

TALES OF A LUPUS BUTTERFLY



by Julia Sherred

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BY JULIA SHERRED

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For more information, email: lupus@juliasherred.com

*IN MEMORY OF AND DEDICATED
TO:*

*ALL THE LUPUS WARRIOR WHO HAVE
GONE BEFORE*

*MAY ALL YOUR LUPUS BATTLES BE REMEMBERED. MAY YOUR
LIVES BE CELEBRATED FOR BOTH THE GOOD AND THE BAD.*

*FURTHER DEDICATED TO:
ALL THE LUPUS WARRIOR WHO
CONTINUE TO DO BATTLE*

*MAY WE CAN CONTINUE TO FIND THE STRENGTH WITHIN
OURSELVES AND EACH OTHER TO CONTINUE THE FIGHT.*

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INTRODUCTION

It all started after I sent the following Tweet: “Wanna know what my problem is? I'm afraid to stop. I'm afraid that if I stop, I'll never be able to start again and it will be over.” And with that little bit of introspection, I knew what my contribution to the Lupus Awareness Virtual Art Gallery, for the Lupus Awareness Month 2010 update, would be.

I, like many others people, if not all, who live with Lupus, have a list of fears as long, if not longer, than symptoms. One of my biggest fears is that if I give into the pain and fatigue caused by Lupus, if I completely stop doing, I will never be able to start again. I need to feel as if I am being productive in some way at all times. I do cut back on my activities, but I never completely stop.

I do not know if I could ever adequately explain the aim and purpose of this little book. By the time you are finished reading it, I hope that you fully understand its purpose. But if I had to try and summarize it in a sentence or two, I would say:

This book is so that nobody ever feels ashamed of their fear or anger, ever again. I know that is an impossible hope. Maybe a more realistic hope is, I hope this book lets you know that is okay that you feel the way you are feeling. That you are not alone in what you are feeling. That it really is perfectly okay and natural. There is no shame in it despite your best efforts to beat yourself up over it. That right at this very moment,

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odds are someone else is feeling the same things you are. I hope that if you start to feel alone, isolated and that nobody gets it, you can pick up this book, read it and really know you are definitely not alone.

And with that, another book was born. This is my gift to you, created from a number of my personal blogs, regarding my own struggles with Lupus. I hope that you find it useful. I hope that it helps in some way.

Julia “Jules” Sherred
October 2, 2010
Duncan, BC. Canada

THE EMOTION OF DANCE

I am not an emotional being by nature. I am very thought driven and it isn't until I have had time to really think about a situation, that I attach some form of emotion to it, if any. I wrote about this before. However, there are four things that, as a general rule, can illicit huge emotional reactions from me. They are prose and poetry, movies, music and dance.

All four of them are able to beautifully illustrate things that quite often I find I am unable to express myself. Even though growing up I was heavily into math, chemistry, physics, computers, etc., and they turn me on to no end since they are so rational, it would be safe to say the reason that I was also equally into dance, writing and acting was because it gave me an outlet to express emotions I cannot express in my day to day living. Out of the four, dance does this most effectively.

Dance has always had a special place in my life. When I was younger, if I was not herding by friends together to put on some play, we spent our lunch hour choreographing some dance number. I would be able to lose myself in the music and the motion. I was able to escape the pain that was my childhood and enter new realms. Acting had and continues to have the same affect on me but not to the same extreme as dance. Even if there is no music to accompany the dance, you can carry yourself off into an unheard rhythm. Your body becomes the rhythm, it becomes the base line.

You flow from one beat, one motion into the next. It is not unlike the process of ice turning to water turning to vapor. You can transcend states of being. It is like the process of pressure being built up along a fault line, waiting for a release and then followed by the wonderful release of an earthquake or the forceful eruption of magma from a volcano turning in a beautiful red lava flow.

Dance can tell stories from the worst tragedy to a wonderful comedy. It can lift you up and it can bring you down. As I sit here now trying to express all the wonders that is dance, I do not think I could ever adequately illustrate the power that it has for me. Dance saved my life. So did acting when it came to escaping pain and trauma and finding a constructive way to deal with the crap that happened to me as a child instead of turning to other options such as drugs. However, dance did so in more ways than one.

A dance teacher I had for quite a while had Lupus. Now she wasn't only my dance teacher. Her husband was my grade 11 English teacher. Her oldest son was one of my best friends in high school. When I was going through some of my darkest moments in high school, my English teacher would always write little notes on the back of my papers or my poetry, letting me know that I was not alone in what I was experiencing. He also went as far to share with me the struggle he and his family had with his wife's debilitating illness. It wasn't until after high school that she became my dance teacher. She taught dance for many years until the Lupus really took hold. And then she spent most of 20 years in and out of hospital. She was told that she would never walk away. Not only did she walk again but she taught dance right up until a couple weeks before her death, right

before she lost her final battle with Lupus. It was her love of dance that propelled her to walk and dance again.

She was also instrumental in my diagnosis of Lupus. One year the pain got so bad I missed close to a month of dance. When you dance over 8 hours a week, missing a month is a lot. I came to her after the month and told her that I had to drop out, I could no longer move. It felt as if knives were being dug into every single joint in my body and nothing was working for the pain. She asked if I had ever been diagnosed with any muscular or skeletal disorders and I began to name a list the length of my arm. She told me that I am a very gifted dancer. She sees me shine when I dance and she sees the release it gives me. She told me that she cannot do without me in her class. She told me that I need to sit down with my doctor and say, "Look, since I was 15, you and a whole whack of doctors have diagnosed me with this and that and this and that, don't you think it can all be one thing?"

So that is what I did. My doctor said, "Hmmm, wow I can't believe we missed this, I am sending you to the Rheumatologist." And that started the road to a final diagnosis of Lupus. Dance saved my life. Eventually, I was able to return to class and finish out the year. Unfortunately, that is the same year that the complications of Lupus took the life of my dance teacher. Thinking about this now brings tears to my eyes. She inspired me in more ways than I could ever express. She gave me the strength to get out of my wheelchair three years ago after I suffered my stroke. She was an amazing woman, who brought so much joy and love to this planet. I was very fortunate to have her in my life.

So given the above, it is no wonder that I love, LOVE, *So You Think You Can Dance*. I cannot watch a single episode without crying. Tonight was no exception. Normally I will cry once, maybe twice, during an episode. Tonight I cried more times than I can count. The recaps of a couple of the dancer's journeys made me cry as I could relate to the obstacles that they faced to be where they are now. Two of the dance numbers made me cry. The first number, which was a beautifully choreographed hip/hop number, was about a couple that could not get to sleep because they had unresolved issues to work through from the day. It spoke to me on a very personal level.

My relationship ended a month ago today. Maybe one of the contributing factors was because we broke my number one rule a few too many times about never going to bed angry. And that is what that dance number was about. The other, was a Bollywood number to Jai Ho. Jai Ho is one of my pick me up songs. If I am in a down mood, I crank it up as loud as I can and do the silliest dance either in my chair as I am working or all around the house. The dance was alive and loving and upbeat and beautiful. There was one particular move about 30 seconds into the song that just made me break down in tears because of the sheer joy of the number.

I cannot type anymore. I have not even come close to expressing all that dance is to me. And for now I am going to stop as the tears are starting to flow again. Both tears of pain and tears of joy. So in ending, here is a poem that I wrote the night before my dance teacher's *Celebration of Life*. Her husband, my former English teacher, read it during the ceremony. As we (her students and close friends) were meeting in her dance studio before the service, someone saw the

poem. It touched her so much that she took it from me and blew it up so that it could be turned into a poster, giving everyone a chance to not only hear it but read it. As well, (because my dance teacher had such an impact on the local community) it was printed in the local newspaper. This poem was my first published piece.

CATHERINE'S DANCE

The day she was born the dance took stage,
A courageous spirit that would never age.

It moved in all aspects of her life,
Her love and her compassion, her pain and her strife.

The dance was apparent when she did succeed,
But there was a time when it seemed to recede.

When she could not move and it always seemed night,
The dance still raged on, fighting to see the light.

It leaped and it turned trying to break free,
Emerge from the shadows for everyone to see.

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Out of the dark, the dance broke its chains
Like the sun breaking through the clouds and the rain.

Her dance continued to move until the very end
Surrounding all of her family and friends.

She lived a life, which inspired all she did meet:
A mother, a wife, a teacher; she did not miss a beat.

Although she is gone and she will be missed very much,
Her dance lives on in all that she did touch.

Story Originally Published: June 10, 2009

LUPUS RELIEF COULD BE COMING

After 50 years (yes you read that correctly) there could be a new drug to treat Lupus. I swear, this is the best news I have heard in a very long time! It could be the best news ever! For me, as of this moment, it is the best news ever. The only way this news could get better is if this new drug is approved and it actually helps with my Lupus. I so wish I could be part of the second trials. Lupus is such a difficult thing to live with.

For me, the most difficult aspect of the disease is that it is invisible. I can live with the chronic infections. I can live with the chronic inflammation of joints and tissue. I can live with the crap like having a stroke and needing a hysterectomy due to the disease. I can live with the chronic pain and the chronic fatigue. I can live with the cognitive impairments. I can live with the hair loss. I can live with never knowing one day to the next how I will feel or what system will be attacked next. The hard part is that people look at me and do not see a sick person, as outwardly I look healthy and I do a good job of hiding the war that is raging on inside of my body on a daily basis.

Those with Lupus tend to be looked at suspiciously since most of the time they do not look sick. They get treated as if they are hypochondriacs by a lot of people, even those close to them, who just cannot understand the difficulties of this disease. They get this treatment even from their own families. I remember after my

hysterectomy my family saying, “Hmmm, well maybe there is something wrong with her.” And then after my stroke, a year later, there was more, “Hhmmmmm, I guess she wasn’t faking after all.” And even after that and a few other major health crises, most people do not get it. There are maybe (and that is a big maybe) 3 people who do since it has affected them and their families directly. Lupus has also been the cause of a few failed relationships because they find it difficult to deal with health crisis after health crisis and my lack of ability to do a lot of things.

I am currently on a huge cocktail of medications that only work to a point. They give me about 25% relief from symptoms. I currently take 7 different medications. At one point it was 9, however I developed an allergy to one of them and the other treatment was way too painful to go through once a week. The pain of the treatment did not outweigh the benefits of said treatment. So for there to be a new treatment that may actually work for me and maybe, just maybe, drop my medication count. That idea is beyond awesome! (With Lupus there is no set treatment. Doctors have to play a medication game since Lupus affects everyone differently.) I was starting to lose hope when it came to Lupus research, since there has been nothing new in so long. This is so welcomed news to me and many other lupus sufferers.

Story Originally Published: July 20, 2009

PUTTING A FACE TO LUPUS - THE ELEPHANT IN THE ROOM

Hi, my name is Julia and I have lupus. Today has been a joyous day for those of us who suffer this disease and to our friends and family, who take the time to really understand it. Unfortunately, among all the news surrounding the results of the latest drug trials for Benlysta, all the focus has been on money and not the faces of Lupus. Lupus is called the disease of a thousand faces for a reason. There is no cure and it is unknown what causes Lupus. And despite television programs like House constantly throwing out the word Lupus on every episode like some meme, most people have no idea what Lupus is.

