



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.



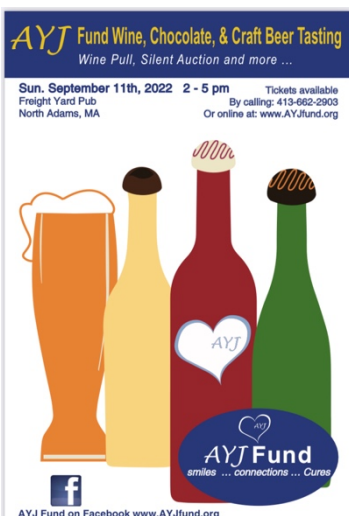
AYJ FUND 2022 GOLDEN SMILES CAMPAIGN

We have so much to share in this newsletter: children we have connected with through our SMILES program, advances in research we are currently funding, and the launch of our largest fundraising campaign to date. We are making an impact, thanks to all of you, and we are inspired to continue to make a difference for children with cancer, and to reach for gold.

Gold is the color for childhood cancer awareness. Gold was selected because "children are more precious than gold." We will be spreading gold this September—Childhood Cancer Awareness Month—throughout our community and beyond, and hope you will join us in any way you can.



On September 11, we will hold our first-since-2019 AYJ Fund Wine, Chocolate & Craft Beer Tasting in North Adams. We cannot wait to see everyone together again. We also plan for a Boston version of this event in Spring 2023.



Kathy + Joe



GC RESEARCH UPDATE

From the time we heard our doctors at Dana-Farber tell us that there was no research being done on gliomatosis cerebri, we knew this had to change. In the almost ten years since that time, we have worked with the brightest researchers throughout North America and Europe to advance research.

At the 3rd International Gliomatosis Cerebri Conference, the AYJ Fund, together with four organizations like ours, announced we would be funding a multinational grant. The grant proposal "Targeting cellular connectivity in gliomatosis cerebri" won the funding for the grant. This research project (GC-PY) is led by Chris Jones, PhD, of the Institute of Cancer Research, London, in collaboration with Mariella Filbin, MD, Dana-Farber, Boston, Maria Vinci, MD, Ospedale Pediatrico Bambino Gesù, Rome, and David Castel, MD, Gustave Roussy, Paris.



We received the 1st year interim report in May, with a complete analysis of the research work, graphs of results and goals moving forward. The report included this summary:

"We are a group of researchers studying childhood brain tumours from the USA, UK, France and Italy, who have come together to study gliomatosis cerebri (GC) as a result of the GC-PY funding. This is also supported by a PhD student (Shauna Crampsie), primarily based in the UK, but also spending time in the other labs. Although we have been delayed by Covid restrictions,

we have made progress in three key areas during the first year of funding

- *In London, Paris, and Rome, we have attempted to establish 15 new GC cell lines. Upon careful analysis, many have turned out not to be cancer cells at all, and we are trying to understand why this is the case, what the cells may be, and how to improve our methods. We nonetheless have several new GC cell lines for further experiments.*
- *Shauna has spent time in Boston, and completed one of our main experimental goals, the single cell RNA sequencing of 30 GC tissue samples. This allows for us to examine tens of thousands of GC cells individually, to see what subpopulations may exist, how they interact, and what other non-cancerous cells may be part of the tumour sample which may also play a role in GC biology. We are currently analysing these results jointly across our labs.*
- *To look at some of the results we get in the above data in more detail, in Rome we have been developing techniques to look at many specific markers in GC tissue samples at the same time. This is working well, and Shauna is spending the summer in Rome to include some new markers, and to apply these techniques to GC samples."*

CART T CELL RESEARCH UPDATE

Groundbreaking DIPG brain cancer research is also occurring at Lucile Packard Children's Hospital at Stanford University, California utilizing a patient's own cells. The AYJ Fund is helping to fund the expansion of this clinical trial to reach more patients. The scientific journal, *Nature*, published an article on this research and shared the story of Jace Ward, one of our AYJ Fund friends. "We see significant anti-tumor activity with these CART-T cell therapies in this dreaded disease." Although the research team has yet to achieve a cure

