

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 SMILES IMPACT

Thank you to all who helped to make this September our most impactful Childhood Cancer Awareness Month yet. Our AYJ Fund Golden Smiles Campaign raised over \$18,000 to support children with cancer. In total, with our additional activities throughout the month which you will read about in this newsletter, we raised a total of over \$30,000. We are grateful to each one of you who participated in any way to make



this possible, to raise awareness and funds for these brave fighters.

We were so excited to hold our first-since-2019 AYJ Fund Wine, Chocolate and Craft Beer Tasting in North Adams. It was wonderful to see so many friends gather

together in person, in support of children with cancer. We thank all of our local businesses who helped us to provide wine, beer, chocolate and delicious goodies, and all who donated to our auctions.

We are now actively planning our AYJ Holiday SMILES Project. We hope you will join us and sponsor one or more Holiday SMILES. We will be providing gifts and gift cards for children who will be spending much of their holiday season receiving treatments and scans and visiting doctors and clinics instead of friends and



family. Each sponsorship brightens the holidays for these most deserving children.

Kather & Joe

CHILDHOOD CANCER AWARENESS – AYJ GOLD!!

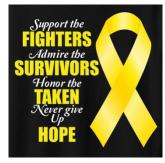
September was Childhood Cancer Awareness Month, and the AYJ Fund was very busy going gold to share



Anna's story, and raise awareness for all of the thousands of childhood cancer fighters, survivors and angels.

We started the month with North Adams Mayor Jennifer Macksey presenting Kathy and Joe with a Childhood Cancer Proclamation at the North Adams City Council Meeting.

Massachusetts Museum of Contemporary Art (MASS MoCA) turned its iconic installation of upside down trees gold throughout the month. AYJ Fund thanks North Adams for their support of children with cancer.







NAPD SUPPORTS CHILDHOOD CANCER

Our North Adams Police Department has always been a strong supporter of the AYJ Fund. This year, they



went gold for Childhood Cancer Awareness Month by wearing specially created police patches sporting gold ribbons and Childhood Cancer Awareness. They both wore these patches and sold them. We thank the NAPD and all who purchased

these patches. We heard from childhood cancer families as far as California and Texas how much it meant to them. NAPD raised \$ 1,340 for the AYJ Fund.



SVMC CHILDHOOD CANCER AWARENESS ANGELS

Southwestern Vermont Medical Center (SVMC) recognized Childhood Cancer Awareness Month this year with many of our staff wearing gold. Our wonderful food services staff prepared gold ribbon cookies, lemonade and bananas and our staff created cards to send to children being treated at Dartmouth-Hitchcock Medical Center. We also honored all children connected with our SVMC community.





DAVID ORTIZ BASEBALL RAFFLE

Thanks to AYJ Fund Board member Pam Wilk, AYJ Fund was gifted a signed baseball at the Red Sox Game honoring Big Papi's induction into the Hall of Fame. Congratulations to lucky winner



Barb Pecci and thanks to all who purchased tickets.

MAKING A SPLASH FOR KIDS WITH CANCER

Two cancer Moms from Pittsfield, Christen Simmons and Stephanie Maschino, held a Dunk Tank fundraiser at the Pittsfield Walmart to "Make a Splash" and raise funds for children with cancer. Signs featuring survivors, fighters and fallen angels lined the parking lot. AYJ Fund joined in the event, sharing information



and making cards for children with cancer.



SNEAKER DISPLAY at CUREFEST

Anna's sneakers were a part of an impactful display at the base of the Washington Monument in D.C. during CureFest for Childhood Cancer. 1,800 pairs of shoes worn by children who died of cancer paid tribute to them. Thanks to Strong Little Soul's Madison Quinn, who located Anna's sneakers and sent us these photos.



AYJ FUND WINE CHOCOLATE & CRAFT BEER

A number of people went the extra mile to ensure this event was a success. From a last minute beer delivery by Chris at Wandering Star on his way to the airport, to Elise Prince filling in as wine pourer for Balderdash

Cellars, and Freight Yard Pub assuring all went well, to our professional bartenders – we thank you all.