I am going to try and put a face to Lupus. I am going to try my best to be very blunt and write from the heart. I am not going to talk so much about the physical effects of the disease. My focus will be about the psychological and sociological effects of the disease. This scares me for many reasons that you may understand as I try my best to tell my story openly and honestly. I hate talking about this as I always get met with pity and the "I'm sorry" replies when people become uncomfortable and do not know how to respond. I am not sorry I have this disease but I am always sorry for sharing that I have this disease. Hopefully this time I will not be sorry. I am not going to get into stats or give a bunch of links. It may help a reader understand and at the same time, since no two Lupus sufferers are the same, it may not.

When I was first told I may have Lupus, my heart sank. Lupus = death and I knew this better than most people, as I had just lost someone close to me due to the complications of Lupus. The death was awful because we had no warning. It is not uncommon for someone with Lupus to be told many times, "This flare may be the one that kills you. It is time for you and your family to prepare." So you do what you have to do and you get better, only for the next time. With the person I lost, we were told that many times over decades and every time she got better. Then without warning, she was dead.

Many of us who suffer from Lupus have to see doctors regularly. I personally have 6 doctors who monitor my condition. When I am not fed up with living for doctors appointments and am being a "good" patient, I have to see some sort of doctor every two weeks and have blood tests done a minimum of once a month. My friend went in for her regular blood work. Her liver levels were off. Less than three weeks later, she was dead. When I got the phone call, I thought it was a cruel joke. What do you mean she was dead? She was just teaching dance a couple of weeks ago. Why now and without warning? Why not the many times in the past when we were told this may be it? It was at that time that my own road to diagnosis had begun. The last thing I needed was a reminder that I was about to be handed a painful death sentence.

The elephant in the room was becoming bigger. You do your best to ignore it. You do your best to live each moment in the now and not worry about the what-ifs. Because let me tell you, there are thousands of them. You find yourself every now and then looking at your

children and fighting back tears. You have these moments often where you think, "I have to take a snap shot of this and remember it always always and make sure they remember it always always, as next week I could get bad news." Then you beat yourself up for acknowledging the elephant and forgetting to just live. But then you beat yourself up again because you need to be realistic. You need to make sure that those whom you love know it and you really need to make sure that your children know it.

My heart breaks every time my youngest brings up my stroke. That was a scary period for my children and I HATE that they have to go through my illness. Two movies that make me bawl to no end are *Finding Neverland* and *Stepmom*, as they deal with children losing their mothers to disease. My heart breaks because my children will go through that one day unless there is drastic change in the treatment of Lupus. Today gave me hope and for the first time I was not afraid for what my children will have to go through despite my best efforts to ignore the truth and just enjoy them.

It is a very sad thing (and hopefully they find the why's to this soon) that most women who are diagnosed with Lupus are in their child-bearing years and get the diagnosis shortly after having children. I love my children with all that I am. However, had I been diagnosed with Lupus prior to having them, I would not have had children. And admitting that out loud is hard for me since for as long as I can remember, I knew I was going to be a mom. I always wanted to be a mom first before anything else.

It is hard not to live in fear when you have Lupus. There are so many things that can go wrong. There is no rhyme or reason to any of it. You go through your days and live until you hear news of some illness spreading or some letter comes home from your child's school reminding you the cold and flu season is here and what extra precautions to take. You get this news and you have to stop living, even if its for a split second while you think about how this impacts you, your family and your daily life. You have to think about things that most people never have to think about.

It is not uncommon that I have to be put in reverse quarantine because if I get these illnesses, they can kill me as I have no immune system. To make matters worse, I cannot be vaccinated to even be able to give myself some form of immunity to some of them. There was one period where I was not allowed to leave my house, not even to go to the store, for 2 months because I had 5 infections in as many weeks and the next one my doctor was afraid would be fatal. This always makes traveling scary as well. The last time I traveled my doctor actually said to me (and some may find this harsh but my doctor and I are very blunt with each other), "You better be careful or you will end up in a body bag."

All the what-ifs that go through your head. Is the vacation worth getting an illness that could become fatal? An illness that for most people would be nothing to recover from. Is the fatigue that is sure to occur worth it? But you cannot live your life in a bubble. You take these risks because you need to live. That does not stop the fear and doubt that crops into your brain every time you start to plan anything. And even so these thoughts may be short lived and they do

not consume you (or at least you need to believe they are not consuming you), they are still there. The elephant becomes bigger.

And then comes relationships and the dread of forming real bonds with people. I feel a stupid sense of guilt when it comes to forming both romantic and platonic relationships. I am not talking about acquaintances here but real meaningful relationships. I do not want more people than absolutely necessary to suffer through this with me. It is unfair of me to ask that of them. And if they are truly close to me, suffer they will even so they do it willingly because they care for me and love me.

It is very difficult for me to really open up to people and let them into this part of my life. Two reasons for this is because I do not want them to suffer emotionally as they have to watch helplessly while I go through a flare, and the other is because in the past the elephant in the room got so big, the relationships ended when finally they could no longer deal with it. I am always afraid this will happen despite the fact I tell myself and others, otherwise. I pretend I do not care and that I do not need anyone. When it is time to have "the talk" about the elephant, panic sets in. This is the moment where you can no longer ignore the elephant and you have to prepare the person who tells you they want to take a journey with you in life, "Guess what? I have this thing and well odds are that I will die before I am 60."

What a joyous conversation to have to have with someone who has told you they want to take a life journey with you. I have had this conversation more times than I want. Having it one time is more times than you want. Some have said (and very naively. I thought in

my mind at the time and now, still do), "Yes I am capable of walking this road with you. I want to take a journey with you. Let us build a future together even if its a shorter future because you are worth it. Let us live in the now and not worry about the future." Then when the battles with the elephant begin, they decide they do not in fact have what it takes and leave. I cry. I pick myself up. I tell myself it is okay because I knew this was a possibility. I move on.

I trick myself into thinking I do not need or want deep relationships only for the next opportunity to present itself and the fear and panic to once again set in. I want the elephant to die. It is so draining to ignore it and so depressing to face it. Then when moments come up where it starts to stomp its feet and make noise, you wish you had a gun.

I have suffered with illness all of my life. I was diagnosed with my first auto-immune disorder when I was 6 (psoriasis). I have spent a lot of my life ill and spent many years misdiagnosed with a myriad of things (some of them were almost fatal) until finally I got some much needed answers when I was finally diagnosed with Lupus. That diagnosis was a mixed blessing. On one hand, I had answers. On the other, possible death. I do my best to ignore the elephant.

I do my best to live harmoniously with it and not let it depress me. For the most part I am cheery and grateful for the wonderful life I do have in spite of it. I do not take a single moment for granted and I have experienced and done some pretty cool things with my life. I have overcome so many obstacles that have been thrown in my path. I hope to be an inspiration to even just one person who suffers from

any disease or chronic illness. Growing up, I was fortunate enough to have two great women in my life who dealt with chronic illness. They taught me that no matter how bad it may be, for someone else it could be worse and you do what you have to do to get through each moment.

I look at it like a 12 stepper does, second by second if that is what it takes you to get through the day. You do whatever it takes to help people (even if its just a shoulder or by example). You do whatever it takes to get better even if there is no getting better. You know what, you can have a great life regardless. You are also allowed to have moments of anger and rage. There are moments (even if they are brief) that I rage against it. Periods where I stop seeing the doctors because all they tell me is, "We are giving you the best treatment we have at the moment and hopefully this will pass." There is never any hope when seeing the doctor. Periods where I stop taking my meds as they only offer 25% relief and what is the point of living if I am tied to drugs, doctors appointments and blood tests.

Periods where I want to tell everyone close to me to go away because having me in their life will only bring them pain. Periods of depression. But I am human and I am entitled to these periods (even so I beat myself up over them and feel weak). Moments where I think why me? Something would be terribly wrong if I did not have these periods.

Today though is not a day to ignore the elephant. Today is a day of hope. Today is a day to look the elephant in the face and say, "AHA YOU SUCKER! After 50 long years we may finally have a gun. Not

just a tranquilizer found accidentally while treating other illness but a real gun! It is time for you to leave the room forever."

Looking back at my blog, I admit I am not as open and honest as I wanted to be, as I had hoped to be. However, I do hope for once I am not sorry for talking about the elephant. I hope that next time anyone is confronted with the elephant that they are not afraid to acknowledge it. I hope that next time someone tells you about this elephant, you may understand even a small fraction how your reactions to the elephant amplifies how extremely difficult it is for the person sharing that they indeed have this elephant living with them.

I hope...

Originally Published: July 20, 2009

RAGING AGAINST LUPUS

Dear Lupus,

Lupus, I hate you! And not because you are ravaging my body, but because you are destroying my children! I am currently in tears because my children are in constant fear that you are going to kill me and I was just served with a quick reminder of this.

My children have still not recovered from the emotional trauma they endured when I had my stroke three years ago. Thanks to you, my non-existing immune system and being on immuno-suppressants, I contracted the dreaded H1N1. A lot of people may think “it’s just the flu” and no big deal, but for me it is. And for my children, it is even a bigger deal. Thank bob, the doctors diagnosed me early enough and I was put on Tamiflu. However, this does not put my children’s fears to rest.

It breaks my heart to no end (after I tried very hard for my oldest to not find out I have H1N1 but due to the lovely thing called the internet, he found out while he was at his dad’s) when I receive the following email from Kid1:

Kid1: um u have the swine flu

Me: yes I do

Kid1: um will u live?...dont lie...

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Me: I should live hun. They have me on heavy duty meds to treat it. Try not to worry too much. I love you

Kid1: no freekin duh im going to worry u have like no immune system and ur my mother..i love u to

Me: Well I should be okay. They were able to get me the medication in time. I just have to rest more than the normal person and have to stay quarantined longer

I should not be having these conversations with my 14-year old! It breaks my heart and I cannot stop crying because of it. Please just go away! I cannot wait for the day when they come closer to approving new medications to shoot you dead. You are ruining my children's lives. Did I tell you I hate you because of it?

With much loathing,

Jules

Originally Published: September, 12, 2009

IS IT REALLY FRIDAY?

I have been really lax the past few weeks when it comes to updating my blog. There are many reasons for this: I was away for 2 weeks in August; I am sick; I have been working on my book which I am happy to report is being completed much quicker than I thought it would be. Turns out that I had more of it written than I had thought.

This week has been a very emotional week for me for many reasons. It has been a roller-coaster between many moments of surrealism and “Wow, I can’t believe this is my life” to moments of fear and panic as my book gets closer and closer to being ready to go to the printers.

One of my followers on twitter asked me why I am so terrified of publishing this book as I am on the radio, and tweet and blog personal things. The answer is really simple. The radio is a fleeting moment in time. Tweets and blogs can be erased. This book will be in a permanent print form available for the whole world to see.

And to be honest, this scares me. One on one, I am an open book and will share anything. This book is not one on one and once it goes to the printers and becomes available, I will lose control over how some very personal information about me is distributed. On one hand, this excites me as I feel I have a very important message to share. Then when I really think about it, I feel as if I am going to vomit. There is a small part of me that feels I am about to do something pretty awesome. This may be the most important thing I do aside from being a mother. This part needs to be the loudest voice in my head at the moment so that I do not chicken out yet again and not publish.

But it is now beyond the point of no return. The word is out there and all that is left is for me to receive the cover and off it goes. Earlier today, I received the sales copy for my book. When I read it, it brought tears to my eyes. I am going to take time right now to once again thank Chris Knight for all of his support as I went through this process. Without him, I do not think I would have found the personal courage to continue through this process. Besides providing emotional support, he also proofread my manuscript and wrote the following sale copy.

