

# The AYJ Fund smíles ... 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 aliomatosis cerebri and other brain cancers to find a cure.



# **AYJ FUND HOLIDAY SMILES CAMPAIGN**

We know our last newsletter was only a couple of months ago, but the AYJ Fund has been guite busy and we have lots to share. In this newsletter, you will hear about: our 4th International GC Conference; which was held at Weill Cornell Medicine in NYC; our busy Childhood Cancer Awareness Month activities: and our AYJ princesses and friends, who joined us in the Fall Foliage Parade and for our popular and fun "Once Upon A Dream" children's concert.

After a beautiful and busy fall in the Berkshires, it is hard to believe that the holidays are almost here. Once again we will provide AYJ Holiday SMILES for over 200 children with cancer this holiday season. With your donation of \$25, you have the opportunity to sponsor these special gifts for a child spending their holidays undergoing testing and treatment for cancer. See page 7 of this newsletter for the details.

Mark your calendars now for AYJ Fund's 10th Anniversary Celebration on February 10, 2024, when we will celebrate the end of our 10th year and launch



our next decade of connections and cures.

Walky + Joe

### **GRATEFUL BEYOND WORDS**



Campaign to support children with cancer in recognition of Childhood Cancer Awareness month. With your support, we raised over \$15,000. Thank you to all of the individuals and businesses who are helping us to make a difference for these kids. It's never too late, if you still want to contribute.

We were also very honored by the beautiful gift we received from the new Mr. and Mrs. Joe Nuccio. Anna's cousin Samantha and new husband Joe made a donation to the AYJ Fund in lieu of traditional favors at their recent beautiful wedding.





# **AYJ FUND SMILES**

# **PRINCESS LIZZIE**

Lizzie is one of the strongest princesses we know. She is fighting leukemia at four years old and loves to be silly with her brother and sister.

She is just adorable posing in her special princess wig. Thanks to The Magic Yarn Project for supplying us with



these handmade wigs for us to share with these beautiful princesses.

"We received a box of goodies from you this week for my son Jackson and I just wanted to thank you so very much! He is obsessed with the remotecontrol dump truck – you really hit the nail on the head there! We so appreciate the thoughtfulness you put into this package. Thank you so much again!"

Jackson's Mom

# **TEAM SOPHIA**

Sophia was admitted to Children's Hospital Boston. When we heard she liked huskies, we knew we needed to send her a husky



Team Sophia >

"Warmies." (Our Anna had an Alaskan Klee Kai dog that looked like a mini husky.) These soft and cuddly stuffed animals can be put in the microwave to give a warm hug and comfort when not feeling well. Sophia's Mom shared that "Sophia is into chickens, bracelet making, Bluey, makeup, music and stickers." Sophia will be receiving more packages when she is readmitted for her next round of chemo!

# SADYE JADE

Sadye Jade is a sweet little girl who has been battling neuroblastoma for over a year. We were so happy to see the wonderful photos her Mom sent with all of her AYJ SMILES.

"Thank you so much for the box of gifts you sent Sadye Jade. She loved them. She was super excited to get a package. We really appreciate everything and the prayers."





Sadye Jade's Mom

# MASON

Mason is 10 years old and was diagnosed with leukemia in April. Since he continues to be in active treatment this fall he started a hospital/ homebound school program. AYJ Fund sent Mason a laptop so he could continue his education, and also sneak in a little movie time!

THANKS FOR THE CHROMEBOOK <u>@AYJFUND</u>! MASON IS SET FOR HOMEBOUND SCHOOL TO START LATER THIS WEEK, UNTIL THEN, MOVIE TIME!





"William just received the SMILE pack! Thank you for sending such a thoughtful gift. We could right away see that every item was carefully chosen for William. Seeing him happy really made our day. Thank you!!"

### 4th INTERNATIONAL GC CONFERENCE

The AYJ Fund was proud to be a sponsor of the 4th International Gliomatosis Cerebri Conference, which was held at Weill Cornell Medicine in New York City, September 14-15.

