

## **JUNIOR AMBASSADOR ~ JAIYA, age 12, North Carolina**

Jaiya is a 7th grader in North Carolina. She was diagnosed at the age of 2 with Chronic Severe Neutropenia-Autoimmune. Jaiya's body responds poorly to Neupogen and as a result has not been able to remain on it as a form of treatment. Her Neutropenia has caused her and her family to spend countless nights in the emergency department resulting in extended stays at the hospital. She is blessed with an extremely supportive family and community who are giving Jaiya a strong foundation to define Neutropenia on her own terms. She has certainly found her voice in raising awareness and being an advocate for the Neutropenia community. Her mother, Anyua, has shared the many opportunities Jaiya has been involved with, earning Jaiya the title of one of our Junior Ambassadors for 2019-2020....

### **#1: Project JPAC "Packed with Fun, Just to Bring You Joy!"**

Project JPAC was created 9 years ago on behalf of then, 3-year-old Jaiya. To comfort Jaiya and her older brother during their long waits in the ER, her parents packed bags that were filled with arts and crafts. After many nights of sharing their arts and crafts with other patients at the hospital, Jaiya and her brother began insisting on bringing extra bags for the other children.

In 2010 Jaiya's church, New Birth Community African Methodist Episcopal Church (NBC) and one of its ministries, The Jarena Lee Missionary Society, joined the effort and donated 300 JPACs to Moses Cone Hospital in hopes of bringing joy to children in similar situations as Jaiya's. Every year, NBC sponsors the project by collecting donations from church members and partnering with other community organizations by assembling the bags and delivering them to local medical facilities. The zip lock bags of hope were geared to entertain children receiving care in local hospitals containing fun activity items to keep children occupied during their visits to the hospitals. This includes crayons, coloring books, stickers, books, colored paper, colored pencils, pencils, markers, and wrist bands. Literature about Neutropenia and Jaiya's story are also included in the packs. In November 2018, a record number of 800 bags were delivered!

Jaiya continues to lead the movement by collecting items, designing publications, and most heart wrenching, hand delivering the JPAC to hospital bedsides. Jaiya has spent over 50 hours or more each year collecting JPAC items from her schools and various extra-curricular activities. She has been interviewed and written short speeches to encourage her friends, classmates, teammates, and family members to give to JPAC. Her hope is to have Project JPAC in all 50 states.

### **#2: Books for Brenner's: "Share a Tale to Share a Smile"**

Jaiya is a patient at Brenner's Children's Hospital Hematology Clinic. In the Hematology Clinic, she is always blessed with "goodies" and "treats" that volunteers have donated. In addition to delivering Project JPAC each year, Jaiya wanted to restock the clinic's bookshelf. She partnered with a local high school to plan a book collection. She wanted to launch a project with a focus on lifting the spirits of those who are sick, all while encouraging reading. Her hope is that patients will find the books to be places of peace and comfort; that they will have the opportunity to escape their current state of mind and literally get lost in the stories they are reading.

In December 2018, students at the high school and Jaiya's family members were encouraged to donate new or gently used books to a project she titled "Share a Tale to Share a Smile". She created flyers and sent text messages and emails to everyone. She designed inspirational bookmarks and labels for the inside of each book as well as promoted the service project on her social media outlets and presented the project to friends and family members. In May 2019, 506 books were delivered to Brenner's!

### **#3: Color Me Healed**

In November 2018, Jaiya collected crayons, coloring pencils, and markers from her friends and family to help supply her Project JPAC. She advertised the drive and people came to a local school to donate where she collected 153 items, all the while educating donors about Neutropenia and her Project JPAC.

### **#4: Classroom Presentation**

Each year Jaiya does a PowerPoint presentation for her classmates about Neutropenia. She provides great information through statistics, videos, and pictures. She demonstrates how Neutropenia effects the body using candy. This has been a way to educate her peers about Neutropenia, encourage safe hygiene practices in the classroom, and introduce her struggle to the school...all of which help the school year to be a little better for everyone.