“Julia Sherred’s *From the Mundane to the Insane* is the touching tale of one woman’s love of life and hope for the future despite overwhelming challenges. Written as a love letter to her two children in an intimate, conversational tone, Sherred explores the contours of her fascinating life as a dancer, actor, daughter, mother, and Lupus sufferer. It is a tender and humorous celebration of life and family, of creativity and geeky obsessions, and is an inspiration and invitation for each of us to grab life by the horns and truly enjoy every aspect of our wonderful journey without destination.

One dollar of each sale is donated to the scientific search for the treatment and cure for Lupus.”

Originally Published: September 18, 2009

BECAUSE SOMETIMES THANK YOU IS NOT ENOUGH

I have had a lot to deal with the past few weeks, both professionally and personally. It has been a very emotional period for me to say the least. My blog postings have been very reflective of that. Some people understand why I sometimes get overly personal and some may not. If you are among the ones who may not, I think the best way I can explain this is, people get scared. And those of us who live with Lupus live with a lot of fear. I want to allow people to know that it is okay and they are not alone, even at times when they feel they are alone, as I often do. Most of my feelings of being alone are self-inflicted for reasons I have explained before. I think the emotional battles one goes through living with Lupus are much harder than the physical ones. At least this has been my experience living with this disease.

And on top of those day to day battles (which get worse this time of year) I may lose one of the major things (aside from my children) that keep me battling and going. And that is my Geeky Pleasures website and radio show. I have been so tempted the last few weeks to just write the “Goodbye, it was a pleasure. Maybe we will see each other again sometime in the future” post and have my site, blog, Twitter and Facebook go silent now instead of at the end of the month when it is time for the bills to get paid and there is no paying them.

Then one of my friends who are on the inside of all of this will kick me in the ass and I decide to prolong it. I lose faith in myself and I

begin to think none of it really matters to anyone. And even so one of the primary motivations for me doing what it is that I do is so that I can at least pretend the elephant is not in the room, and because I love it with all I am, I want to leave a legacy that was left to me by my grandma and dance teacher. As I have written before, they had chronic illness as well. Lupus took my dance teacher a couple weeks after my road to diagnosis had begun.

And if it wasn't for her, I probably would have never been diagnosed. My grandma was on oxygen most of my life. Both of these women did amazing things with their lives and did things to help others, despite their challenges and obstacles. They are my heroes and I live my life hoping that I can pass on their message to others and give them hope, even if it is just one person. If I manage to do this, then my life meant something. Living with Lupus meant something.

And then shit happens like it has been happening over the past few weeks. Yes, there have been many amazing things going on as well, which cause me to stop and say, "Wow, I cannot believe this is my life!" But, sometimes the shit gets so heavy it is hard to see and appreciate the good. I feel as if I have failed on what it is I hope to accomplish. That I need to accomplish in order to keep some form of sanity and dignity. Yes, my friends tell me they appreciate me and it is so appreciated and cool but that is what friends do. They love and support each other through the dark times so that they can celebrate the good together.

And then something small happens that brings me to tears. I am completely overwhelmed at the moment and cannot stop crying. I

was checking my stats for my Geeky Pleasures website and I found a post that linked to my site, which stated how much I have inspired them. Just when I am about to give up on humanity, somebody will do something small that brings me to tears and everything is fresh again. My purpose has been served and if everything ends at the end of the month, at least I know all of this was not in vain.

I want to say thank you, but sometimes thank you is not enough.

Originally Published: November 14, 2009

Tales of a Lupus Butterfly

INITIATE AUTO-DESTRUCT SEQUENCE. AUTHORIZATION: LUPUS, 4, 7 ALPHA TANGO

There are things that no matter how many times I experience them, they still fascinate and amaze me. My body breaking down when I am getting sick in rapid fashion is one of those.

I have been living with Lupus for over a decade now. I am constantly sore and fatigued because, aside from my primary disorders of Lupus and Antiphospholipid Syndrome, I have many secondary disorders, Chronic Fatigue Syndrome and Fibromyalgia being two of them. On a good day, my pain levels are about a 4. On a normal day they hang between a 6-8. This is despite being on 8 different medications to treat my various faces of Lupus. A bad day is when I finally have to visit my doctor or emergency for prescription pain killers because I can no longer cope with the day to day pain. My doctors have been wanting to put me on Prednisone and daily prescription pain killers and antibiotics for years now. But that is the last line of defense and I am not willing to roll over, give in and stop fighting.

It is very hard to explain all of this to people. Especially when I share this very painful part of my life. And instead of just listening, I am greeted with pity. My days are difficult. Simple tasks such as walking to the bathroom take me a long time, as I need to talk myself into taking the steps necessary to walk. Every step is like knives are being dug into my joints. But I get up and do it. I move through my days

moment to moment if that is what it takes to make it through the pain. And that is on a not so bad day.

There are many other inconveniences that I live with thanks to Lupus. Normally I do not think about them as they are always there and I just do what it takes. And then events like tonight happen and I become fascinated with just how Lupus works and I wish I had some way of examining my cells as this process takes place. It would be very interesting to be able to sit in and hear the conversations between the different systems and cells in my body, as the battles that rage inside my body advance from little and quiet skirmishes to full out brutal and bloody war.

I have spend most of the last 6 weeks sick (and by sick I mean it becomes more difficult to do the moment to moment and I am at a point where I have to make a complaint about it). It started off with a really bad chest infection right at Christmas that started off feeling like a simple cold to becoming close to the point of hospitalization overnight. I was put on antibiotics and was as fine as you can be with Lupus for about a week. Then shortly after my birthday, I got another cold. This one hung in there for a very long time. I kept tweeting that I needed to get better by Feb 3 because I was going to GottaCon and I knew that it would completely breakdown my defensive system. One small phaser blast and my shields would be down.

I did not get better, however I learned from my experience at PAX, when I ended up contracting H1N1, what extra precautions to take on top of the already extra precautions I took. (Yes going to GottaCon may not have been the best choice, but I need to actually

live life once in awhile and there are acceptable risks you take especially when you are at war. Sometimes you need to sacrifice a few troops in order to win the larger battle.) I made sure to spend as much time as possible off of my feet. I made sure to drink more fluids. I made sure to always have something in my hands whenever possible so that I had an excuse to not shake hands. I was there on a public appearance as a special guest and didn't want to appear rude when introducing myself and wanted to avoid having to go into some explanation as to why I wouldn't shake their hand. I washed my hands even more frequently than I normally would. And even so I didn't get as much sleep as I should, I did get a lot more than I did at PAX.

I left GottaCon feeling tired and exhausted. However, unlike PAX, it wasn't an unusual level of tired and exhausted, it was within my range of what I would consider normal for me. Then tonight it happened. Within less than an hour, my cold progressed from a mild cough now and then and a somewhat irritated throat to being barely able to swallow and feeling as if my throat is being ripped up my neck and out my nose every time I sneeze. My glands went from normal to the size of walnuts in what felt like a nanosecond, my sinuses are pounding and my head is all fuzzy. It is as if the auto-destruct sequence was initiated and somebody forgot to abort it.

As awful as this may sound I cannot help but to be enthralled by the whole process. All I can think right now is that I wish I had Dr. Crusher's sickbay so that I can place myself under the scanners and just watch the chaos that is currently going on inside of my body. Would it not be awesome if we had even a fraction of this

technology? Technology that does not require giving blood or more invasive procedures. Technology that can help us scan and map in real time, to listen in on the communication process between all the different factions currently at war. Imagine all that we could learn about disease, especially a disease that fights as covertly and in such a guerrilla manner as Lupus. Imagine the possibilities. I just can't help but to think of the mechanics and the wonder of it all.

Fascinating.

Originally Published: February 12, 2010

IN WHICH I FEEL TRIUMPHANT AND DEFEATED ALL AT ONCE

So the lovely Denise Hudson wrote a very wonderful song for my World Lupus Day project. Lyrically, it spoke to me. It very nicely tells of some of the struggles I personally go through with my Lupus. Musically, I thought I could sing it. I thought maybe I can do this. And then I attempted it and failed miserably.

Her original version would musically go one way and my brain wanted to go another. At first, I thought my inability to sing it was due to a number of factors I do not think I can explain, so I won't. I'll just say it didn't quite work for me even so it was a very good piece. So I asked her to send me the guitar only and I would attempt it that way. I listen to her vocals 3 or 4 times, I then played the guitar only once and then attempted to sing. I failed. The song in that version did not breathe in a way that was natural for me and brain was still wanting to go directions, musically, that the first version was not going. If I had more time to learn the piece, then maybe. But we are on a deadline here.

I listened to the guitar only a couple more times in an attempt to *get it*, when I realized that I couldn't get it, in its current format. So presumptuously, I thought of how it would work for me. I found a melody in my head. I hummed it a couple of times to see where it would go. Then without thinking, I horribly recorded what I heard. I felt so defeated. I use to be able to sing. Melody wise, I think the song works. However, vocally it really is shit.

I do not write music. Music really isn't my thing even so I know music. It just isn't something I do. Apparently, I have now co-written my first piece of music (even so there was no actually writing involved. I heard a melody and recorded what I heard in my head with one take and one attempt). Given this, I do feel a bit of a personal triumph. I did something that I never thought in a million years, I would do. I made music. But I could not sing it. Not even close despite what others may think.

Maybe it is because they have never heard me sing. Maybe it is because I know what I am capable of. What I produced was a million miles away of where I use to be vocally. I was so frustrated with this yet another reminder of how I once use to be brilliant and now I am dim. I cried. It is very frustrating for me when I am served with harsh reminders that I am no longer capable of the things I was once very capable of. Not even close to the same ballpark of capable. I thought briefly that, with some practice, I may be able to do it. Nothing but failure ensued. Mind you, I only attempted it a couple more times. However, this is one of those things that I immediately know if I will or will not get it. There was no way I was going to get it. So I said, "I'm not going to do it." Then I stopped thinking about it. I walked away.

I had put it completely out of my head. So far out of my head, that I forgot the melody that I had created. That part isn't really all that surprising as I had only attempted to sing it a handful of times and only listened to it a couple more handful of times. Then last night, out of the blue, it was back in my head. The melody kept repeating itself over and over. I could not get it out of my head. However, it was

slightly different. It was in a different key. It was one step lower than what I had originally attempted it at. One step lower of the miserable failure. I took this as a sign that even so I had quit, my brain was not going to let me quit so easily. I am supposedly a fighter after all and do not give up.

So without thinking and without attempting to sing it once through first, I recorded what I heard in my head. I didn't put any more effort into it than the first time I did it. I sang it sitting down, with my knees up to my chest and with no air behind it whatsoever. I just spat it out. And you know what? It wasn't terrible. It was still shit. It was still a million miles away from what I am capable of. A million miles away of where I once was vocally. However, given the fact I have a cold, my Lupus Auto-Destruct Sequence is activated, and I made no real attempt to sing it, it isn't that bad. I think I may just be able to do this after all. I'm not feeling so defeated anymore. I feel as if I could be brilliant once again.