52 leading physicians and researchers from North America and Europe participated in the conference along with 31 GC family and foundation members. It was a truly collaborative effort as researchers presented results of the research which the GC Foundations had funded over the last four years, as well as presentations on the most current advances and research efforts being made to effectively impact brain cancer treatments for children.



GC Family Foundations that Cerebri Conference sponsored the conference along

with the AYJ Fund were: The Children's Brain Tumor Project Foundation at Weill Cornell Medicine; Rudy's Mission and The Brain Tumor Charity, both of the UK; Unions un Rayons de Soleil of France; Izas, la princesa guisante of Spain; Elizabeth's Hope/The Minter Family and The Joshua Bembo Project of USA; and Patrick Bayly Foundation of Peru. The families have all lost a child to this devastating disease and are committed through their foundations to this research.

Presentations included: information on how tumor cells react with healthy cells surrounding the tumor; comparisons and recent knowledge of both adult brain cancers and those diagnosed on canines; and methods to help drugs cross our body's blood-brain barrier, a natural protection of our brains, which works to not allow toxins, and therefore cancer drugs, to effectively get into the brain to kill the cancer cells.



A number of the physicians and researchers attending the GC Conference in NYC.



GC Families on the Empire Hotel rooftop in NYC

We were excited to hear the presentation of the International GC Grant research project, which is funded by the AYJ Fund, Un Rayon de Soleil and Izas la princesa guisante. There were presentations from each of the four international labs where the research is being conducted, including Dana-Farber in Boston. Conference attendees heard for the first time the unique differences of GC cells from other brain cells.

There were interactive discussions involving both families and scientists on the work that now needs to be done, based on the information presented. Next steps include: discussions of a GC Molecular Tumor Board, a protocol on biopsies, and work on educating other physicians and radiologists on the importance of including the diagnosis of GC in medical reports and increasing the availability of clinical trials for patients with GC.

# DUTCH

We are heartbroken to share that our friend Dutch of Williamstown, MA, joined our angels in heaven as he was receiving treatment in preparation for his bone marrow transplant after



a relapse of his leukemia. These treatments are so brutal on these little children's bodies. Dutch, who was two will always remain in our hearts as we continue our fight against childhood cancer.

# INTERNATIONAL COLLABORATIVE GRANT INTERIM REPORT

This is a summary report of one of the research projects the AYJ Fund is sponsoring in partnership with other GC Foundations; Izas, la princessa guisante (Spain) and Unions des Rayons de Soleil (France). This three-year research project is a collaboration of the Filbin Lab at Dana-Farber and research labs in London, Paris and Rome. Shauna Crampsie is a PhD student at the Institue of Cancer Research, sponsored by the Rudy A Menon Foundation (UK).

### Executive summary of second year funding

Over the past year, we have made substantial progress over several fronts across our four institutes

- In Boston, Ilon Liu and Shauna Crampsie completed the single cell sequencing of 25 GC samples, a completely unique set of data to our knowledge. We have identified GC-specific gene signatures associated with how the cells spread through the brain, and are investigating these further.
- In London, Shauna has completed the characterization of 15 samples that we attempted to establish as new laboratory models of GC. We have noticed that a blood vessel-like cell tends to outgrow the cancer cells when we do this. However, we have four unique and bona fide GC models available for further work.
- 3. In Rome, Shauna's placement allowed for the analysis of these cells grown on mouse brain slices to investigate how they grow and spread across brain tissue. She also started to use the "imaging mass cytometry" system to look at dozens of markers of tumor and non-tumor cells in a single human GC tissue section.
- 4. In Paris, mouse models of GC have been established for the first time, with cells from these shared with the rest of the group for the above



experiments. In the clinic, the first patients have been treated with drugs targeting EGFR, identified from the European SIOPE study as being enriched in GC.