MEDICAL MATTERS WEEKLY with DR. FILBIN



with DR. TREY DOBSON

Mariella Filbin, MD, PhD, a leading brain cancer researcher at Dana-Farber Cancer Institute, joined Southwestern Vermont Medical Center's Chief Medical Officer, Trey Dobson, MD, to discuss childhood brain cancer research on *Medical Matters Weekly*, SVMC's multimedia weekly medical show. Dr. Filbin is currently conducting GC research funded by the AYJ Fund and our GC family foundation partners.

How did you get interested in research?

And it was all based on a little girl ... I was a young medical student, and there was this little girl and I will never forget her. I learned she had a tumor called DIPG or Diffuse Intrinsic Pontine Glioma ... And when I asked what this tumor was and what we were going to do to treat her, I just heard, "There's nothing we can do." So, that was a fact that I just could not just accept, and since then, I've been working on this disease and many other terrible tumors where we don't have answers yet, and I believe that will change in my lifetime.

Why is it more difficult to treat pediatric brain cancers?

What drives cancer in kids is very, very different from what drives cancers in adults. And that has many implications, because it not only means the classifications are different, it also means that the origin is different, and it also means we have to treat them differently. We can't just take drugs from adults and assume it will work in kids. And, sure enough, many of the clinical trials we did in children did not work because they were based on adult tumor types and not specifically tailored or targeted toward pediatrics.

On the single cell transcriptomics research in your lab

"What it means is that you look at every single cell within a tumor, rather than at the tumor as a whole. Instead of grinding up a tumor piece (I know that sounds a little gross) and sequencing the mixture, you sequence every single cell with the thought that maybe the answer lies in the subtle differences between the tumor cells and the normal cells that are mixed in there...I always had this thought in my mind, if I sequence single cells of the tumor, maybe I will find that stem cell that that drives the whole thing and if I knew what that cell was all about, I could hopefully target that. I adapted the methodology, the single cell sequencing, to very precious brain tumor samples from here, out of the OR, and sure enough, we found that in DIPG, there was a difference...What we learned in the lab is now moving to the clinic.

How do you deal with the sad, difficult patient situations?

It's a great question. And you know, once I started having kids, everything became even harder. What I experience is you see yourself in many of the situations right, you see your children in those children and you see yourself as the Mom sitting there with you.

And it doesn't get easier at all over time, only harder ... So this pain never goes away. And it motivates me though, to come back to the lab. I even take people

"I do believe that at some point we will crack that stone and really, really make some progress toward making it a chronic disease, or even a cure. We will see that in my lifetime, is my guess."

Mariella Filbin, MD, PhD

from my lab with me when I round on my patients, just so that they see why we're actually doing this. This is not for papers. This is not for grants. This is because we want to have a true impact on our patients. And if we don't do it and nobody else will do it, like we'll have to do it. I feel very, very strongly that that's my life's mission, my career's mission. And, so even though it hurts, it's very important for me to continue to do that, despite the pain.

You also have another passion: fundraising for research?

I'm very passionate about philanthropy. First of all, because I want to bring families in to really know what's going on in my lab and the labs around the country. I'm very happy that I'm co-chairing the next big pediatric neuro oncology conference in the United States in 2023. We want to bring in parents, advocates, nurses, you know, of course, MDs and researchers to all learn about what's new in the field, and how we can think together to really, you know, increase our impact. And what I learned, the hard way also, is everything needs funding, and the traditional funding mechanisms, especially federal funding oftentimes lags behind for pediatric cancer... I think it's changing slowly, but it's changed because of advocates and moms, like Kathy Arabia, coming to the table and saying, but this is really important, every single child we are losing, every single child that is suffering, is one too many. We have to change the field, and we have to do it together. So I speak a lot, as much as I can at national conventions or fundraising events because I want people to know that change is on the horizon. But then we have to do it together. It's no single person's, you know, child, even if we dedicate 100% of everything on finding a cure, we have to do it together.

Access this full interview and more on this research as a podcast, or at svhealthcare.org/medicalmatters.