Given I only have 5ish days to do this thing (if I do it) it will never be up to my standard. It will never be up to what I know I am capable of. And this isn't overly self-critical Jules talking. I am realistic and I know what I am capable of and what I am not. Now even so it will not be up to what I use to be able to do (when you don't sing for 3ish years and are very out of practice, it takes a long time to get the old vocal cords back into shape), I think I can get it to a level where I think it is passable.

We will see I suppose. I am still at the maybe stage of doing this. I am going to attempt it anyway. And if I can't, then I can't and Denise will sing it for me. And if I can, I can. At least I am attempting it. It may be a foolish attempt. We will just have to wait and see, won't we?

Originally Published: May 2, 2010

IN WHICH I'M ANTSY AND EXCITED

What a freaking crazy week! I don't even know where to begin. And the crazy isn't over yet. I have a feeling I will not have enough hours in the day to get everything done that needs to get done this weekend. Submission deadline for my World Lupus Day project is tomorrow and despite over 100 people saying they will do something, I have yet to receive much.

Then add to this that I am currently experiencing one of the worst flares I have experienced in a while, a cold and stomach bug, a happy Jules is not a well Jules in any sense of the word. To say I was ill would be quite the understatement. I wish I had a dark corner that I could crawl into and sleep for eons if that is what it took to feel slightly more human. The way I'm feeling at the moment, it feels that it would take forever and a day to feel better again.

And then there is the song. But OMG YAY, I managed to get my vocals recorded and in 3 takes. And let me tell you, that was quite the trial. I can't count how many tears were shed out of frustration. To begin with, I haven't sung in at least 3 years. Nothing more than humming around the house and maybe quietly singing a line or two. Nobody has heard me sing in quite a long time. Then add a cold, which leads to a sore/ hoarse/ laryngitis throat/ voice... it is not a nice mix or sound at all. As well, I was afraid that I would have to sing sections of it at a time, over and over again, and then piece it together to create a final track. But nope. I managed to sing it straight through and in a pretty consistent fashion, without it sounding atrocious.

There really isn't too much that needs to be done with the vocals besides EQ and cleaning up the noise and a few other small things. Or at least, that is what I think. Also, my pain levels are at a 8.5-10. I had to sit to sing as, at the moment, I am not capable of standing for more than 30 seconds without the pain becoming intolerable.

I have a whole new appreciation for those who participate in Song Fu. I kinda co-wrote this song and I still had quite the difficult time learning it. I received the very first draft of the song last Friday, made changes over the weekend, received the changes, tried working with the new music and couldn't wrap my brain around it it, asked for more changes, learned the changes really would not work after trying to work with them, went back to the second incarnation and really listened to it to hear where exactly it wasn't working for me, made some changes, moved around and edited some of the music, and sent the changes back to Denise and then attempted to bang out the vocals in one day.

Okay now that I actually listed this process and I realized that I've only had the basic demo music for not even 2 full days, I think I'm even more impressed with what I've accomplished, especially considering I don't write music/songs, haven't used my vocal chords besides talking in years and am extremely ill.

Now, it still isn't perfect. Far from it. It isn't any where near close to the caliber I was once capable of. However, considering I only worked with the music in its current form for maybe 5 hours total, sang the song maybe 10 times, am ill, it is passable. I do not hate the results. That is something. Especially considering I am a huge perfectionist and my own worst critic. And after listening to the finished demo

with my vocals for the past hour, I still don't hate it. I still think it is passable. I am actually smiling when I listen to it. I don't want to go as far as saying I like it but I am satisfied, considering. And despite me cringing every time I hear my mistakes (they are extremely loud to me), I still feel it is passable. If you knew me, you would understand that is actually a pretty major thing for me say.

And now the above is in the wonderful hands of Denise for her to clean up a huge amount of noise on my tracks and add some other touches, including her own vocals. Oh yes, aside from the above obstacles, my sound card has been acting up as well. If there wasn't a lot of white noise (I don't understand why all of a sudden), there were a couple quick demo recordings for the first couple incarnations, where the sound was quite distorted. Hopefully the white noise can be removed adequately without distorting the sound.

I'm antsy and excited to hear the finished product. I will either have it late tonight or tomorrow at some point. I am also antsy and excited to see and hear what else comes in for this project. And hopefully I make it through this weekend intact and Monday's launch will be a success. I'm also worried that everyone who said they'd do something won't come through. I get that way when people cut it close to deadlines. I always finish well ahead of deadlines and I have a hard time dealing with people who wait til last minute. It causes me anxiety. However, if every one does not come through, at least I will have some material. And hopefully, next year it will be bigger and more successful, as it won't be such a last minute idea.

Phew. Must. Remember. To. Breathe!

Originally Published: May 7, 2010

Tales of a Lupus Butterfly

YOU WOULD THINK I WOULD LEARN OR SOMETHING

Maybe the “or something” is the only thing remotely relevant to what is on my mind at this moment. This something has been plaguing me all week. It is frustrating and irritating like nails down a chalkboard while a gnat buzzes your ear.

“I use to be brilliant” has been something my brain has been saying for a few weeks now. I’m sure if you searched my last few blog posts and listened to my Lupus podcast, you’d read and hear me say this. I have come to realize in the last week, after the successful completion of my World Lupus Day project, I’m still brilliant. Just in other ways. I may not be able to hike for hours upon hours anymore. I may not be going for long runs anymore. I may not be dancing over 8 hours a week anymore. I may not be shining on stage anymore. I may not be spending hours crafting and painting anymore. I may not be able to recall the huge amounts of information stored within my database of a brain with the same ease as I once could. I may not be able to vocalize my thoughts as effectively and succinctly as I once did. But I can still create and be productive.

My latest project is proof of this. Hindsight can be a royal bitch at times. I just had the thought that I wish I had taken screenshots of the virtual art gallery before I transformed her from a caterpillar to a butterfly. When I told people that it would be going through a slight redesign, they didn’t understand what was wrong with it. They thought it nice to look at and functional. But I had a vision. I had a

strong idea of how I wanted this transformation to happen. The caterpillar phase used the colours from my book. The butterfly phase uses the colours from the World Lupus Day logo, but with a stronger background to make all the elements pop. The layout is basically the same. But with a redesign of the colours and adding some elements, the transformation was quite noticeable. Beautiful and gorgeous are some of the words people used to describe the new site.

I don't know where I'm going with my thoughts at the moment. I do think what I did is quite impressive. Even if you do not take into account that I have been having to spend roughly 12 hours of my day sleeping the past couple of weeks, I did something few would be able to accomplish. Well at least not in the time frame that I had set for myself. Before the site underwent its transformation, it had 3 pages and 10 posts. In less than 24 hours there was an almost complete template redesign, now has 13 pages and 36 posts, 6 videos (4 of which I had to edit, including 1 that I created), a dedicated YouTube channel, 12 photo galleries comprising of 73 different photos, 4 songs and a whole bunch of links. I accomplished all of this in less than 24 hours. I even had a couple of hours to spare before my self-imposed deadline. And when I was done, I was beyond exhausted. I still am. I thought I would look forward to a week of rest and nothing added to do. I was wrong.

I have been so bored this week. I am use to having a million projects on the go at once. My brain needs to be kept busy and engaged. I like deadlines. I like having more to-do lists than should be legal. I need to have these things. If I don't, my brain because listless and it wanders. I have been beyond exhausted. My current flare is kicking

my ass in more ways that I can articulate. Despite it, I still have drive and ambition. My passion is still ignited and my need to be productive has not been stamped out. I can still accomplish huge things despite it. My body may not physically be able to do much these days but my brain (even when really fuzzy as it currently is) can still accomplish great things.

This frustrates me in a way. I think what frustrates me is there are so many jobs I can do. There are so many things that can be accomplished over the net. But for whatever reason, it seems potential employers are hesitant of either creating new telecommuting jobs or transforming jobs, once thought of office jobs, to telecommuting jobs. And there are so many tools that make this transformation so simple and these jobs effective. This past week has reminded me that I can still get a lot of things done and in very little time. And while a lot of people close to me are probably thinking I should be resting and recuperating instead of trying to find myself another big project, afraid that I am going to collapse and my flare get worse (which could very well happen and yes I do need rest), I know what I need.

I NEED to feel productive. I need to feel as if I am accomplishing something ESPECIALLY when I am feeling dim, instead of brilliant. I need to have something that reminds me, sure I am not as brilliant in some areas of my life as I once was, but I have found new ways to be brilliant. I have found new ways to shine. I found ways to turn things that are a huge disadvantage into an advantage. I have not given up.

Yes, I still need to find balance. Or better yet, I need to learn balance. I tend to overdo it as a result of a variety of things. But honestly, the resulting beyond exhaustion is so worth it. Because I feel good about myself. I do not feel like something that should be thrown out with the trash or shot like a lame thoroughbred because I cannot race like I once could. I think for once I want to be noticed. I try to fly under the radar for some weird reason. I have asked people I have interviewed to not make a big deal out of it, so that I could remain unnoticed. I don't do things so much to get noticed by others but for my own sense of self-accomplishment.

But I think this may be changing. The more I accomplish, the more I see the finished results of the crazy ideas that I keep having, the more I think "Holy shit! That is pretty awesome! Even if you do not take into account my disability, that is pretty awesome!", then I look at the world and feel a little slighted. I know that there is so much I can do from the comfort of my home, despite my crazy but necessary sleep/rest cycle, yet I cannot find opportunities to use my very unique and what I consider awesome skill sets. I feel defeated when opportunities are not presented to me. I know you have to work to find things. And even though I don't get huge recognition, I still get my fair share.

Receiving close to 200,000 page views in less than a year on Geeky Pleasures, without any real promotion is an indication of this. And when I think that Fark only received 50,000 in their first year and in a time when they had no competition like I do now, I feel accomplished. People keep telling me how much they love what I put out there and there is a part of me that cannot help but to think "then why isn't it paying off in some real way?"

I really do not know where I am going with this, either with my current thoughts that I am spewing out as I think them or with anything that I am currently working on or want to work on. Maybe that is part of the problem. As I've said, I'm bored. Even so I am still producing things on a daily basis, I am feeling unproductive. I need something that I am not getting at the moment. I need something that will really engage my brain. I need something where I feel creative. Maybe something will present itself, maybe it won't. Maybe I'll find an opportunity, maybe I won't. I do know that something needs to happen soon before I start once again feeling dim instead of the brilliant that I am.

Originally Published: May 15, 2010

Tales of a Lupus Butterfly

THE BITTER-SWEET OPPORTUNITY

I am a ball of nerves like I have never been before. You may think it crazy but it is what it is.

When I awoke this morning, I was greeted with an email regarding *Love Simple*, an independent film that deals with Lupus. Starting on Monday, partial proceeds will be going to S.L.E. Lupus Foundation (in New York and in Los Angeles).

I think it is really apparent by now, Lupus awareness, treatment and research causes are near and dear to me. Also in this email was a request for me to interview actress, Patrizia Hernandez. She plays the main female character, Seta, who has Lupus. Of course, I said I would love the opportunity. I think some may be perplexed about this decision, because at this moment in time I have stopped doing interviews and have put a lot of them on the back-burner until certain circumstances change. I have had many interview requests and I have turned them down. And for others, it will make complete sense because of the subject matter. I have made it one of my personal life goals to do anything and every thing I am capable of to bring greater awareness to this very mysterious disease.

But this opportunity is bitter-sweet. The main character's situation greatly mimics my own. This interview hits very close to home and is very personal. I am very nervous. You would think that after interviewing for as long as I have and considering the people I have

interviewed, it wouldn't be an issue. But this interview will probably be one of the most important and most difficult interviews I will ever do.