# International GC Collaboration - The Team



## Future work and perspectives

A key goal is to integrate the various data we have across different assays – linking the gene expression metaprograms identified by scRNA-seq in Boston with those from the IMC in Rome and bulk invasive cell RNA-seq from London. We will also now move to use our in vitro models for drug assays aimed at modulating the infiltrative phenotype, as well as the specific cell states identified. Hits from these cellular assays will then be explored in vivo using models developed in Paris.

**AYJ SIGHTINGS** 







Bernie at Stonehenge



Emma in Tokyo



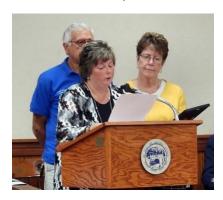
John's VT Ski Pass

### CHILDHOOD CANCER AWARENESS MONTH

The AYJ Fund had a very busy September, raising childhood cancer awareness throughout the month.

### PROCLAMATION

We were honored that Mayor Jennifer Macksey presented the AYJ Fund with a proclamation at the North Adams City Council Meeting proclaiming



September as Childhood Cancer Awareness Month in the City of North Adams. This is a very important honor that demonstrates the support of our North Adams and North Berkshire community.

### TREE LOGIC GOES GOLD AT MASS MoCA

MASS MoCA, the largest museum of contemporary art, located in North Adams, MA, went gold for Childhood Cancer Awareness Month. They lit the iconic art



installation of upsidedown trees, Tree Logic, with gold lights. This was the last September that Tree Logic will be displayed at MASS MoCA, as the installation was removed shortly after. We are so grateful they honored children this September.

### NORTH ADAMS LIBRARY



Our North Adams Library, which holds many community programs for both adults and children, invited us to share information on the AYJ Fund. We spoke about our mission and programs, and how others could join us in supporting children with cancer.

# NATIONAL BRAIN TUMOR SOCIETY ADVOCACY

The National Brain Tumor Society holds two advocacy days each year to meet with our

Congressional Offices to advocate for



legislation to support brain tumor patients. Kathy joined other advocates from Massachusetts on Zoom calls with the offices of Senators Elizabeth Warren and Ed Markey, and Representatives Richard Neal, Jim McGovern, and Lori Trahan. This year, we advocated for: increased funding for the National Institutes of Health/National Cancer Institute; the Department of Defense research funding; and passage of the The Pallative Care and Hospice Education and Training Act (PCHETA) legislation.

### **DRURY HIGH SCHOOL'S DAY OF SERVICE**

We were very happy to be invited to Drury High School's Day of Service. The AYJ Fund met with students who helped make cards



for children with cancer. These students did an outstanding job and created so many beautiful and creative cards. They will be included in our AYJ SMILES packages and mailed to hospitalized patients.

### EAGLE STREET PARKLET

Every Friday morning at the NAMAzing Eagle Street Parklet, local community members are invited for

coffee and breakfast treats. AYJ Fund sponsored the September 1 event to start Childhood Cancer Awareness Month with discussions and facts about childhood cancer.



### FALL FOLIAGE PARADE

Each year, as our beautiful Berkshire foliage creates a colorful backdrop, our local community lines up to watch



the Fall Foliage Parade. This parade includes large floats, bands, community organizations and more. This year's theme, "Once Upon a Time," was perfect as we planned for our upcoming AYJ Fund "Once Upon a

Dream" children's concert. Local high school AYJ Fund volunteers dressed in Disney-themed costumes, walked in the parade and greeted excited children all along the route.



Serena Johnson sang Disney songs throughout the



parade route and a number of our young princesses led the way. We shared information on our AYJ Fund and the upcoming children's concert and thrilled the crowds of parade goers.

This year's group of princesses was our largest ever, and the onlookers loved them. We included a few extra characters, including Belle's Beast, Star Wars Rey, and Cruella de Vil and

Ursula. They generated lots of excitement and lots of smiles throughout the crowded North Adams strets.



