

# ***Josie's Journey***

*(NOTE: Any current/future updates will be added at the end of my story)*

My name is Josie Gaffney. I am 16 years old and live in Central Pennsylvania. I have been asked to share my story with you, which spans back the last 6 years.

In April 2008 after getting home from my brother's soccer game, I immediately went to my mother complaining of something on the back of my neck that was hurting. There it was...a deer tick. Three weeks later, a bulls-eye rash appeared and I was treated with 3 weeks of antibiotics. I suffered with the Lyme Disease, and as a result to be seen over the next few months, it attacked my genetic makeup, leaving me with arthritis that would very soon be diagnosed as severe rheumatoid arthritis or JIA diagnosed by a rheumatologist. Prior to this, I was always healthy, and very active,...a dancer, cheerleader, gymnast and model, also active in the community and at church, and always running to take care of others in need.

In August 2008, I heard a loud popping sound and thought I twisted my right knee in gymnastics. It immediately swelled from my normal petite size to the size of a large grapefruit and remained that way for several months. At the time I weighed 68 pounds. Five months later, my joints from the neck down started troubling me. One joint at a time, one right after the other. Within the next year, all my joints were crippled, my knees, ankles, elbows, wrists, fingers, back and hips.

During the winter of 2009, I went to bed every night in great pain and woke up every morning crying in agony. I was constantly missing school and struggled just to make it through each day.

Somewhere in late 2009 or beginning of 2010, I was taken to an infectious disease specialist. Upon my parents' explanation of my condition and the specialist's examination, that specialist wrote a letter to my then rheumatologist saying she saw no apparent reason to test me for lyme disease or other co-infections for that matter, that I simply had arthritis.

By Spring 2010, I was unable to roll over or sit up, unable to move my upper or lower body. Every little thing I tried to do myself was too difficult, trying to button a shirt, bending over to put on socks, even brushing my hair. I started to need a lot of assistance. I could not bend over at my waist or bend my knees and elbows. I couldn't raise my arms above my head or barely turn my neck from side to side. I was being carried around the house, unable to stand up on my own without crying in pain.

July 2010 was one of my worst periods, I dropped down to 50 pounds, and by October 2010 I was in my wheelchair.

By this point in time, I had tried arthritis drugs and/or immune suppressant drugs, such as sulfazaline, naltrexone, methotrexate, methotrexate injections, and enbrel. In early spring of 2011, as I continued to worsen, I was taken off enbrel, placed on remicade with methotrexate and later we tried actemra.

I have suffered greatly with sciatica, excruciating pain all over, severe stomach pains, and I have been scoped, biopsied, MRI-d, X-rayed, placed on a feeding tube, given very aggressive inpatient and outpatient physical therapy, put on a PICC line, and more.

Up until May 2012, when I was in school, I could function a little with assistance from my aide, amazing friends and a school district that goes beyond the call of duty in supporting my needs at their own will.

After being told by a rheumatologist there was no understanding as to why my case was so severe, not improving and that I was downright one of the most toughest cases that physician witnessed, we were informed that my next step would be a more advanced form of chemotherapy drugs.

As my parents continued to see other odd symptoms in me that made no real sense in connection to arthritis, they decided that it was in my very best interest to take me for other opinions with other types of physicians, as they were not convinced that there were not other types of active infections in my body or reasons as to why the meds weren't working.

In May of 2012, my parents found two new physicians to take on my case as the arthritis medicines clearly weren't working. Traditional medicine and physical therapy may work for some lyme patients, but others that suffer with lyme and several co-infections, like myself, require additional treatment or an alternative form of treatment as in herbal treatments. I have also discovered a new type of manipulative therapy I never knew existed until recently which also helps my body to repair itself slowly and naturally. I am now focusing on my treatment thru these herbal and manipulative therapies, and in just 3 short weeks, I have finally started to see some small improvements begin. Although small I will take them, as I know it is just the beginning of a long, long road ahead for a severely chronic patient such as myself. I also know it will lead to more positive improvements over time. With my new lyme doctor (**LLMD**) and specialty testing, I have finally received confirmation of co-infections that are hindering my recovery, and we are working together to treat them.