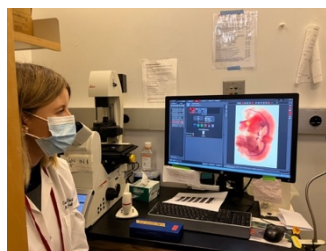
"The findings are a hopeful sign for many types of brain tumors, not just this one."

for this type of glioma, they consider their findings a milestone. We honor Jace's fight through our support of this Clinical Trial.

nature
International journal of science

CHILDREN'S BRAIN TUMOR PROJECT FAMILY DAY

We spent an informative day at Weill Cornell Medicine in NYC in April at the Children Brain Tumor Project's (CBTP) Family Council Meeting. Families received

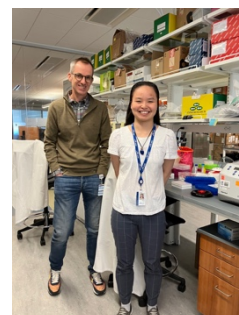


information on brain cancer research advancements being achieved in the CBTP Lab. The day started with a tour of the lab discussions with individual researchers.

We were also able to view new images of brain tumor cells and how they invade the healthy brain. Exciting updates from Jeff Greenfield, MD, and Mark Souweidane, MD, followed.

VISIT TO THE VERHAAK LAB

We were invited to tour the Verhaak Lab at Jackson Laboratory in CT, and spend time with Roel Verhaak, PhD, our niece Megan, and other researchers. We learned about the important brain tumor research being done in this lab on ecDNA, a type of DNA which carries cancer-causing genes and contributes to chemotherapy resistance in gliomas. Our visit reinforced the importance of continuing to fund brain cancer research.



KAILYN'S TISSUE DONATION

Recently a Mom of one of our GC angels, Kailyn, reached out to us with a wish to include Kailyn's tissue in current GC research. Brain tissue is essential for advancing research. Tissue is obtained either at the time of a biopsy or post death.



Most tissue samples are preserved and stored in hospital labs. Donating tissue is a very emotional experience for families. We are grateful to Kailyn's Mom for this important donation; we were able to assist with the tissue being sent from the hospital lab in Canada to the Filbin Lab at Dana-Farber, so it can be used for advancing GC research.

"My daughter will be smiling down from heaven...The more tissue that is donated, the more research can be done."
Kailyn's Mom

ADAMS COMMUNITY BANK PARTNERSHIP

Adams Community Bank has had a very busy spring supporting cancer patients in the Berkshires by partnering with our AYJ Fund and our friends at Pop Cares. Their employee team held a ribbon campaign, a Pick Your Pace for Purpose Walk, Run or Hike virtual event, a Golf Tournament, and more, all to raise funds for local cancer patients. We were overwhelmed by the generosity of our local businesses and individuals. Bank President Charlie O'Brien presented the AYJ Fund with a check for \$14,441.42.



We are also grateful to Cutting Edge Fitness of Adams and owner Aimee Sinopoli, who donated \$5 for every donation received through this fitness center for Adam's Community Bank's Pick Your Pace for Purpose event, raising an additional \$700 for the event.



VETERANS SUPPORTING AYJ CHILDREN



The AYJ Fund received a donation of \$2,000 from the North Adams Vietnam Veterans of America Chapter 54. Thank you for your generosity and your service.

PAM THE BERKSHIRE MEDIUM



The snowstorm couldn't stop Pam the Berkshire Medium from connecting with our loved ones and providing special moments for so many at our first in-person event in over two years! Thanks to everyone who came, those who donated, to Freight Yard Pub, and to Pam for sharing her gifts with us.