### **ONCE UPON A DREAM CHILDREN'S CONCERT**

Just two weeks after the Fall Foliage Parade, our princesses and friends joined us again for our wonderful AYJ Fund children's concert "Once Upon a

Dream." St. Elizabeth of Hungary's Parish Center was filled with smiles, music, dancing and lots of little girls and boys enjoying the Disneythemed décor, treats, and photos with the princesses and their friends.

A special thanks to all of our princesses and friends, who created so many special moments. They were so wonderful interacting and dancing with the children. We are grateful to Pam Wilk for her vision, Mary Scanlon and Serena Johnson for their beautiful voices, and all of our great volunteers.











### **BURCS RACE**



Our friends from the Berkshire Ultra Running Community for Service (BURCS) held their annual Sweltering Summer Ultra event in August, and once

again donated the proceeds to our AYJ Fund. Each year, we are amazed at the endurance, the strength, and the joy that these runners bring to the track at Clapp Park in Pittsfield, MA, as they run for 8 hours...8 hours!

In addition, Wally the Watermelon is carried by one of the runners each lap. For every lap that Wally is carried, additional money is donated to the AYJ Fund. We love Wally, and all of the BURCS runners.

## LEE POLICE PATCHES

The Lee Police Department selected the AYJ Fund to

benefit from their Pink Patch fundraiser for cancer again this year. This year has an extra special meaning for us as Michael - one of the children we have connected with who was



diagnosed with cancer and spent months in the hospital — is from Lee. We are grateful to the entire Lee Police Department and the Lee community.

# AYJ HOLIDAY SMILES

Each year at this time, we invite you to participate in our AYJ HOLIDAY SMILES project. Again this year, we will fill string backpacks with gifts to send to a number of hospital clinics where children will be

spending much of their holidays, instead of being able to enjoy this time at home with friends and family.

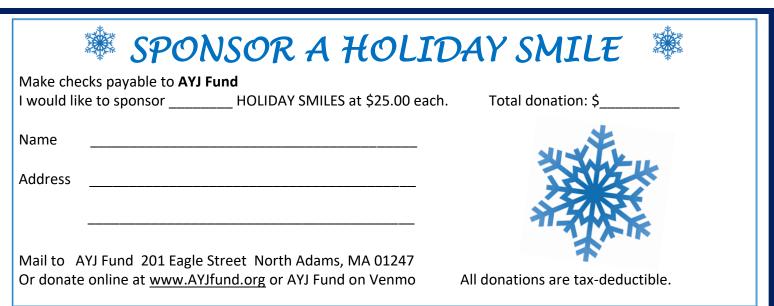
We will send over 200 AYJ HOLIDAY SMILES to children in treatment at The Jimmy Fund Clinic at Dana-Farber in



Boston, Baystate Children's Hospital in Springfield, MA, Weill Cornell Medicine in NYC, and Dartmouth (NH) Children's Hospital. We will send gift cards to children at Children's Hospital of Los Angeles. We will send additional AYJ HOLIDAY SMILES packages to a number of children with whom we have connected individually and are also spending much of their holidays enduring testing and treatments or battling side effects of their cancer treatments.

The clinic staff at these centers, and children's parents share with us priceless stories of the children who we give 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. Please help us to share more AYJ Holiday SMILES this season.

Stathur + Joe



# ARE YOU RECEIVING OUR AYJ FUND MONTHLY UPDATE?



Our update keeps you informed about our AYJ Fund programs, new cancer research, and our AYJ Fund kids SMILES.

Send us your email address and we will add you to our mailing list. You can send a message through our Facebook "AYJ Fund" page, or through our website at AYJFund.org.

If you would prefer to receive our newsletter only by email, and not USPS, just let us know.

# AYJ FUND CALENDAR

### November

 LUMINAMA – Check out our holiday window on Main St North Adams Nov 22-Feb 2

### December

 Holiday SMILES Project – sponsor a holiday gift for a child with cancer for \$25

### February

♥ Feb 10 - AYJ Fund's 10th Anniversary Celebration

### March

♥ March 10 – Pam the Berkshire Medium