In January of 2013, another infectious disease specialist from Maryland had evaluated me and agreed with my LLMD, and together they are treating me. I currently receive 2 to 3 HBOT treatments every week, as well as continuing my mix of traditional and non-traditional medicines. These oxygen tank treatments help to reduce deep inflammation, replenish my red blood cells and replenish my body with 100% pure oxygen.

In some cases, traditional antibiotics alone may be enough if lyme and coinfections are caught quickly within a few days or weeks. If not, many many other cases are treated better with a combination of both, so you can help build up and support your body organs and immune system, which would help to better support your treatment overall, instead of using antibiotics alone. Also, antibiotics alone aren't always enough depending on the strain of lyme or coinfections. Different strains require different antibiotics or antibiotic mixes. Couple that with other herbal remedies under the careful eye of an LLMD seems to be one's best bet in many chronic instances. I've found this to also be true in the many talks with fellow lymeers.

Herbal remedies/natural therapies are not covered by insurance and some prescription medications are not covered by regular insurance or medicade, like Alinia. \$500 a month not covered depending on the dosing. Many lyme patients are forced to use only drugs that are covered, but they are not the best drug needed to treat or they forego their treatment and get worse because they can't afford to buy them. So if that's the case, or if you need herbals that work, severely chronic lyme patients can spend approximately \$2,000 to \$3,000 a month on their medications/natural remedies/therapies. Even specialty testing isn't covered. Many of these special tests cost \$500

to \$3,000 a pop and again not covered by any insurance. Insurance companies don't even like to cover long-term antibiotics saying the antibiotics are bad for you. Well, they have pros and cons, but shouldn't that be the patient's choice if they want them or not... if it might help? Or that should be the parents' choice in case of minors like myself. Its okay for a doctor to prescribe Proactive, which is actually antibiotics, on a monthly basis for severe acne, but its not okay to prescribe long-term antibiotics to treat lyme?

Today, I still have problems with my hips, knees, elbows, shoulders, ankles, wrists and fingers not bending or working properly, they are still "stuck", but I am better in many other ways,... my organs are operating better, although I have a very long recovery ahead of me...years of recovery. My knee that was the size of very large grapefruit for 4 years that one prior doctor insisted I have a knee replacement, has shrunk to normal size over the last year...after my parents made the switch to mixing traditional/no- traditional medicines. There is so much to be said for natural remedies when used under an experienced care provider. The swelling in all my other joints has gone down as well...something that arthritis medications were NOT capable of doing...and I hope to soon be starting extensive inpatient therapy again to get my joints moving. I still deal with eye pain and major vision problems where things look like one big blurry rainbow of colors and I can't make out shapes or details...and I see millions of black dots it seems like. My sensitivity to sound has gotten better, but I still have extreme sensitivity to light and watery painful eyes. With each day that goes by, I pray the day comes sooner than later, that I can fully function again all on my own.

My school district is still a tremendous support...continuing to provide me with whatever I need to move forward with my education. Teachers from school come to my house 2 or 3 times a week for one on one tutoring sessions...for that I'm very grateful. They write for me, read to me, teach me and study with me...and occasionally laugh with me...always with a smile on their face. Thank you Mechanicsburg Area School District...because of you I look forward to graduating with my friends in two years!

Thank you to my church, St. Elizabeth Anne Seton, for all your prayers and visits, and for all that you have done to support me and my family and graciously helping us through these crucial times. God Bless you all, you all know who you are.

Through this nightmare, our family has endured other major obstacles, not only emotionally and financially, but of another nature...that which comes from the miscommunication and misunderstanding of many people looking in from the outside who do not 100% understand my medical situation. Unfortunately, in October 2012, my parents were turned into Children and Youth Services (CYS) for complaints of child neglect, because an anonymous person told CYS that he/she felt that my parents were not making the best medical choices for me because herbal/natural remedies were added to my protocol and because I wasn't gaining any weight. Weight loss was being caused from the disease. I struggle to gain weight because I had developed many intolerances. Gluten free, organic and as much sugar free as possible is what cleared up those intolerances. Putting weight on is still a struggle, but nonetheless, I'm now 70 lbs and I no longer have all the severe stomach pains and cramps that I had for two years. My parents endured numerous visits from CYS during the course of their investigation into my medical situation and how my parents care for me and why they made the medical decisions they made. According to CYS, they found themselves in uncharted territory with respect to complaints related to a lyme medical situation. My parents were the first in Pennsylvania if not across the country that our attorney could find, and they won their case. In the end, at my parents' final hearing...the Judge said..."Beyond any shadow of doubt, Lisa Gaffney and David Gaffney, together have shown that they provide more than admirable care to their daughter Josie and should be respected and commended in the manner in which such an extremely difficult situation was handled." I love my parents 😊

