



# ATK PROGRAMS

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- **BIRTHDAY CLUB**

All Things Kabuki loves to celebrate our Kabuki Kids. Too often children and adults affected by rare disease do not have the same opportunities to celebrate, or be celebrated, as healthy children do. The ATK Birthday Club was established in 2014 for individuals with Kabuki Syndrome across the globe. Upon enrollment, Kabuki Kids / Adults receive a welcome and VIP membership card. A personalized birthday card is mailed (ideally) prior to their special day. Donations to ATK make it possible for us to provide this program at no cost to more than 690 individuals with Kabuki Syndrome!

- **FAMILY SPOTLIGHT**

Throughout the year we shine the spotlight on a Kabuki family and their medical journey. These stories give others in the Kabuki Syndrome community a chance to relate to other families, as well as an insight into the struggles and victories our warriors endure. We've also heard that individuals outside of the community frequently read the Spotlight stories to gain a better understanding of what life is like, *growing up Kabuki*. Visit our website to view published stories and/or sign up to shine the spotlight on your journey.

- **PEN PAL CLUB**

You've got SNAIL mail! The ATK Pen Pal Club re-launched in January 2020 and the Sibling Pen Pal Club re-launched in March 2020. This program, first started by the King family for homeschool purposes, was a hit! Kabuki Kids / Adults (and siblings) sign up to correspond with each other through snail mail. Pen Pals can be local or spread out across the globe.

- **ANNUAL AWARENESS CAMPAIGNS**

Join our online awareness campaigns every February and October. February is Rare Disease Awareness Month, with the last day of February being Rare Disease Day. October is Kabuki Syndrome Awareness Month, with October 23<sup>rd</sup> being Kabuki Syndrome Awareness Day.

- **OPERATION KABUKI CHRISTMAS**

Operation Kabuki Christmas (OKC) was launched in 2013. Kabuki Syndrome families experiencing a financial hardship are invited to apply for Christmas assistance in October. The program has evolved over the years due to increased community needs. Siblings of the Kabuki Kid / Adult are not excluded. This program is currently only available to families living in the United States and is made possible by generous donors.

We are grateful to have been able to support and provide Christmas gifts to a total of 347 children in 122 families over the past 10 seasons.

\*Elizabeth Golab was the inspiration behind this program, which later evolved into All Things Kabuki. Elizabeth passed away in 2015 at the age of 16.

- **ATK KABUKI SYNDROME PATIENT REGISTRY**

With the support of the Kabuki Syndrome community, we were able to raise the initial funds required to launch the first ever, Kabuki Syndrome Patient Registry. The registry will be established through NORD's IAMRARE platform. The test phase will be live late January 2022.



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- **SELF CARE GROUP**

Parents, friends and caregivers are invited to join ATK's private self-care group on Facebook, Self Care & Raising Rare. This group is moderated by parent volunteers.

- **OPERATION INSPIRATION**

Women supporting women! ATK's newest initiative was launched in September 2021. This program was established to support Kabuki Syndrome Mama's, especially during those hard, lonely days. As we identify struggling Mama's, we activate a Call To Action in the private Facebook group, requesting 10+ women agree to reach out via snail mail. All women are invited to participate in this effort. We hope to expand this program to others in the future.

- **OPERATION KABUKI SMILE**

Our newest initiative! This program focuses on Kabuki Syndrome tweens, teens and adults experiencing physical and/or emotional struggles. Our kids LOVE mail! As we identify patients experiencing hardships like surgery, hospitalizations, loneliness, isolation, etc. we post a Call To Action in the Facebook group, requesting active participants reach out to the individual via snail mail. The FB group is made up of Kabuki Syndrome parents and patients of all ages. While parents and siblings are welcome to send mail, we encourage other individuals (of all ages) with Kabuki Syndrome to participate too. Group members can send cards, letters, drawings, coloring book pages or even post it notes to say hello and bring a smile to the face of the recipient. In an effort to protect the privacy of patients, participation in this group is currently only open to known Kabuki Syndrome parents and caregivers.

- **ADVOCACY OUTREACH PROGRAM**

While this program and resources are currently still being developed, the intent is to provide tools and resources to help caregivers become better advocates with their medical team, friends and family, and with the general public. Visit our website often to see what resources are available, or send us an email if you have a resource idea that would be beneficial to your family and others.

- **GREEN STAR FAMILY PROGRAM & MEMORIAL FUND**

ATK honors the families who have lost their Kabuki warriors. We make every effort to help families experiencing financial hardships fundraise for, and cover, the cost of final expenses. With parent permission, ATK offers memorial decals in our online store. Merchandise proceeds benefit our Green Star Fund.

Why Green Star? ATK's Founder is married to a combat veteran. Dating back to the 1930's, when a servicemember was killed in combat, the surviving spouse (family) would be referred to as a Gold Star Spouse. While the King's don't take lightly comparing military loss to others, they feel strongly that individuals with Kabuki Syndrome fight a fierce battle their entire life. As a gesture of respect, ATK established the Green Star Family Program to honor the individual that lost their battle with Kabuki Syndrome and support the family that is left to mourn their devastating loss.



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- **ELIZABETH GOLAB MEMORIAL AWARD**

The Elizabeth Golab Memorial Award was established in 2015. Elizabeth Golab, daughter of Joe and Fran Golab, was born on April 29, 1998. Elizabeth was diagnosed with Kabuki Syndrome in October 1999.

Elizabeth's 2013 Christmas wish, denied by a local PA charity due to her age, led to the launch of Operation Kabuki Christmas, now ATK's most successful annual charity program.

Elizabeth passed away on March 15, 2015 after a long, fierce battle with Kabuki Syndrome. This beautiful, young warrior was the inspiration behind All Things Kabuki, the only U.S. patient advocacy organization serving the Kabuki Syndrome community globally.

When Elizabeth passed away, her mother asked ATK's Founder to not forget her daughter. With the promise to never forget the little girl that inspired OKC & ATK, the Elizabeth Golab Memorial Award was established.

With Joe & Fran Golab's blessing, the Elizabeth Golab Memorial Award is presented annually to an individual that has made a significant impact within the Kabuki Syndrome community.

## **AWARD RECIPIENTS:**

2015: Cheryl Lee

2016: Dr. Hans Bjornsson

2017: Serena Burks

2018: Dr. Olaf Bodamer

2019: Tara Daly

2020: Holly O'Brien

2021: Tiana Capri