SUPPORT FOR CHILDREN WITH CANCER IN UKRAINE

When the war broke out in Ukraine and we saw pictures of children with cancer being cared for in the basements of Ukrainian children's hospitals, we knew we had to help these children who were fighting two battles: the war on their country and their war with cancer. We vetted nonprofit organizations operating in Ukraine, and found that the Tabletochki foundation had been serving these children for years



and had partnered with St. Jude Global's SAFER Ukraine. SAFER Ukraine was a humanitarian effort launched after the

invasion to provide safe passage for childhood cancer patients and their families.

Thanks to so many of our supporters, the AYJ Fund was able to send \$5,500 to the Tabletochki Foundation to assist these children and their families in crisis and help them continue their treatments in other safe countries.

We received this grateful message from the foundation:

*"Dear Kathy,
We wanted to let you know how much we appreciate your support of Ukrainian children and Tabletochki Foundation. ❤️ 🇺🇦"*

When we see how much urgent help children receive thanks to you, we feel boundless gratitude to you and your team. Your generosity and kind words give us confidence that no Ukrainian child will be left alone in this cruel war.

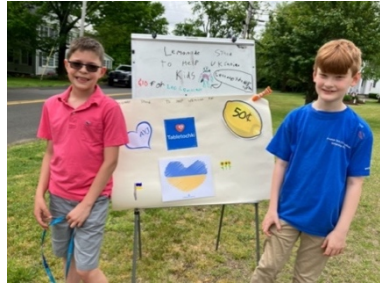
Today, we wanted to share Tabletochki's quarterly report to show the impact donors such as AYJ Fund make. Thanks to tremendous international support, in the first weeks of the war, Tabletochki helped to evacuate nearly 800 families with children with cancer to the world's leading clinics in the US, Canada, and Europe. These children continue their life-saving treatment in safety!

*With faith in Ukraine,
Olga and Tabletochki team ❤️💛*

*"We feel boundless gratitude to you and your team"
—Olga and Tabletochki team*

LEMONADE STAND FOR UKRAINE

When Tage Flowers turned 10 years old, he thought of others instead of gifts for himself, and held a lemonade stand to help children with cancer. Tage had heard the AYJ Fund was raising funds for Ukrainian children with cancer, and he decided that was where he wanted the proceeds to be directed.



With the support of his friend and family as well as all who purchased lemonade and snacks, Tage raised \$500 to help these children. We are

grateful for his hard work, creative marketing and successful fundraising effort. Well done Tage, and Happy Birthday!

GIRLS ON THE RUN

Clarksburg Elementary School's Girls on the Run program held a lemonade and bake sale to support local children with cancer through the AYJ Fund. These girls raised an amazing \$800 through this event! Girls on the Run is a national program that incorporates running along with service learning and empowerment programs. It was wonderful to meet these girls who definitely are demonstrating the values of this organization and the best of young students today.



ONCE UPON A DREAM PRINCESS CHILDREN'S CONCERT

After two years delay due to COVID, we were thrilled to welcome our princesses and all the little princes and princesses who came out for our Once Upon a Dream concert. Thanks to St.



Elizabeth of Hungary Parish in North Adams for our new location, and the efforts of AYJ Fund Board's own Pam Wilk, and all of our volunteers for making this such an enchanting day.

The music of Samantha Talora



and Ron Ramsay had the children singing along and dancing to the popular children's music. Ron's students Jennie Collins, Lelia Gillespie, Cate, Claire and Cora Welch blessed us with their beautiful voices. We enjoyed them so much.



PRINCESS PARTIES

In addition to walking in the Fall Foliage Parade, and spreading smiles at our AYJ Fund Once Upon a Dream princess concert, our princesses found the time to celebrate two very excited little princesses and surprise them at their birthday parties.



Thanks to our very busy princesses for volunteering their time, and to these families for their donations to the AYJ Fund.



FINLEY'S BACKYARD SMILES

Two-year-old Finley will be spending more time at home this summer to avoid crowds during her treatment. AYJ Fund sent some fun backyard toys so she wouldn't miss out on any summer fun.