Over these last 5-1/2 years, I have also been blessed with great supporters, my family and my friends. Journey 4 Josie has several annual fundraisers, as our tax-exempt and non-profit organization was started in September of 2010, by two of my best friends, Julia and Caryn, to help aid in payment of my medical bills. Journey 4 Josie is also proud to say we generously share those donations with HALDSG (Harrisburg Area Lyme Disease Support Group). Funds going to HALDSG are for research purposes and for the development of more adequate testing, and for victims who can not afford the testing and to aid in advocacy work throughout PA as we bring awareness of this disease, as well as the education and treatments that are so desperately needed.

There is so much more yet to be learned and discovered through research and education. This disease effects victims not only physically, but also emotionally and financially, and has a great impact on the victims' families as well.

Every few days my mother receives questions from other fellow lymees or she is asked to help direct someone who thinks they have it or had it and was misdiagnosed.

PA is #1 in the country again this year for the most reported cases...and Central PA areas are severe. Our first suggestion: find a good LLMD Second suggestion: contact your local lyme disease support group or the closest one to you. Third suggestion: always listen to your gut or your intuition...if you suspect something is wrong or not right, you are right. You have the right to question any diagnosis as you have the right to multiple opinions. Learn from fellow lymee experiences. We can only prevent this devastating disease from spreading by joining forces and fighting this together.

If you know of someone with lyme disease, or someone that has arthritis, MS, bell's palsy or any disease that mimicks lyme disease, and was bitten and despite previously being treated for lyme or not, please, please encourage them to be rechecked thru an LLMD also known as a Lyme Literate Medical Doctor. Lyme disease is known as the "Great Immitator" for very good reason. You do not need a bullseye rash to have or have had lyme. It is very often over looked, under tested and misdiagnosed. There are many strains of lyme disease that are not detected by the testing we have today. Standard testing is very inadequate, as I am just one case in point. Most of all, please research and educate yourself on lyme disease and know that there are support groups available to answer all your questions and concerns. Lyme disease is treatable if caught early enough. Once you are chronic it becomes a whole different ballgame as you can see and then the disease becomes dormant if you are lucky...but yet there is no cure.

When you see or hear of someone who has lyme, please take the time to talk with that person, share stories, questions and concerns...and when you see the battle we fight with our government begging them for help at the house and senate levels....we beg you to join that fight as well! We can't do it without YOU! You do NOT have to be a fellow lymee to show your support and help us to fight for our needs and our rights to better health care where lyme is concerned.

Most recently I was named Ambassador to the American Dreams Pageantry for my advocacy work thru J4J. This work means so much to all of my family and supporters. Please know that J4J, our supporters and volunteers, my family, as well as myself, will continue to pay forward the support, the godness and the graciousness to as many victims as we can, just as it is shown to us.

Your donations today will touch the lives of so many in a very special way, by helping them get back the quality lifestyle they deserve. Through my experience I have also quickly developed a great respect for all the doctors, the

nurses, the foundations, the programs, the supporters and the victims and their families. You are all in my heart and the hearts of so many.

We must unite to fight...and we can then win this battle together, the ugly and painful battle against lyme disease and co-infections.