I need to approach this interview in a way that I have not had to deal with others. I am afraid in order to cope that I may become detached and emotionless while I do it, so that I do not do something stupid, like cry. Every time I have talked about this in some public way, whether it be on the phone with the BC Lupus Society, when I was interviewed over on Too Much Awesome or when I did my personal Lupus podcast, I cried. But I cannot detach myself from this. It would be a huge disservice to every one involved if I did. It needs to be real. It needs to be honest and open.

I have never been as nervous as I am right at this moment. I have had my fair share of nerve-wracking experiences, but this one takes the cake. I feel a responsibility with this interview that I have not felt with the others. The others were for fun and for shits and giggles. There was no motive behind it other than geeking out with fellow geeks. This interview is very purposeful and meaningful. This is different.

When I was speaking today with one of the people involved in helping to organize this, he said, "Patrizia looks forward to speaking with you, and we appreciate your interest. Your site looks terrific by the way, so we're honored to be a part!" Like that doesn't add a bunch of other nerves. I am very happy and honoured they asked me to do this. There are no words to describe exactly what it means to me to be able to use my voice and bring awareness to this, what it means that I

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have been sought out to use my voice for this. I am humbled and touched.

I just hope I don't become a mess while I do it. I also hope, despite the bitter-sweet nature of this opportunity, that more happen to come my way.

Originally Published: June 9, 2010

Tales of a Lupus Butterfly

IN WHICH I TELL THE TALE OF WEIRD AND WONDERFUL COINCIDENCE

I live in a cone of silence. Meaning, my suite is very much sound proof. It is rare that I hear the noises from the outside world. Today, my cone of silence was broken. Most likely this is due to the fact I was on extra alert as I waited for a much anticipated package to be delivered by FedEx.

I had difficulty falling asleep last night. It may as well have been Christmas Eve. My thoughts were going at warp 10, as I wondered what was in store for me once *Love Simple* arrived at my door and I could finally sit down and watch it in preparation for my interview tomorrow morning. You see, judging by the trailer for the movie, I have a funny feeling a lot of what I am about to see will mimic my own life. Especially when it comes to having “the talk” about the elephant that takes place when you form real relationships. I have a feeling it will be a weird and wonderful experience, watching part of my life played out on screen. Especially as most people have no idea what Lupus is.

This morning, I awoke much earlier than I normally would. I was one edge (a good edge) anticipating the arrival of the package. Now, I was like a kid on Christmas morning waiting for the house to wake up. I had difficulty focusing on my tasks for the day. I was pacing the corridors of my mind, daydreaming about what my evening had in

store. I kept getting out of my chair and peering out through the cracks in my blinds any time there was a hint of noise coming from the outside world. And then the delivery van arrived minutes after tweeting, “I feel like a kid on Christmas morning waiting for the house to wake up.”

I jumped out of my chair and leaped to the window to see if the vehicle, which had just pulled into my driveway, was in fact the package. Seeing that it was, I gave a little squeal and ran to my door. What was about to happen was all kinds of weird and wonderful. I opened up the door just as the delivery lady was about to ring my doorbell. I am going to try and recount this amazing tale as accurately as possible, but it an hour later and I am still shaking.

Delivery lady, “Wow. You must have been waiting with great anticipation for this package.”

Me (barely able to contain myself), “I was!”

Delivery lady, “You are like a kid on Christmas morning.”

Me, “I am!”

Delivery lady, “What is in this package that has you so excited?”

That is when I began to recount the story. The story of this movie called *Love Simple* and how it is about this girl who has Lupus. Before I could get any further, she interrupted.

Delivery lady, “Does this affect you personally? Do you have Lupus?”

I told her that I do have Lupus. That I have SLE. Tears began to swell in her eyes as she told me that she too has Lupus. She has Discoid Lupus. She said how she knows that it is not as bad as what I am going through, as Discoid Lupus is not as severe as SLE, but that she gets it. Tears began to swell in my eyes and my hands could not stop shaking, which caused the package to rattle.

I gave her a quick synopsis of the movie. How this girl, who has Lupus, falls in love and has to tell this dark secret to her romantic interest. How that conversation is the worst conversation to have to have with someone. How I myself have had to have it more times than I want. Her eyes swelled with tears even more, as she nodded her head and quietly said, “I have had to have that same conversation more times than I want as well. I know how difficult it is. Not many people are aware of what Lupus is. It is not easy.”

I then told her how I kinda interview people and do things “on the web” in an effort to raise awareness and funds. I told her about the interview that I have tomorrow morning, with the actress who plays the main character and how difficult it will be, as it hits so close to home.

We stood there and stared at each other in silence for what felt like an eternity. In reality, it was probably only a few seconds. We both seemed to have the same revelation at the exact same moment that there were no more words that could be said. That this weird and amazing set of circumstances are much too profound for that. We both understood what the other was thinking. We both “knew” equal amounts of pain and joy were being felt by both parties, as we stood on my doorstep.

Before she left she told me that this was the best delivery she could have ever made. Neither one of us expected to have made that type of connection with someone today. The odds of one person with Lupus delivering a movie about Lupus to another person with Lupus are staggering, especially as only .0007% of the world’s population has Lupus.

She started to walk away but quickly turned back to face me and say, “Thank you for sharing this with me. Thank you for doing what you are doing. More awareness needs to happen. I am very happy and fortunate to be the one who got to make this delivery today. I hope you enjoy your movie.” I thanked her in return and with that she walked away, as I closed my door.

I came back into my room, barely able to breathe and my muscles seizing up with nervous energy. The sheer awesomeness of today’s random events will be one that will never be forgotten and I will take it with me for the remainder of my days. We were both able to touch each other deeply and in a way that does not happen often.

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I may be forgetting a few things as I recount this tale. Some of the dialogue may not be completely accurate. But my mind has been blown again and my heart and soul touched. I seem to be having a lot of experiences such as these as of late. So please forgive me if my database of a brain decides to sputter for a few moments while it tries to grasp the awe of these events.

Originally Published: May 10, 2010

Tales of a Lupus Butterfly

THE WEEK THAT WAS

I remember a time this space would be updated at least 5 times a week. Now it is lucky to be updated 5 times a month. Things just feel very odd lately. I have a lot of things I could say but I do not know if it matters if I say them or not. And by that I mean, I don't know if it matters to me if I say them. Whether it matters to others really isn't my concern.

I have been totally neglecting my personal blog lately. There are various reasons for this. 1) I have been so busy keeping Geeky Pleasures updated and by the time that is done, I really am not in the most communicative of moods. 2) I'm in this weird place at the moment. I've been in this weird place for quite some time and my brain is having a hard time wrapping itself around these events. 3) Lately, I seem to be at a loss for words, A LOT. And even so it has been a nice slow week for Geeky Pleasures and I've had a lot of time to reflect, I just can't get my thoughts to translate into words that would make any type of sense.

I think part of this has to do with having a huge amount of moments of squee. There have been a lot of moments of WTF as well. The events of my life seem very bipolar at times. It seems that every time something really big happens, something equally really shitty coincides with those events. And you cannot really talk about the moments of squee (or at least I feel that I cannot) because: a) I think that people may think I am bragging or putting on airs or something; and b) some of it involves talking out of school (even so it is not "bad" gossip but I see all gossip as bad) or talking about things I am

not really at liberty to discuss. And well, the moments of WTF, nobody wants a downer.

But this past week has been quite the emotional roller coaster. It has put me in a spot, mentally and emotionally, that causes me to feel both happy and uncomfortable at the same time. I find it quite strange. I am unable to decide exactly how I feel about what has gone on. It is nothing negative, but I do find it a bit unsettling. Only because I have a hard time with “I don’t know.”

I did something this past week, that for me, was a bit of a triumph. And not for reasons many other people might see it for. For me it was a triumph because I overcame another fear. And the weird thing about it, is I’m the one that is getting the thank yous. I find this so very odd! All I did was help someone get a message out. All I did was agree to an interview. All I did was allow someone to talk. Sure I did some of the talking as well, but it was in relation to this other thing. If you haven’t figured out what I am talking about yet, I am talking about my interview with Patrizia Hernandez and my review of *Love Simple*.

The amount of feedback and the things said to me in private about this whole thing has left me speechless. I do not know if I should go into too many details because I do not want people to take it the wrong way. It feels weird to be told that it is an honour that someone got to work with me. It feels weird to be told that I’ve inspired. It feels weird to be told how I touched someone deeply. It feels weird when I am shown genuine appreciation. I think maybe that is what it boils down to. Is that I have genuinely inspired and touched people

and that I was genuinely appreciated. This does not happen often. And an even bigger bonus, I made new friends in the process.

And despite the fact it being one of my goals in life (to inspire and to be an example when it comes to dealing with certain things), I never imagined it would happen to the degree it appears to have. I thought I would be lucky to accomplish this with one person. However, thankfully due to technology, my reach appears to be broader. And even so the internet allows my voice to be heard by a potentially unlimited audience, I never expected nor was I prepared for the reach it appears to have. I am humbled and in awe. And as selfish as this may sound, it lets me know that the shit I have to deal with on a daily basis is not in vain. That I have been able to do something positive with it. Even so I do these things altruistically, it does help me get through the really bad days.

But here is the thing. I feel “guilty” (for lack of a better word) accepting the thanks I have been given. At least with this latest bit of overwhelming events. Because if it were not for Mark von Sternberg creating this movie, if it were not for LupusNY reaching out to me and asking if I would do this interview, if they had not thought about me, well then I would not have had a voice to use. I am so greatly touched that I was the one asked to do this. I am sure there are many other people who could have done this, but they asked me. Why? I doubt I’ll ever know. I am not going to even ask. I am just thankful they did.

I am so very thankful to every one behind the making of *Love Simple*, John Casey at Magic Star Entertainment and LupusNY for all they are doing to raise money and awareness for Lupus. They are the ones

that deserve the praise I have been receiving. And hopefully they are getting it. But all I'm seeing lately is comments directed towards me. They are the ones that have done the good deed. I'm just the messenger.

I do not know if this makes any sense to anyone. Any time I try to explain this in more detail to those close to me, they don't quite get it. Which is not their fault. I think it is one of those things that you have to experience to understand. Or at least have my strange way of looking at the world.

And despite how weird this all feels and my opposing feelings towards it, I do hope I get more opportunities like this. It does feel good to know you have done something for "real good". It is nice when you are allowed to be a part of something that will benefit so many people. Again, I am humbled and touched that I was asked to be a part of it. This experience has been amazing. Regardless of some of the uncomfortableness surrounding it, and I am glad.

Originally Published: June 17, 2010

I THINK I MAY WANT TO SCREAM OR...

Cry or break something or just collapse into a heap in a dark corner and give up. I'm so bloody frustrated at the moment. I'm also very angry with myself for allowing my current physical state to affect me in such a manner. But the moment by moment is incredibly difficult at the moment and for the first time in a few years, I may actually be afraid. And I have to admit, I hate myself for possibly being afraid.

My Lupus auto-destruct sequence as been activated again. But for the first time in years, it is affecting more than one of my systems simultaneously. It is much easier to distract myself from the added pain levels when it is just one part of my body, but when it is more than one, I just want to say "FUCK THIS! I am so done with all of it! Time for me to give up the fight and go on the narcotics and prednisone ." And then I feel like a bloody coward. I start to cry and I loathe myself for it. I start to feel even more alone because most people just don't get it and they give me those looks and words of pity. And it sucks big blue hairy monkey balls.