Southwestern Vermont Medical Center

From her lab at the Dana-Farber Cancer Institute, Mariella Filbin, MD, PhD, leads the search for children's brain tumor cures. She spoke with host Trey Dobson, MD, on this week's Medical Matters Weekly. https://svhealthcare.org/medicalmatters



GAMER'S OUTREACH GO KARTS

When the AYJ Fund was looking for a new way to support children at the Jimmy Fund Clinic and the clinic at Weill Cornell , we reached out to our teen advisor Jake. He told us it would be wonderful if they had gaming units that they could use while they are in the clinic. He knew that lots of kids like gaming and it would really help pass the time.

We were thrilled to work with Gamers Outreach, which builds these GO Karts for hospital use.





"We have a newer teen boy who has been hesitant to interact or accept anything we offer. When I wheeled the cart over to him, he truly lit up. I checked back in about 20 minutes later and he was having a blast. His mom said it was one of the first days she felt she had her son back."

Kate Nixon Child Life Specialist The Jimmy Fund Clinic



"Thumbs Up" from Jake

"It's HERE and it's so cool!!"

"We are SO GRATEFUL."

Cindy Campbell Weill Cornell



FINLEY'S PRINCESS PHOTO SHOOT

We were so happy to connect Princess Finley with our friend and talented photographer, Tiffany Weissbrodt,



of Polka Dot Portraits. Tiffany created the most magical photo shoot with our friend Finley, who posed reading princess books, ironing her dresses, and being her own beautiful self.

"Thank you for setting up the photo shoot for Finley. Tiffany did such a wonderful job! We love them! Finley's Mom



CAEL IS ON THE MOVE

Cael is 3 years old and is being treated for ALL leukemia at the Jimmy Fund Clinic. Cael's Mom shared that he would really enjoy a new scooter. Between

clinic appointments, he can now be seen cruising down the street on his new scooter.





Love that SMILE!

TRAIN TIME FOR WALTER THE WARRIOR BABY

Walter loves trains a lot more than he likes spending time at Children's Hospital Boston or at the Jimmy Fund Clinic. After a difficult day at the clinic, Walter arrived home to a SMILES train-themed gift pack.

Wooden trains, a train book and a cozy comforter brightened his day. This will keep him busy for a while, until we surprise him with a trip to Edaville Railroad in South Carver, MA, which is opening soon for the Edaville Christmas Wonderland.





SMILES FOR TOMMY'S PLACE

Tommy's Place is a very special vacation home for families of children with cancer. It was created to provide a special escape for a full week from thinking about cancer, and just being a kid. The first Tommy's Place is located in Falmouth and a new one is being created in Centerville. A number of families we know have been granted a week in this magical place filled with theme rooms, music, crafting, sports and more. When they recently posted a list of items they needed for their new location, the AYJ Fund ordered a number of fun items to help support the smiles they create for these special kids and their families.



AYJ FUND PRINCESSES IN THE FALL FOLIAGE PARADE



Each year, the City of North Adams and 1Berkshire collaborate to host a festive, fun and popular



downtown parade celebrating our beautiful fall in the Berkshires. This year's theme was "Holidays on

Parade", and AYJ Fund's Board Member MaryAnn and Leon King (aka Santa and Mrs. Santa) were named one of the two Grand Marshals.



This year, the AYJ Fund had another wonderful group of local high school and elementary school students

participate as Disney Princesses. Santa Mickey and Minnie also joined the princesses to celebrate this year's holiday theme.



PARADE FLOAT WINNER

Floats are a big part of the Fall Foliage Parade. Community members, organizations and



companies get together to build impressive, creative floats. This year's second place float winner was Very Good, a local property development business. Their float was a very creative and impressive depiction of a scene from *A Christmas Story*. We were not surprised they won second place, but were so surprised when they donated their \$300 prize to the AYJ Fund.



SAFELITE AUTOGLASS GRANT

We are so grateful to Kelsey & Billy Shedd-King who recommended the AYJ Fund to the Safelite AutoGlass Foundation's grant selection committee. Billy is a Safelite AutoGlass employee who was made aware of this grant process. As a cousin of our friend Jake Tullo,

they recommended the AYJ Fund. We were so excited to hear that the AYJ Fund was awarded \$1,000 to support our mission to help children



with cancer. Does your employer have a grant program? We can assist with the application process.