HUGS and Good Thoughts to you all,

*Josie*

## UPDATE – April 2014

Hello to all my family, friends and supporters of Journey4Josie! I am happy to share that I have seen so much progress. After 5 years of being on multiple pain meds all at once, I have been **100% completely pain med free for the last 6 months!!!** On occasion, I have a little pain when the weather is bad, but nothing I have not been able to handle on my own with my heating pad ☺. I am feeling so much better! The swelling of all my joints is now all but gone, so we are focusing harder on my physical therapy. I have been steadily gaining weight over the last year, and my weight is now just under 90 pounds, the MOST I have ever weighed! My food allergies have all ceased, and I have had no reoccurrence of my gastrointestinal issues. Eating is finally so much easier! My sleeping at night has also greatly improved. I am proud to say that I have been able to catch up with all my schoolwork thanks to my school district and my wonderful tutors...and, as of now, I am on target to start my senior year this fall and graduate next year with the rest of my Class of 2015! I still have a very long and hard road ahead of me...but I have every confidence I will get there! My family, my friends, and all of you have been a major part of my recovery...you have all helped me to receive treatments that were and still are in great need, and for that my family and I will always be grateful. I am truly blessed. Many of you we have had the privilege of meeting, and many of you we have not...but you all are appreciated just the same ☺.

Please help us continue to fight...not just for me and my family, but help us to help other fellow victims. There are so many aspects of this disease in which lyme victims need help... medically, financially, emotionally and in other ways that impact the victims and their families on a daily basis. They just can't get the help they need for one reason or another it seems. So please continue to raise lyme awareness through Journey4Josie and on your own too, and continue to educate yourself about Lyme. Please continue to follow the lyme bills being presented to our government and the upcoming "Josie's Bill" currently being drafted by Senator Wiley. Join us by writing letters to your Representatives and Senators...share your stories or the story of someone you know that needs help. Pennsylvania, particularly Central Pennsylvania, is still reporting the most cases. The lyme communities are making progress, but it is still going to be a continuous fight for help...a fight in which we need you!

Hope to see you at our 2014 Race this year...Senator Wiley will once again be participating in our event...he has been and will continue to be a strong supporter of Journey4Josie to help me and to help all my fellow lyme victims!

Good Blessings to you all...

*Josie*

## UPDATE – September 2017

Wow, where to start....

Although I had finally gained weight and the pain in my body had subsided...and despite my persisting vision issues which had worsened over the next two years to where I had next to no vision, I had been able to attend Prom with my friends and graduate from high school. Unfortunately, we discovered that along the way, my elbow, hip and knee joints and the joints across the tops of my feet had all fused together, as well as some complications with my shoulders. It wasn't long til I found myself scheduling what would be excruciating surgeries with the best elbow and hip/knee surgeons on the East Coast, not to mention finding out how rare and complicated elbow replacements are in young adults and children. Timeline ended up as....Double elbow replacements right after Valentine's Day 2015 with 2-3 weeks of recuperation and therapy in a Philly hospital and then home to focus on finishing school to graduate in June. Then the day after graduation...back to Philly for double hip replacements and recuperation and therapy for one month until they dove right into performing my double knee-4 replacements, which after 2 more weeks of recuperation and therapy....I was transferred to an inpatient extensive physical therapy program in a Philly hospital. I spent 3 months in this inpatient program. Operations were successful, yet my range of mobility is still challenged. I can do more for myself, however some simple things are still very challenging. Since I returned home the end of October 2015, I've attended physical therapy 3 times a week, locally, and went back to focusing on my vision issues. Also during all this, I started new and extremely expensive immunotherapy treatments that eventually aided in the partial restoration of my vision and required a monthly trip to Philly for an infusion.

I spent the remainder of 2015 and most of 2016 preparing for major eye surgeries with countless trips to Boston to the eye surgeon most qualified to handle my unique situation. In August 2017 I had surgery on my right eye. Cataract removal which proved very tedious as well a cleaning behind my eye and rebuilding my pupil as the inflammation damaged my eyes most severely that the cataracts stuck to my pupil. My surgeon, known world-wide, told my parents that in all his 30+ years of severe cases, never has he seen such a case of this severity. Although my vision was not restored 100%, he was able to regain some of my vision when it was questionable that I would regain any at all. Then while my right eye continued to heal and I have learned to wear specialty contacts and glasses, I was preparing for the same surgery on my left eye. One again, successful. Not restored 100%, but more than anticipated. God is good, and I'm so very grateful.

Figuring out how to proceed with my shoulders and feet will be forthcoming. One thing at a time.

Currently I am still attending therapy 3 times a week and monthly treatments in Philly, and I have finally been able to focus on college this fall. After everything my body has been through, it feels amazing to be able to focus more on my dream now...my education as a biology major...look out world of medical research...here I come!

Continued Blessings to you all...

*Josie*