The auto-destruct sequence started with a sore throat and pounding sinuses. And now my left TM joint is so incredibly swollen, that I can barely open my mouth to speak. Eating and drinking is impossible without yelping and tears streaming down my face. I can't yawn. Last night, I awoke multiple times to the most excruciating pain. When the boys ask me a question or want a conversation, it is all I can do to not say, "Please, just go away" and then I feel like such a terrible parent. And I loathe myself even more.

I'm afraid that will I have to start getting weekly cortisone shots in my jaw again (a 2 inch needle jammed in between joints is FUCKING PAINFUL). I haven't had to get those injections in at least 6 years. I was doing so good despite the fact I have not been really well in years and the constant infections. But the cortisone and gold injections were stopped because the NSAIDs, muscle relaxants, methotrexate and other meds, were finally doing their job.

How do I talk to anybody about this in any real way? I can't even admit to myself right now that I may be afraid and accept it. If I can't accept my own fear without beating myself up over it, I can't expect others to accept it and not feel let down. I'm getting to the point once again where I just want to tell every one to go away because I have a strong feeling things are going to get worse before they get better.

I should have seen this coming. The last few weeks, my sleep has been terrible. I had chalked it up to my OCD being in overdrive because I am stressed out with other things as well and it is not liking the change in routine. Ever since the boys got out of school 2 weeks ago, each morning I've been waking up in a panic, thinking I've overslept. I had assumed that because I am such a creature of routine and structure and a lot of my life has been disrupted lately, it was my brain's way of trying to cope with too many changes at once, by not allowing itself to give up yet another routine and constant. Or maybe all these stressful things are what has contributed to my body experiencing thermal nuclear war.

I have been trying so hard to remain optimistic, cheerful, to keep my sense of humour and keep joking around with people, but it is getting

increasingly difficult. I just want to rage right now. I need it to be okay with people. Correction, I think I need it to be okay with me. I need to give myself permission to be something else other than brave. But I am afraid.

I really want to just scream and rage but I can't even open my mouth to do that. So maybe I'll cry instead and find it within me somewhere to forgive myself for this moment of fear and weakness. A moment that if it were anybody else, I would tell them it is okay and understandable and they are entitled to feel that way. I need to give myself the same permissions and messages I give others. I just don't know if I can face what it would mean to fully surrender and admit to the fact that I may be afraid.

Originally Published: July 11, 2010

Tales of a Lupus Butterfly

REFLECTIONS OF A HECTIC SOUL

This poor space of not much happening. The tumbleweeds and cobwebs have been finding their home in this once frequently updated spot. I wish I could fully explain what has been happening. But once the crazy hectic that is my day is over and it time for quiet reflection, communicating with others is the last thing on my mind.

My friends have suffered. My personal blog has been sorely neglected. Once upon a time, I had told myself that I would update this spot at least three times a week. Even if it were just a paragraph or two. But I am the type that does not believe in stories that begin with “once upon a time.” They are filled with grand dreams and desires, but contain little reality.

My life continues to take twists and turns that were never envisioned and I find myself sorely unprepared. The last three months have been overflowing with high highs and low lows. I realize I find myself thinking and sharing this often. And no sooner do I think, “Things cannot get any more insane and peculiar”, life decides to show me different.

And because I am a person of privacy, a person who keeps the really good things and really bad things close to my chest, because I’m the type who withdrawals frequently to a Fortress of Solitude, which later became my Batcave, during these moments, the rest of the world outside of my teeny tiny circle becomes invisible. For me it is a

necessity. And if something threatens the inner then the outer starts to collapse. I am the type who needs to feel secure within my nucleus world before I can feel secure in my interactions with the outside forces. And at times, I am feeling as if my core is beginning to fracture. So my energy has been focused on making sure that I remain whole.

It really isn't all doom and gloom. There have been way more moments of awesome than not. And the not isn't what I would consider terrible, it just needs a little more support and care. I've been needing to focus my energies on the things that fall under the category of "makes a real difference in my life at the end of the day" and allowing the "it is pretty window dressing, neat and cool but at the end of the day, when all is said and done, it doesn't really change anything" to be ignored.

At times though, I feel as if I am not being perfectly honest with people. And I'm not quite sure what to do there, especially as I'm known for being unfailingly honest and blunt. People ask me how I'm doing and they get the default answer of, "I'm good." Which isn't a total lie. Overall, I really am quite swell. Sure my Lupus has been a real pain lately. I'm the worse I have been in years. I'm not as bad as I once was but I haven't been this beat up in a couple of years. So "I'm good" is a completely valid answer to an extent, as it could be and has been much worse. However, I guess this is my own "Lupus Lie". I've never fully shared the extent of my Lupus until just very recently. And only one person has heard the full, unedited truth of the situation.

People ask how the boys are doing. Again, the answer is, “They’re good.” And they are. But they are each going through different things right now. My heart breaks for them. But they fall under the sacred category, so only one person will hear the entire truth on that situation as well. I had a conversation with Kid2 the other night that nearly devastated me. I suppose I haven’t been doing as fantabulous a job as normal masking the pain that I am in lately.

As we were curled up watching a movie together, out of the blue he asked, “Mom... why isn’t there more focus on Lupus fundraising? Why do people care more about Cancer than they do Lupus? Do they not understand Lupus can kill you too? I don’t understand why nobody cares...” And then he went into his quiet place. I considered him for a moment and tried to mask the tears in my eyes and voice, and responded, “I think maybe it is because more people get Cancer than Lupus. Cancer is easier to understand, treat and diagnose than Lupus.” He came back with, “More reason to research Lupus instead of Cancer. They have the answers for Cancer. They don’t for Lupus. I don’t want you to die.”

What do you say when your 11 year old says that to you? How do you respond to such adult questions coming from such a young child? How do you cope with something that no child should ever have to think about? I did the only thing I could think of. I gave him a hug and a kiss on the head and told him that I loved him and he is never to forget that.

And then there is my relationship. Despite the fodder, it is doing just fine. We may each be going through different things at the moment

and individually may not be doing so brilliantly, but we are fine. I suppose people ask because they are concerned. However, my gut reaction is to respond with either “None of your fucking business” or “We are doing horribly. Does that make you happy?” As with my children, this is sacred. So the really important things do not get discussed in public. If I wanted people to know, I’d tell them. But only after clearing what is okay and not okay to talk about with the other person in this relationship. Because after all, we are the ones that are in it. Not the observers who whisper and gossip in dark corners and then fish for information. So again, they get the “We’re okay” because we are, even if individually, it isn’t the entire truth. But the whole truth is nobody’s business but our own.

It feels weird even sharing this much. But I am tired. I am feeling like a dartboard caught in the middle of all these different spheres that I use to keep quite separate from each other. Somehow they have managed to meld and collide. My friend life has mixed with my relationship life. My family life has mixed with my friend life. My relationship life has mixed with my family life. What use to be quite distinct worlds, that never shall meet, have mixed and mingled. What use to be clear and defined boundaries have become a blur, leaving me to build new lines in an effort to keep the core whole and secure.

At the end of the day when I’ve had time to reflect, after being bombarded by “how are things?” emails and messages and feeling like every body is being nosy and not respected my boundaries, I can conclude that they do it because they care. They may not show it in a way that I am comfortable with and instead show it in a way I find quite intrusive, but for the most part I can conclude they care. The

problem is (and most would not agree this is a problem), too many people care. And I'm not always sure that they care for the right reasons. My energy is finite at the moment. It only has enough real focus for my inner most relationships: my children, my relationship and myself. Everything else is just window dressing. So instead of answering a million questions about how life is, I blog. Then I just have to say it once and if they honestly wanted to know, if they honestly cared, they will read it and understand.

I also have so much awesome going on right now. Like a lot! And I can't share that either. SETEC ASTRONOMY (too many secrets). When the time is right, people will know. As I've written, things are mostly really good. I have a lot of pretty amazing things going on right now. I've been presented with some really cool opportunities as of late. These opportunities may not be paying off monetarily (which seems to be important for a few people in my life) but... well I think people will understand why that does not matter once I am able to share.

I'm blessed. I have solid relationships and a beautiful family. But my core is a little rattled at the moment, leaving my soul hectic and feeling frenzied. In time, I will reach a new state of equilibrium. I just ask that people are patient. I ask that people allow me to come out of this on my own time. The more I feel pushed and pressured into being sociable and "happy Jules", the more I retreat because I don't feel as if my needs are being respected. I feel as if people only care about their need for a happy Jules and not my need for space.

Honestly, I am good. I am just in my cave at the moment, taking care of the things that are truly important. When I am ready, when I am done reflecting on my hectic soul, I will emerge once more. I always do. And honest to bob, I think you will all squee with me when I can share the really awesome that is going on at the moment. I just thought I owed it to every one (mostly myself because I needed to get a few things off of my chest and erect some lines) to update this space and disperse with some of the cobwebs.

Originally Published: August 17, 2010

LUPUS *IS* MY SUPERPOWER

Now, isn't that such a strange statement. And today, I got to use this superpower to do some real good. This story involves other people and normally I wouldn't share without first talking with the others involved. However, as the bulk of this story played itself out (thanks to the wonderful internets) on Twitter, I think it is safe to share.

There is this guy I know. I'll call him @rulesaremyenemy. I know him through PAX but more specifically, through a group of us Twitter PAXers aka The Twitter Shitters. He has this other friend. I'll call her @alexandrathegr8. I had no idea who alexandrathegr8 was until a couple of hours ago. She had tweeted something, to which rulesaremyenemy replied, "Sorry to hear that. I suggest that you talk to @geekyjules." Being curious as to why I was suggested as a person to talk to, I clicked on the "in reply to" link to find this, "Parents know. I've pretty much been in tears for the past hour and a half. I tested positive for lupus, which runs in my family."

My heart dropped into the pit of my stomach and tears came to my eyes. I replied, "Please do. I have Lupus myself and do a lot of work (including write for a Lupus mag) surrounding this." Alexandrathegr8 sent back the message, "@rulesaremyenemy Thank you so much. I appreciate that so much. @geekyjules, would you mind if I emailed you?" I told her, "Please do!", and gave her my email address.

I am not going to go into the details of the emails, as those are private. I think it is safe to share she asked many questions. There are

many things which run through your mind when you face a disease that has a thousand faces and a thousand manifestations for each face. Questions, fears, anger, loneliness, sadness, desperation, naturally come into play. To make it even more difficult, she lost a family member to Lupus. My heart goes out to her. She has a difficult road ahead of her and she will be faced with a huge amount of misunderstanding from those around her. I really wish I lived closer to her so that I could hold her in my arms and allow ourselves to cry together.

I wish I had that when I was going through this, someone to just hold me and cry with me, without telling me it is all going to be okay. Because at the very moment this road begins, you do not think or feel that things will ever be okay again. You have to face things you don't want to in order to give yourself the best tools possible to tackle this demon head-on.

Unfortunately, she lives in the States and I live in Canada. So all that I could do was answer her questions, give her links to some resources she will need, give her e-hugs and insist upon her once more to please ask me any question at any time and I cried for her. I'm still crying for her. Her life totally sucks right now. It won't always be this way. She is a smart girl and she will get through this. But this really sucks big blue hairy monkey balls and she needs to know it is okay to admit that. You can have fear yet still be brave enough to fight it.