SMILES DONATIONS

Thanks to Hector and Petra Nevarez, who reached out

to us and brought four large boxes of donations, all items for our SMILES program. They wanted to find a way to help after having childhood cancer touch their lives. We are so grateful.

AYJ FUND MEMORIAL DONATIONS

STEVEN ST. GERMAINE

We are so grateful for the family of Jacob Tullo, who directed memorial donations to the AYJ Fund for their fun-loving Uncle Steve.

MILDRED WALL

When grief struck Jacob Tullo's family for the second time in a very short time with the loss of their Nana, the family once again blessed the AYJ Fund with donations in her memory.

BARBARA MACKSEY

A wonderful supporter of the AYJ Fund, Barbara Macksey lived her life full of family and favorite times surrounded with her grandchildren.

DANA-FARBER VOLUNTEER OF THE YEAR

We are so proud of AYJ Fund Board Member Mary Costa, Anna's Auntie Mary, who was selected as Dana-



Farber's Volunteer of the Year for 2022. This recognition comes with a \$10,000 gift to a hospital department or lab. Mary selected the lab of our friend, Dr. Mimi

Bandopadhayay, to receive this

award. "We are on this shared mission togetether and I appreciate every single thing that you do. We won't stop until we find those answers," she said.







AYJ FUND HOLIDAY SMILES PROGRAM

This holiday season, the AYJ Fund is once again spreading smiles through our AYJ Fund Holiday Smiles Program. You have the opportunity to sponsor an AYJ Smile for a child for only \$25. Through this program, we reach hundreds of children fighting cancer and whose holiday schedules are filled with testing, treatment and post-treatment scans and medical challenges.

AYJ Fund sends gift certificates, funfilled backpacks, gift packages and more to children we have connected with who are at home, and those



currently in treatment at the Jimmy Fund Clinic in Boston, Baystate Children's cancer center in Springfield, Weill Cornell at Sloan Kettering in NYC, Dartmouth-Hitchcock in NH, and Children's Hospital of Los Angeles.

The clinic staff at these centers share with us priceless stories of the children who we help to find a reason to smile during a difficult day. We are so grateful for all of the sponsorships we receive, which help us to reach more children and spread more joy and smiles throughout the holiday season.

We ask you to join us this holiday season. Thank you in advance for your support.



* 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	AYJ
Mail to AYJ Fund 201 Eagle Street North Adams, MA 01247 Or donate online at <u>www.AYJfund.org</u> or AYJ Fund on Venmo	All donations are tax-deductible.



AYJ FUND LOGO WEAR IS BACK!

Our popular clothing line of AYJ Fund sweatshirts, Tshirts, vests, jackets and more is available once again for a limited time online. What a great holiday gift! These items are produced through Beck's Printing in North Adams and all proceeds support the AYJ Fund. We will launch the line every few months; these items are now available through a link on our website,



AYJfund.org. Thanks to all who have been sporting our AYJ Fund clothing. We love to share photos of you wearing AYJ Fund gear, so please continue to send them. You may just find yourself in a future newsletter!

WAYS TO SUPPORT CHILDHOOD CANCER THIS HOLIDAY SEASON

- ♥ Sponsor an AYJ Fund Holiday Smile.
- Honor someone you know with a donation to the AYJ Fund in their name. AYJ Fund will send a special card you can send in place of a gift. Perfect for the person who has everything.
- Purchase an AYJ Fund clothing item as a holiday gift for someone special. Let them know that all proceeds help children with cancer.
- Select an item from our AYJ Fund Amazon Charity List next time you place an order from Amazon. These items will be used for children for the holidays.
- Sign up for AYJ Fund on Amazon Smile AYJ Fund will receive a percentage of your purchase all year long.
- Follow the AYJ Fund on Facebook, Instagram and Twitter, and share our posts.
- Share this newsletter with a friend.
- ♥ Contact us at 413-652-1602.

