

LUPUS

Advocacy Day

Thursday | March 1st
Georgia State Capitol

Put on your PURPLE
and let's take LUPUS to a bigger SHOUT!

Join us for Governor's photo, House and Senate
resolutions, meetings with legislators and their staff.

8:30 AM - 2PM

Help Us Solve
The Cruel Mystery

LUPUS™

FOUNDATION OF AMERICA
GEORGIA CHAPTER

REGISTER AT LupusGA.org
or call 770-333-5930

Advocacy Story Writing Workshop

Presented by
Geri Hillegass and Tamie Miller



Gerri Hillegass



Tamie Miller

Advocacy Story Writing Workshop

Email questions during this
presentation to info@lfaga.org.

Why you need to tell YOUR story:

- **You can affect change** - Your elected officials want to help! They need to hear from you about your life with lupus to make a difference.
- **You can see things in perspective** - Sometimes simply writing out your experiences helps you make sense of what is going on with your body and your life.
- **There is a healing power in telling your story** - You allow the listener to understand your circumstances and your reality, giving them the opportunity to support you in a way that truly meets your needs!

Effective Story Telling Prioritizing Your Message

OPENER – INTRODUCTION

- Name
- Occupation (optional)
- Who you are/were without the presence of lupus (5 Adjectives)
- Date you were diagnosed / How long you have had lupus (No. of years is important!)
- How long you had gone without being diagnosed.

MEAT – HOW LUPUS HAS AFFECTED YOUR LIFE

- Physically -
 - How many pills / chemo / dialysis / hospital trips
 - Ability to work – Now -vs- Then
 - Types / How many Doctors
- Mentally - Depression / Anxiety / Memory Loss
- Socially – Isolation / Missed Functions / Paranoia
- Financially – Doctor’s Bills / Hospital Visits / Medicines / Loss of Income / Lack of Insurance

CLOSING – WHAT ARE YOU AVOCATING FOR

- Federal & State Funding
 - Research
 - New Drugs targeted specifically for Lupus (w/o toxic side effects)
 - Finding a Cure

LUPUS

January 28, 2018

MY LUPUS AFFECTED LIFE

1. Introduction –

Hello. My name is Tamie Miller, and I am a former professional hairstylist and makeup artist. Before my official diagnosis in 2005, I did not know much about the autoimmune disease except that one of my older sisters had been diagnosed with it and passed due to complications of lupus. Since being diagnosed, I began to educate myself on what lupus was exactly, I began to realize, like many others, I had symptoms of lupus going as far back as to when I was a child. Lupus had, unknowingly, been part of my life for a long time.



(678) 699 - 3107
Pureindulgence21@yahoo.com

2. How Lupus Has Affected Your World –

Since being diagnosed, I no longer work in the industry, and I have hung up my apron as a hairdresser (except on special occasions). Lupus has greatly affected my life in the fact that I am unable to do the thing that I used to be able to do. Lupus has drastically affected my energy level. Tasks that used to be so simple for me have now become strenuous challenges. There are days when my joints are in so much pain that it becomes extremely challenging to physically move. I take about 13 pills daily just to keep my symptoms from flaring up. My life consists of going to neurologists, dermatologists, and rheumatologists, while sometimes being required to go to specialist in between those major doctor visits. I go to counseling for my anxiety and depression since being officially diagnosed, and there are some days where I do not feel like participating in daily life, not because I do not want to, but because my body feels completely drained of energy. Paying for all my medications, doctors' visits, and necessary counseling has caused a financial strain, and there are times where I must choose between getting my medication or paying bills. Pretty much 99.9% of the time, I choose the latter. So, in other words, Lupus has completely change my life as I once knew it. I went from being the woman who felt like she could do everything at once to a woman who must learn to pace herself. Though living with lupus is a tough learning experience at times, I am fortunate enough to have strong support from others around me. Joining one of the local lupus groups truly helped me in the beginning because I could see that I was not alone. I am now a proud lupus advocate, and my goal is to educate others who may not fully understand what lupus is all about or who may be misinformed.

3. What You Are Advocating For –

I am advocating today for Federal and State Funding. There needs to be more funding for more research in curing and understanding lupus. We need new drugs targeted specifically for lupus without the toxic side effects. We will not discover these necessary medicines without research. Furthermore, I am advocating today in the name of all my fellow lupus patients and their loved ones. This is not a simple disease, and it can have a huge effect on not only the patient, but also their families and relationships. Today, I am advocating for me. Thank you for your dedicated efforts and support in helping us put an end to lupus. With your help and funding, a world without Lupus can be possible.

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GERI HILLEGASS

It was 1990 and I was 27 years old. I had a job I loved as a computer specialist, loved to travel, friends and a wonderful husband. It was time to start a family! I was working full time but my "morning" sickness was more like "all day" sickness to the point I had to stop working until this phase passed. But other problems began almost immediately, the most noticeable change is what happened to my face. I started getting lesions all over my face, it got worse and worse every day. The lesions that covered my face were large disgusting sores so embarrassing that I wouldn't go out in public unless I had to, mainly for check-ups. I went to a dermatologist and got cortisone injections in my face to try and help heal it.



But now, the pain began. It was mild for a few months but never really put much thought into it figuring it was the pregnancy. It started out with my legs, the pain became so intense as the pregnancy progressed that all I could do was sit and cry. Several months after my son was born and the symptoms didn't go away, I finally went to my internist and after a battery of test and a list of symptoms, I was diagnosed with Lupus. I began a regimen of medications and had to make some life changes. So many things I used to be able to do without thought, I just couldn't do anymore, my body wouldn't let me. In 2000 my life really got shook up when I was having a strange symptom of traveling white lights in my peripheral vision and an MRI revealed white matter lesions, on all different layers of my brain. The reality of Lupus was more real than ever now that it was attacking my brain. I began Cytoxan chemotherapy treatments that lasted for over 2 year along with all the side effects of chemo. It was a very difficult time in my life but I was fortunate to have the support I needed to get through it.

Lupus has affected my life both physically and emotionally. When I wake up in the morning, I never know if I will have the energy or ability to do what I want or need to do that day. It can be very depressing. My social life has been adversely affected because I am in too much pain or just don't have the energy to interact with people. Most people don't understand that just because we may look "normal" we feel anything BUT "normal."

I take about 15 prescription medications daily which gets very expensive even with insurance. Not all medications are even covered by insurance which limits some of the relief available. I have about 10 different doctors each a specialist that I see several times a year. Some weeks are filled with doctor visits or tests which becomes very tiresome and expensive.

Financially lupus has been a huge burden! Due to the high costs of frequent doctor visits, prescriptions and tests. The inability to be able work adds to the financial burden.

I've been through a lot, but others have been through so much more and even lost their lives to this horrible disease. We need funding to help with research to find a cure.

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FINAL THOUGHTS

- Bring the story with your photo (4 copies) to Lupus Advocacy Day on March 1st
- If you are not attending, email it to your elected officials.
- Go to <https://capwiz.com/nra/dbq/officials/> for contact information for your legislators.

LUPUS MATTERS

- YOUR story matters
- We NEED you!
- Intention without action won't move the needle



QUESTIONS

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