After we exchanged our first in what will be many emails to come, she tweeted, "i thank god for people like @geekyjules." This touched me. And I cried some more. When I made the decision last year to start

talking publicly about my Lupus, I was a lot nervous. I didn't want to be known for the girl with Lupus. I didn't want people to see me just for this disease. It was something my Alfred and I discussed when I was preparing for the interview I did with Patrizia Hernandez for "*Love Simple*." Yes, I have Lupus. Yes, it can certainly kick my ass in painful and unpredictable ways. But that doesn't mean I, myself, cannot kick ass and take no prisoners. I am still quite productive despite Lupus. I still get a lot of stuff done, I just have to go about it differently. Both my Alfred and I were afraid that doors would close, rather than open for me, if I got too vocal regarding my Lupus.

Today, I got to use Lupus to help someone else when they needed it the most. Today, my Lupus did some good. Yet again, today, Lupus was my superpower. I think I needed it as well. Today has been a wee bit painful. I have Chandler Claw Hand and I haven't even been gaming.

And people wonder why I love the internet so much. A few years ago, I don't think my Lupus would have been a power in this way. And thank you, rulesaremyenemy, for telling alexandrathegr8 to talk to me. It means a lot! <3

Originally Published: September 9, 2010

Tales of a Lupus Butterfly

SATURDAY SIMPLICITY

I'm ill. I'm ill to the status of turning into a "sucky baby". I don't complain unless it is really bad. My Lupus is really trying to kick my ass, showing me no mercy. I haven't had a flare last for this long in a very long time. Even so I always live with a good amount of pain, I had forgotten just how bad, bad can be. I've been running a fever since I awoke yesterday. Today, I woke up with mouth ulcers. I'm grumpy. I'm irritable. I'm liable to lash out at any poor unsuspecting soul. But thank Bob for my children. At least they can keep me laughing through all of this.

It started this morning. I got up feeling like shit and as if someone beat the crap out of me in my sleep, yet again. I put on my glasses and hobbled down to the kitchen to put on a pot of coffee. I sat down in front of my computer to check my email and Twitter, while I waited for the blessed coffee to brew. Because I'm ill, my vision is also being affected and every thing was blurry and as if it had a white film across it. That is when the following conversation took place:

Me: Where are my glasses?

Kid2: What?

Me: I can't find my glass. Help me find them. (*Starts searching*). Wait. Never mind. They are on my face.

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Kid2: BWAHAHAHA! OMG! I thought that only happens in movies! Too funny. Mom, that was pro. You are so fail today! Way too funny, mom.

Shortly afterward, his dad picked him up to do some clothes shopping. Upon his return, I hear the following:

Kid2: Mom, look at this! I picked it out all on my own. You want it, don't you? You're jealous aren't you? You'd wear this to your next convention, wouldn't you?

Me: OMG! DUDE! That is so awesome! YES! I do want it! Man, you're awesome!

Kid2: *giggles* I knew it!



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And just now, the following conversation occurred while I was outside getting some fresh air as I'm burning up.

(After Kid2 and his friend rounded the corner into the backyard)

Kid2's friend: I hear that you can walk on your hands.

Me: Yes, I can.

Kid2: She can also lick her elbows! I don't know how she does it. It is freaky but still cool. Mom, show her!

Me: Honey, I'm not feeling well. My body really hurts right now. Otherwise, I'd love to show my freaky skills.

(Kid2 and Kid2's friend try to lick their elbows, while conversing over how they don't understand how it is possible.)

Me: Fine! I'll do it! *(licks elbow)*.

Kid2's friend: WOW!

Kid2: SEE! Told you! They say it isn't possible to lick your elbows, but my mom can!

Me: Well, what "they" say is false. It isn't impossible, it is just rare.

Kid2 *(to his friend)*: She makes a good point. My mom is a rare breed of person. It is one of the things that makes her so awesome. She's rare and weird, but in a really good way. *(To Me)*: She also doesn't believe that you squee'd when I showed you my Mario shirt.

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Me: Yes, I did squee.

Kid2's friend: Then you'd squee over my brother's shirt as he has the same one.

Me: I probably would.

Kid2: Okay, mom. I have to go into the back forest now. I left my winter coat back there.

Me: Why is your winter coat back there?

Kid2: Because I needed it to sing The Mountain Climber song while climbing trees.

Despite feeling like death waiting to happen, at least I can look forward to a day filled with laughter.

Originally Published: September 18, 2010

DIE IN A FIRE, LUPUS!

I think I should start this blog with a disclaimer. Any angry remarks directed towards people is not directed towards anyone in particular. I'm just angry at the moment. I'm in a lot of pain and am just overall "stabby". It is quite difficult to remain my normally rational self when my body is saying, "Oh. You want to be productive today? HA HA! I'm gonna fuck up your vision, put sores in your mouth so that eating is painful, boil your blood and cause you to pass out for 4 hours, thus messing up your sleep schedule more than I have already and there is isn't a bloody thing you can do about it. You're MY bitch today!"

I am so angry right now. I haven't been angry with my disease in a very long time. I'm at the point where I've lost all compassion and sympathy for others. Any time I hear someone complain about anything, I want to scream, "I'm fucking dying but you don't hear me pissing and moaning that I had to crawl to the bathroom today, do you?!? I had a stroke when I was 30. 30! I had to relearn how to walk, talk, dress, feed myself and a bunch of other things. I had to have people wipe my ass and my own children feed me dinner! And you're complaining about what exactly? Suck it up buttercup and get on with your life! Oh... you want me to understand what it is you are going through? Please tell me then, have you made any attempt to understand Lupus and what it is that *I* am going through? No? Then shut your hole!" But then my brain tells me, "We are all dying, sweetheart. Some of us just quicker than others."

I am at the point where when anybody wishes me well, I want to say, “Take your fucking unicorns and rainbows and bugger yourself with them! Your well wishes do not cook dinner for my children when my body has decided to knock me out for hours, when the intent was just to lie down to relieve pain in my back! Your well wishes do not wash the dishes in my kitchen sink! Your well wishes do not remove all of my hair that is falling out, currently clogging my pipes, out of the bathtub drain! Your well wishes do not provide me a car or transportation to get my grocery shopping done! Your well wishes do not provide me a car or transportation to the doctor’s office so that I can get weekly injections in my ass cheeks and joints! All your well wishes are doing is reminding me of the fact I do not have the bloody physical supports I need right now in order to get better!”

Fuck, I am such a hag! I told you that I was stabby. Because really, if I were not this ill, I would appreciate it. But truth be told, I haven’t been this ill since right before my stroke 4 years ago. And before that, when my road to diagnosis had begun and I had to stop dancing because I could no longer move any joint in my body without it feeling as if knives were being twisted and turned inside of them.

People keep telling me to take it easy and rest. It seems all I do is take it easy and rest. Yes, I keep myself busy with my websites and contributing to a few others but lately, a good part of my day is spent lying down in between times that posts are scheduled. I’m not doing a lot. I actually feel quite useless and as if I were a lame horse that should just be shot and turned into glue. I don’t like feeling this way. What I don’t like even more, is the tongue lashing my brain gives me when I feel this way. The venom above directed towards nobody in

particular, I also direct at myself. I tell myself to quit feeling sorry for myself and just get the fuck on with my life because I am not a bloody victim. I'm a survivor damn it! But I am human. I would be more worried if I did not get angry from time to time.

And then I read something from one of my fellow chronic illness sufferers filled with rainbows and unicorns and "positive thinking will get you blah blah blah blah" SHUT UP! Just shut the hell up with the positive thinking stuff! I bloody well know this. Have you not read or listened to me talk. I know how to survive my disease, both mentally and physically. I get that you are trying to help but SHUT UP! Your rainbows and unicorns are invalidating my feelings. These are MY FEELINGS! Let me bloody well have them! They will pass and I will go back to being Data or Spock. Trust me on this! I'm already giving myself a hard enough time and telling myself to cram my anger up my bunghole! I don't need you to tell me the same thing but disguise it with passive aggressive unicorns and rainbows!

Yeah, I'm angry. Irrationally, I feel as if I am failing my children, myself and my friends. I cannot be the things I think and feel I should be or the things I think I need to be and I have no control over it. I've been having to decide if I'm going to up my normal meds from 7 to 9. The extra 2 will just be temporary. But I am having to weigh "is the cure worse than the disease". Because these two treatments require me to go to the doctor, once a week, for painful injections. These injections consists of gold salts in my ass cheeks. This bloody hurts! Because of the solution it is in, if you do not completely relax the injection site, the muscle spasms are ferocious. Once, I was afraid the needle was going to snap off because of it. And

the spasms continue for hours after ward. And the other is cortisone injections into my joints. Let the 2 inch needle jabbing and digging in between the joints begin! JOY!

So aside from the pain to heap on top of the pain I'm currently experiencing, there would be added fatigue. I don't have a car and I have no physical supports. I have to rely on public transport. And of course, it doesn't do a straight line from my house to the doctor's office. So what would normally be a 20 minute round trip (including doctors appointment) if I did have a vehicle, turns into a 20 minute walk (round trip) + 1 hour bus ride (round trip) + 10 minute doctor appointment + time waiting for bus to return home. These trips would require me 2 days to recover from and leave me in a lot of pain. So how am I going to cook dinner, clean and take care of two children? Do I continue with the heavy meds I am already on and hope they get the disease back under control, or do I do the extra measures, which will make things worse but could bring the disease back under control quicker, however they are not guaranteed to work?

I am angry. I woke up this morning feeling shitty. But as I blogged earlier, at least I had laughter. Well that was before I decided to take advantage of kid2 playing outside and lie down to relieve pain. I ended up passing out. He burst into the house as he always does, exclaiming, "Bonjour, mon ami!" I yelled, "I'm sleeping! How many times do I have to ask you to check if I am resting or not before you start yelling and wake me up!", causing me to feel like a complete jerk! But I was so exhausted, instead of apologizing like I wanted to for being a sodding mean monster of a mother, I immediately passed back out. I awoke 4 hours later to discover it was 10 pm and the kid

asleep. I hope he got himself something to eat. I feel like the worst mother on the face of the planet at this moment. I'm terrible.

I am angry. I have good reason to be angry. But why am I sitting here in tears calling myself an idiot if this is true? Why do I feel as if I have let down not only myself, but everyone around me and most importantly, my children.

I am angry. I AM ANGRY!

DIE IN A BLOODY FIRE, LUPUS!

Originally Published: September, 19, 2010

Tales of a Lupus Butterfly

THE LONELY AMONG US

I am not quite sure where to begin with this. I've said a few times today, "I DON'T UNDERSTAND!" However, the reality is I understand all too well. Perhaps that is why my heart is breaking into trillions of tiny shards filled with sadness, grief and overwhelming loss.

The first email I read this morning was to let me know that one of my old Sunday School students hung herself last night. She had just turned 27 a couple months ago, her son just turned five last month and had his first day of Kindergarten last Thursday. Aside from her son, she leaves behind 2 sisters, 1 brother, her dad plus many nieces and nephews. And because we grew up in a town of 1200, a community filled with grief and broken hearts. This loss is being felt on a global level.