"We received Finley's gifts in the mail this weekend, including the Elsa wig! What an excellent weekend she had! We had a blast playing outside with all her new toys. She truly loves each and every item! I feel like any words I say can't fully express how grateful I am to you. I am getting emotional as I write this email and I'm sending you a big hug. Thank you from the bottom of our hearts."
Finley's Mom

SPRING SMILES AT THE JIMMY FUND CLINIC

We love to celebrate Anna's birthday in April with a special fun day for children in the Jimmy Fund Clinic who are undergoing treatment. This year, we sent beautiful yarn wigs and beanies from the Magic Yarn Project organization. These beautiful crocheted wigs brought so many smiles to the clinic.



BERKSHIRES ULTRA RUNNING COMMUNITY for SERVICE (BURCS)

Our friends at BURCS are directing proceeds from their Sweltering Summer Ultra & Marathon on August 13 to the AYJ Fund. We will be there to cheer them on in amazement of their athletic ability and generous spirit.

#CARTERSTRONG

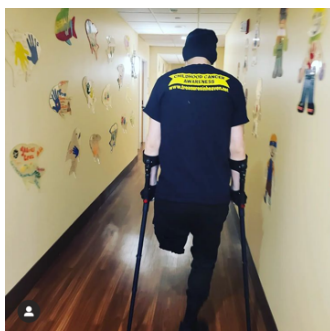
Carter was diagnosed in the fall with a rare form of leukemia. He spent 204 days away from his home in the Berkshires, at Children's Hospital Boston. AYJ Fund sent a number of fun SMILES gift packages, including this Flash hat. Carter surprised us with this wonderful syringe art canvas he sent as a Thank You! Carter still has a long road ahead and continues to amaze us.

#CarterStrong



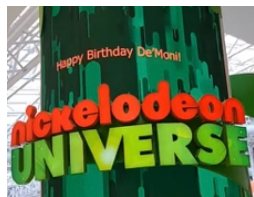
WALKER'S JOURNEY

After a tough fight with osteosarcoma, Walker had to have a partial leg amputation. Knowing how important a fun distraction is during these times, AYJ Fund filled Walker's wish for a Nintendo Switch. #WalkersJourney



KEEP SMILING DE'MONI

AYJ Fund was happy to help De'Moni celebrate his 10th birthday with a weekend at American Dream in New Jersey. Once the team at American Dream heard De'Moni was coming, they welcomed him with his name on the marquee and created a weekend full of amusement rides, special access for the weekend, and a behind-the-scenes tour of the aquarium and Legoland. Once home, as De'Moni developed more challenges walking, his wish



was for a go-cart. We found a two-seater so his Dad could help De'Moni navigate, and enjoy the fun with him. De'Moni has since become an angel, so it was very special to us that we were able to create these smiles during this most difficult time.

BIRTHDAY THANK YOU'S

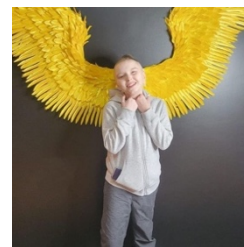
Birthdays are always a wonderful day to celebrate, and we are grateful to both Fran Maruco and Benn Griffin, who celebrated their birthdays by asking for donations to the AYJ Fund instead of gifts for themselves. We received \$1,500 through these generous gifts. Happy Birthday! Thanks to all who donated.



AYJ ANGELS

SILAS

Sweet young Silas was diagnosed with CG like Anna, and he fought this devastating brain cancer bravely, with heart, and a love of silliness!



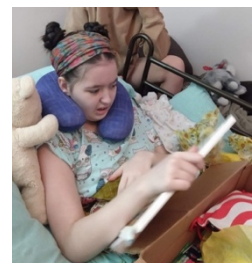
TIM

Our friend and neighbor joined Anna in heaven after a long battle with lung disease. We were honored that the AYJ Fund was chosen for memorial donations.



ELLENA

16-year-old Ellena was also diagnosed with GC this year, and became an angel a short few months later. She is pictured here opening her AYJ SMILES gift pack.