### **#5: Martin Luther King, Jr Day of Service**

Jaiya spent MLK Day (January 2019) at the local mall educating people about Neutropenia and her annual Party for Neutropenia (PFN). She and her mother asked several of her mother's students to attend the event to spread awareness and promote PFN. She shared pictures and video of her events, passed out literature about Neutropenia, and passed out zebra snack cakes. The mall was

packed with other groups presenting service projects, so over 100 people were informed about Neutropenia! While there, Jaiya was interviewed by the local news and was featured on the local news channel!

#### #6: World Rare Disease Day

Each year Jaiya encourages her friends and family to participate in World Rare Disease Day by wearing denim, zebra ribbons, and this year painting their faces. She simply sends a text blast that includes information about her story, Neutropenia, and the national Rare Disease Day campaign. She provides people with zebra ribbon before the actual day. Everyone takes pictures of how they support the movement and posts the pictures on social media and use the hashtag #ilovesomeonerare #1inamillionJaiya.

#### #7: Bowl-a-Thon for Neutropenia

Jaiya and her parents launched their 1<sup>st</sup> Annual Bowl-A-Thon for Neutropenia campaign to raise funds to host two huge Neutropenia awareness events and help purchase items for Project JPAC. They partnered with a local bowling alley and hosted 108 people at the event. Jaiya designed a board about Neutropenia that was displayed as well as a PowerPoint presentation that was viewed at the event. Jaiya's friends and family members spoke to everyone about their knowledge of the disorder and how it has impacted their lives!

#### #8: Party for Neutropenia: Safari Night

Party for Neutropenia is an annual event held to bring awareness to Neutropenia. When Jaiya's mom's students found out about Jaiya's medical condition, they wanted to do a project that blessed and celebrated her. Jaiya is instrumental in planning the event but the students work the event as well as research the blood disorder to educate their schoolmates, so they are encouraged to volunteer. Jaiya and the P.F.N. public relations chair were responsible for utilizing social media to advertise the event and promote Neutropenia awareness. They updated event specific social media pages and created all correspondences that went out into the community about the event.

The students worked the event that offered face painting, a photo booth, viewing of the movie Wonder, basketball, concessions, ice cream bar, science labs and more. Jaiya created a Neutropenia fact wall that was displayed. Jaiya was able to enjoy a day with her friends and be celebrated for her perseverance! The theme was Safari Night! The children were able to participate in a scientific simulation activity about germ spreading as well as look at blood cells under a microscope. The experience impacted several lives, including the 80+ students that attended. The local news was present and featured the event on Spectrum News. It was an event to go down in HERstory!

#### #9: Prom for Neutropenia "A night Under the Stars"

This event is a semi/formal dance for parents and their children. The children experienced "a prom" with their parents and learned about Neutropenia. Jaiya visited several venues with her parents before selecting a place that could be transformed in to a beautiful "Night Under the Stars." She used a software to design the advertisement for the event and asked her aunt to cater with a menu selected by Jaiya ~ Jaiya even made one of the signature punches. Guests were given a favor that had information about Neutropenia. There was a live band, DJ and photographer. Jaiya's story and facts of Neutropenia were shared with the guests before she danced with all the men in her life. The live band sang "Isn't She Lovely" while she danced with her Father, Brother, Grandfather, Uncles, and Godfathers. In that moment, everyone in the room recognized that Neutropenia is a diagnosis for Jaiya and NOT her life - Faith and family are her life.

*"Jaiya's next steps are to start a non-profit organization. She and her parents want to educate people about Neutropenia and connect people across the globe that are living with the blood disorder. It is important that from the day a family receives the diagnosis that they are well educated and supported. In 2018, Jaiya prayed about how she could tell her story without pity and we think she is doing a wonderful job! People in our family and community are well educated about the disorder and they are dedicated to her movement... to HERstory!"*