She was so beautiful. She was kind, sweet, loving and caring. She had a smile and a laugh that would light up the darkest room. I wish she didn't feel so alone and was able to shine the light she showed to others, towards herself. She was loved greatly. I wish she felt she had someone to turn to. I tweeted earlier, "I wish you could CTRL+Z your day." That tweet was directed towards her. I wish that whatever that final straw was could just be undone, forever. Her Facebook page is full of messages about how she was loved, will be missed and how people do not understand, especially when some just saw her shortly beforehand. We will never get these answers. There was no note. She was one of the lonely among us.

I've been one of the lonely among us. I am not ashamed or afraid to admit this. I battled a great deal of depression as I was growing up. If you had my life, you'd understand. I grew up with both physical and sexual abuse, neglect, alcoholic and mentally ill parents, and the list goes on. I first thought about suicide when I was 9. I attempted suicide for the first time when I was 14. I continued to have suicidal thoughts until my late 20s. I was surrounded by many people but always felt so very alone and isolated. Thankfully, I learned how to reach out and vocalize those moments.

There are lonely among you right at this very moment. You work with them. You go to school with them. You socialize with them. You take the bus with them. They paint their faces with a smile, all the while they are screaming and crying on the inside, afraid of whatever the demon is that haunts them.

The last little period has been very difficult on me. I have had moments of feeling alone and isolated. I've been stabby and angry. I've lashed out and have told people to bugger themselves with their rainbows and unicorns. But I thank whatever it is you want to thank at these times that you all realize I'm just angry and venting. Because if it were not for your rainbows and unicorns and well wishes, I would once again become the lonely among you. There is a fine line between having moments of sadness and clinical depression. This line is so very easy to fall over, however it is a mountain to climb in order to reach the other side once again.

I saw a forum post the other day asking how often do you talk to strangers on the internet. Until they had become a member of a

certain community, the idea to reach out to strangers never crossed their mind. For me, the internet is a life jacket. Because of my Lupus, I have to spend a lot of my time either in bed resting, or just generally avoiding the general population of the world because their little germs can kill me. Lupus isolates me both psychologically, as I think people do not understand and physically. If I did not have all you wonderful people who reach my eyes via fiber optics and code, my mental well being would be completely different. And I know I am not the only one (for whatever reason), who has to spend a lot of their time as a shut-in.

I really do not think I could ever properly thank every single one of you who has ever showed me any type of caring or compassion. A lot of people have this idea that the internet is evil and bad. My family does not understand how I can consider some people, whom I've never met in meat space, to be real and true friends. Well those people who are codes reaching my eyes and are "Strangers" to those who don't get it, reach out to me and support me even so I'm just code reaching their eyes as well. That is more than I can say about the majority of the people I know in meat space. Thank you for being my friend. You've probably helped save my life more times than I care to admit.

Today, my heart is breaking for every single one of the lonely among us. Your pain is my pain. I feel it to the very depth of my soul. I wish I knew who you are so that I can pass on some of the love that has been given to me. I wish I knew who you are so that I could give you a hug, even if it is just an e-hug. I wish for you to find peace and understanding.

I hope that the person I just lost has found some peace. I wish she didn't feel so alone and instead, picked up the phone to dial the crisis line. I wish she wasn't the lonely among us. And I hope her family and our community can find some type of closure soon. This will be difficult, as we will never know for sure why. All we can do is speculate and make educated guesses.

Originally Published: September 20, 2010

REFLECTIONS FROM WITHIN THE CALM BEFORE THE STORM

All week long, my inner monologue has consisted of, “Breathe, Jules. BREATHE!” Tomorrow begins, what I’m hoping to be, a very busy months of updates to the Lupus Awareness Virtual Art Gallery.

I started this week in a celebratory mood, which quickly change to anxiety and a sense of being overwhelmed. The anxiety stems from thoughts of, “What if nobody contributes? Yes, I’ve already received a handful of contributions, but what if that is it? What if nobody actually cares enough and are just blowing smoke up my ass, saying that they’ll contribute something? Worse still, what if nobody bothers to visit the site to see the wonderful things that have been contributed? What if it doesn’t raise any awareness? What if my grand hopes and dreams of actually making a difference, completely and utterly fail?” The sense of being overwhelmed comes from exact opposite thoughts. Damn me, my duality and ability to think rationally, seeing all sides of the situation, plus add illness, children and a busy schedule. This combo can create chaos and this is when living moment to moment really helps.

I am also very... ummm... emotional? I am not quite sure what label to attach to my current state. When I launched the gallery in May for World Lupus Day, it brought up a lot of emotions for me that I normally do not have to deal with on a day to day basis. I’m having to look the elephant straight into its eyes and really face it. This project forces me to be real with and about my disease in ways that I don’t

always have to be. The elephant is never completely ignored or denied, but I can paint its toes red and hide it in cherry trees when needed.

I'm also still very angry with my disease at the moment. I have been running a fever for two weeks straight, my vision and brain are being attacked, I'm not sleeping, I'm on day three of a migraine from Hades and the list can go on. But I have had some really good emotional supports and have been able to mostly turn my mood around, even so I'm still quietly raging in the back of my mind.

I woke up this morning with an added spring in my step, despite the fact if I were any more tired, I would be dead. I woke up this morning in a very good mood. I woke up this morning filled with hope. I woke up this morning filled with excitement over the possibilities for the month ahead. I woke up this morning going over my final list of every thing that needs to get done today in order to facilitate the smooth operation of both the Lupus Awareness Gallery and Geeky Pleasures. I woke up this morning and began finalizing my battle plan, created to help reduce any undo stress this month may cause. I woke up trying to pin down what my contribution for this update will be.

My joy, happiness, excitement, wonder and anticipation was turned into profound sadness. I am still filled with intense sorrow over the suicide of one of my former students. Today, I learned that a fellow Lupus Warrior committed suicide because she could no longer deal with the pain of this horrible disease. Sadly, this is not uncommon. I've said it before and I'll say it again, I believe the psychological

effects of Lupus are much more difficult to deal with than the physical.

It is rather difficult hearing, over and over again, “But you look fine”, “Are you really sick?”, “You have what?” “It’s never lupus”, “What do you mean you’re tired?”, “Stop being so lazy!”, “Oh don’t pay her any mind. She’s a hypochondriac.”, and the list can go on and on and on. It gets really lonely when you are surrounded by people who do not understand. To make it worse, they choose to not understand. It makes it more difficult when it is your own family who makes the choice not to make an attempt to understand. Boy, do I ever have stories about that one. Aside from suicide, a number of those who suffer from Lupus turn to drugs and alcohol. The Lupus road is far from an easy one.

I’m so very sad right now and really do not feel as if I should be celebrating. This sadness led to the following status update on Facebook:

As Lupus Awareness Month starts tomorrow, it breaks my heart to learn a fellow Lupus Warrior could no longer cope with the disease and decided that taking her own life was the only way out. Many of my fellow Lupus Warriors are currently getting their asses handed to them, including myself. I hope we can continue to find the strength within ourselves and each other to continue the fight.

Lord knows I will need the added strength to get through this next month. Today’s news has drastically changed my outlook for the

coming month and what I want my aim to be. I never want another person to feel alone again, especially someone who has to live with Lupus. I wish I could reach out to every single of the estimated 5 million Lupus patients worldwide and really let them know they are not alone.

I want to let them know that it is okay to be angry. It is okay to be sad. It is okay to rant and rage and say, "FUCK YOU LUPUS!" I think it is so very unhealthy to paint your face with a smile, all the while you are screaming on the inside. This just leads to a feeling of being further isolated and feeling as if nobody gets it. Which leads to a feeling that you cannot talk to anyone about it because they will try and shove rainbows and unicorns and positive thinking down your throat. Which leads to you feelings as if you truly are alone and isolated. Which leads some to think they have no other option than to leave this life because it is all just way too painful and they cannot go on pretending otherwise any longer. It leads to thinking that if they were honest, they will be rejected.

I want for people to have a place where it is safe for them to just say what it is that they have to say. After all, you cannot tackle the demon that haunts you until you name it and look at it, straight in the face. A place where they do not get met with any sort of, "Cheer up." A place where they are told, "That sucks! And it is perfectly normal for you to be angry. It means that you are alive and still fighting." In my own experiences, having such a place has caused my moods to go from angry to once again finding the humour in situations in quicker fashion. A place of real love, understanding and acceptance. If I had not found that place, I do not think I'd be alive today.

I'm heartbroken. Lupus fucking sucks big blue hairy monkey balls.

Maybe I'll find a way to dedicate the Lupus Awareness Art Gallery to all of those Lupus Warriors who couldn't find their place and succumbed to the part of this disease that is the hardest part to battle, the psychological effects. Their battles and their pain cannot go unforgotten or be in vain. I just don't know how to accomplish this without it being a downer, even so it is really quite sad. I want their lives to be acknowledged and celebrated for all that it was, both the good and the bad.

I don't know. Maybe I'll figure it out. I'm just really heartbroken right now and feeling a bit useless, with many thoughts of "I wish there was something real I could do".

So there we have it. The good. The bad. And the down right miserable. I suppose bottom line as I take time to reflect in this calm before the storm, I still hope...

Originally Published: September 30, 2010

Tales of a Lupus Butterfly

ABOUT

Confirmed to be a “Geek God” by some online quiz and dubbed “The Queen of Geek” by many of her fans, Julia “Jules” Sherred is a mother, writer, author, lupus survivor, radio personality, blogger, gamer, tech enthusiast, science nerd, sci-fi and fantasy freak, hard core Trekker, has an unnatural obsession with Optimus Prime and so much more. She emerged from the womb fully embracing her geeky tendencies, with a book on Astrophysics in one hand and a deck of cards in the other. Growing up, games were always an important part of her family, including family board game nights, Christmas family poker games and trying to pry the ColecoVision® and later NES controllers from her mother’s hands. She has now passed on this tradition to her own children and is raising the next generation of geeks and gamers.

In early 2008, she was hired by Party 934 as their Program Director. When the station finally hit the airwaves in September 2008, that is when she began to host her Geeky Pleasures radio show. Once a week for 2 hours, she played a wide variety of music including many geeky songs and discussed with her listeners some geek topic of the week. She has had some pretty well-known geeks sit across from her during her shows, including interviews with: The King of Geek Wil Wheaton, MTV Executive Producer Shane Nickerson, Bad Astronomer Phil Plait PhD and geek music sensation Jonathan Coulton. In 2009, she also took on the additional duties of Assistant General Manager of the station and launched her Geeky Pleasures website when her show and blog could no longer adequately fill the demand she was receiving to share her “unique brand of geekiness”.

Due to a change in circumstances, she has stepped away from her radio show (hopefully temporarily) and her AGM and PD duties at the station. Hopefully she will be heard back on the airwaves some time in the near future.

Places you can find her online are:

Geeky Pleasures: <http://juliasherred.com>

Personal Blog: <http://blog.juliasherred.com>

Lupus Awareness Virtual Art Gallery: <http://lupus.juliasherred.com>

Follow her on Twitter: <http://twitter.com/GeekyJules>.

Other sites and publications which she contributes to are:

The Lupus Magazine: <http://www.thelupusmagazine.com>

Star Wars Vs Star Trek: <http://starwarsvsstartrek.com>

Nerds in Babeland: <http://nerdsinbabeland.com>

For more information about her book *From The Mundane To The Insane: A Wonderful Journey Without A Destination*, including preview and purchasing information:

Visit <http://juliasherred.com/book/>