DE'MONI

Full of fun and excitement, De'Moni is pictured here on his trip to American Dream. DIPG is a devastating brain cancer, similar to GC, that still does not have a cure.



VIDEO GAMING GO KARTS

In our constant search for new ways to help children in treatment, the AYJ Fund discovered Gamers Outreach. This organization believes that, "Through gaming, kids can explore worlds, connect with others, express creativity and most importantly—simply have fun." AYJ Fund planned to purchase two of the organization's GO Karts, portable video game kiosks built specifically for hospitals, for the Jimmy Fund Clinic, Boston and Weill Cornell Medicine, NYC. AYJ Fund Board member Jim and his wife Kathy Whitney generously funded additional GO Karts for the Jimmy Fund Clinic.

These will be arriving shortly and will be providing lots of fun during long days of treatment.



SEPTEMBER IS CHILDHOOD CANCER AWARENESS MONTH



The AYJ Fund is going gold in September because children are more precious than gold.

CHILDHOOD CANCER FACTS:

- ♥ Every day, 42 kids are diagnosed with cancer in the United States.
- ♥ Childhood cancer is the #1 cause of death by disease in the US. Pediatric brain tumors are the leading cause of cancer-related death among children and adolescents.
- ♥ Childhood cancer receives only 4% of US federal cancer research funding. Our children deserve more than 4%.
- ♥ Five children die each day in the US from childhood cancer.
- ♥ Despite advances in cancer, some types of cancer remain incurable, including GC and DIPG brain cancers.
- ♥ Globally, a child is diagnosed with cancer every 80 seconds.

These are not only statistics, these are children. Too many of them are children we know. Throughout September, we will spread awareness of childhood cancer and do all we can to help these beautiful, strong fighters.

AYJ FUND GOLDEN SMILES CAMPAIGN

We see pure joy in the faces of the children and families we have helped. It is as precious as gold when we see them having fun, and distracted from painful procedures and hours and days, months or years in treatment. We ask that you join us in bringing more smiles to these children fighting the battle of their lives, for their lives.

There are too many children's cancers like Anna's, for which there are no treatments and therefore no cures. Too many children that we have connected with have died. The AYJ Fund believes in our hearts that this is as unacceptable in 2022, as it was in 2013 when Anna's cancer made no further treatment possible. We are committed to making a difference. We are committed to finding effective treatments and supporting research that will lead to discoveries that will make a difference for these children.



Won't you join us in making this happen? This Childhood Cancer Awareness Month, we hope to raise more funds than ever before, so that we can continue to bring joy to these precious faces and bring this research to the next level. Research is costly, but these children deserve everything you can find in your hearts to support them.

Thank you in advance for your support.

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 or AYJ Fund on Venmo





AYJ FUND LOGO WEAR IS BACK!

Our popular clothing line of AYJ Fund sweatshirts, T-shirts, vests, jackets and more is available once again for a limited time online. These items are produced through Beck's Printing in North Adams and all proceeds support the AYJ Fund. We decided to launch the line every few months. We will announce through our social media channels when the logo wear will be available for purchase. Thanks to all who have been sporting our AYJ Fund clothing. We love to share photos of your wearing AYJ Fund gear, so please continue to send them and you may just find yourself in a future newsletter!



WAYS TO SUPPORT CHILDHOOD CANCER AWARENESS MONTH

- ♥ Follow the AYJ Fund on Facebook, Instagram, and Twitter, and share our posts.
- ♥ Share this newsletter with a friend.
- ♥ Make a donation to our AYJ Fund Golden Smiles Campaign for children with cancer.
- ♥ Join us in advocating for children with cancer when we post legislative initiatives that need your support.
- ♥ Make a donation to the AYJ Fund as a birthday or memorial gift for someone special. We'll create a card you can give to let them know of this special gift.
- ♥ Select an item from our AYJ Fund Amazon Charity List next time you place an order from Amazon.
- ♥ Sign up for AYJ Fund on Amazon Smile – AYJ Fund will receive a percentage of will receive a percentage of all year long.

