund GOLDEN SMILES Campaign to continue to make a difference for these children and help keep these families going. We receive new applications weekly from these families facing a devastating cancer diagnosis for their child.

Now more than ever, children with cancer need our support to assure that research continues to find effective treatments that are not yet available for so many kids. This research was already underfunded by both the pharmaceutical industry, and the federal government, but now it is getting even more challenging. We have real concerns that federal cuts to The National Institutes of Health (NIH), will slow the pace of research, impact clinical trials, and lead to fewer new researchers in the field.

AYJ Fund has funded \$1.5 million to support childhood cancer research, and although this is a significant number and we are so grateful to all of your donations that made this happen, we need to fund more research now to assure it continues to advance.

Please help us to continue this critical research and provide more AYJ SMILES through a donation to our AYJ Fund GOLDEN SMILES Campaign.

*Kathy + Joe*

## AYJ FUND GOLDEN SMILES CAMPAIGN

Please make Check payable to **AYJ Fund**

Enclosed is my tax-deductible gift of:

\$50 \_\_\_\_ \$100 \_\_\_\_ \$ 250 \_\_\_\_ \$ 1,000 \_\_\_\_ other \$ \_\_\_\_

No donation is too small.

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Mail to: AYJ Fund 201 Eagle Street North Adams, MA 01247  
You can also donate online at [AYJfund.org](http://AYJfund.org) or AYJ Fund on Venmo



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





## SUPPORT MEGAN'S MARATHON RUN FOR RESEARCH



### MEGAN COSTA

I'm running the 2025 Philadelphia Marathon for the American Association for Cancer Research (AACR) in memory of my cousin Anna, who died from a rare brain tumor when she was only 16. At the time, no research existed for her cancer—no treatments, no options, no hope.

Now, as a PhD student in cancer research at UPenn, I have dedicated my career to changing that reality—for Anna, and for every patient who deserves better. Running through the streets of Philly, I'm channeling my inner Rocky to fight for a future where every cancer has a cure. Please consider supporting my run and this vital cause.

<https://donate.aacr.org/participants/Megan-Costa>

## AYJ FUND CALENDAR



### September – Childhood Cancer Awareness Campaign

- ♥ Golden SMILES Campaign
- ♥ September 9 Childhood Cancer Proclamation, North Adams City Council Meeting
- ♥ September 17-19 International GC Conference, London

### October

- ♥ October 5 North Adams Fall Foliage Parade

### November

- ♥ Wine, Chocolate & Craft Beer Tasting, North Adams  
Date TBD

### December

- ♥ **AYJ HOLIDAY SMILES** – Sponsor a gift package for a child with cancer for \$25

### AYJ FUND on VENMO

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

