Gabrielle Seguin MC 3001-Haydel Speech writing November 4, 2019

Audience: Donors Informational meeting

WELCOME!

HELLO EVERYONE, I AM ERICA SIMPSON AND I AM THE EXECUTIVE DIRECTOR OF THE LOUISIANA HEMOPHILIA FOUNDATION. THE LHF IS HERE TO HELP ALL OF THOSE IN LOUISIANA WHO ARE AFFECTED BY BLEEDING DISORDERS. HEMOPHILIA IS A RARE BLEEDING DISORDER WHERE THE BLOOD DOES NOT CLOT PROPERLY WHICH CAN LEAD TO SPONTANEOUS BLEEDING.

WE ARE GRATEFUL FOR ALL OF OUR DONORS AND CANNOT DO OUR JOBS AND HELP PATIENTS WITHOUT THEM. SO WHETHER YOU ARE HERE BECAUSE YOU ARE ALREADY A DONOR OR DECIDING IF YOU WANT TO DONATE, THANK YOU SO MUCH FOR JOINING US HERE TODAY.

MY FIRST EXPERIENCE WITH A HEMOPHILIA PATIENT CHANGED MY LIFE COMPLETELY. HE WAS A 10-YEAR-OLD LITTLE BOY AND ALL HE WANTED WAS TO BE "NORMAL." HE WAS DEPENDENT ON HIS PARENTS' FOR ALMOST EVERYTHING, EVERY SINGLE DAY, INCLUDING GIVING HIM HIS MEDICATION.

CAN YOU IMAGINE YOUR LIFE BEING DEPENDENT ON A MEDICATION? AND THEN BEING DEPENDENT ON SOMEONE TO GIVE YOU THAT MEDICATION?

IT TOOK SOME CONVINCING, BUT HE FINALLY AGREED TO COME TO THE LHF SUMMER CAMP. AT CAMP, HE WAS ABLE TO HAVE FUN AND LEARN HOW TO BE MORE INDEPENDENT. AFTER LEAVING CAMP, HE KNEW HOW TO GIVE HIMSELF HIS MEDICATION AND HE WAS ABLE TO FEEL MORE "NORMAL" AND THAT IS EXACTLY WHAT HE DESERVED.

LUCKILY, THROUGH FUNDING AND DONATIONS, EVERY YEAR WE ARE ABLE TO PUT ON A SUMMER CAMP FOR CHILDREN WITH HEMOPHILIA. THIS IS NOT ALL FUNDING HELPS WITH. BECAUSE OF OUR DONORS, WE ARE ABLE TO GET PATIENTS TO AND FROM THEIR TREATMENTS, ACCESS TO MEDICATION, PUT ON FUN EVENTS THAT BRING OUR COMMUNITY CLOSER, AND MUCH MUCH MORE.

THESE PATIENTS GO THROUGH SO MUCH AND IT IS EASY TO TAKE OUR HEALTH FOR GRANTED. THE MISSION OF THE LHF IS TO IMPROVE THE QUALITY OF LIFE AND ASSIST PERSONS EFFECTED BY INHERITED BLEEDING DISORDERS BY PROVIDING EDUCATION, ADVOCACY, SUPPORT SERVICES, AND BY PROMOTING RESEARCH. OUR MAIN GOAL IS TO MAKE SURE PATIENTS HAVE THEIR MEDICATION SINCE THEIR LIVES DEPEND ON IT.

HEMOPHILIA IS A HEREDITARY DISORDER SO THOSE WHO HAVE IT ARE BORN WITH IT AND HAVE TO DEAL WITH IT THEIR ENTIRE LIVES. HEMOPHILIA IS THE MOST EXPENSIVE CHRONIC DISORDER THAT SOMEONE CAN HAVE. FOR ONE PATIENT ALONE, THEY CAN SPEND OVER A MILLION DOLLARS A YEAR, JUST FOR THEIR MEDICATION.

THERE ARE OVER 400,000 PEOPLE IN THE WORLD WITH HEMOPHILIA. APPROXIMATELY 18,000 OF THEM IN THE UNITED STATES. MORTALITY RATES ARE 40% MORE LIKELY FOR PATIENTS WHO DO NOT HAVE DIRECT ACCESS TO THEIR MEDICATION.

THE HEMOPHILIA COMMUNITY IN LOUISIANA IS DEPENDENT ON THE RESOURCES THAT THIS FOUNDATION PROVIDES. WE ARE NOT ABLE TO DO OUR JOBS AND HELP PATIENTS WITHOUT PEOPLE LIKE YOU.

I HOPE WE ARE ABLE TO HELP GIVE THEM THE OPPORTUNITIES THAT THEY DESERVE AND WITH YOUR HELP, WE CAN DO THAT. THAT 10-YEAR-OLD BOY WHO CHANGED MY LIFE FOREVER, JUST WANTED TO BE "NORMAL". HELP US GIVE ALL HEMOPHILIA PATIENTS A CHANCE TO FEEL NORMAL, JUST LIKE US.

THANK YOU FOR JOINING ME TODAY. I AM LOOKING FORWARD TO HEARING FROM EACH AND EVERY ONE OF YOU. ONE DONATION, COULD SAVE A CHILD'S LIFE. HELP US, HELP THEM. FOR MORE INFORMATION ON DONATING, YOU CAN VISIT OUR WEBSTIE: lahemo.org