

# **An Open Letter to The Lupus Mom**

**Dear Lupus Mom,**

I wish that we spoke more openly about the parenting struggles we fight daily, along with our lupus diagnosis. Sometimes, I wish that I could reach out to another mom that is so busy fighting her own body that she sometimes can't make it out of bed to be the mom she needs to be. Sometimes, I wish that we could just stop and take a moment to truly appreciate "The Lupus Mom".



AN OPEN LETTER TO

# MOMS WITH FIBROMYALGIA AND LUPUS

IF YOU SUFFER FROM A CHRONIC  
ILLNESS AND ARE A MOM, THIS LETTER IS  
FOR YOU!

## Parenting with lupus

In a world where we are constantly given titles and labels, they often seem to be one or the other. But that simply isn't true when you have lupus and children. You become "The Lupus Mom". Lupus is not something most of us can just forget about or continue living with and not think about often.

It is integrated into our DNA and we are constantly reminded of it's presence through every dark, soul searching night we lay awake from insomnia...or maybe it's because we also have such fatigue that we slept half the day. Or maybe it's because we are in so much physical pain. The same goes for the title of mom. It's not something we do for a few days here and there, it's a title that we fight for daily and have so much love and passion for.

When you struggle with lupus, some days you can be alive...like really alive... and on top of the world. You feel things more vividly, you see the world differently, your lupus fog may ease. Your dreams and hopes slowly float back down to where you can 'almost' grab them. You feel like you are back in the real world and in your real body.

Then lupus eerily rears itself from the depths of your hopeful soul and tries to destroy every hope and goal you have. It feeds off the desperation in the mind of a mother who loves her children so much, but some days may feel they are better off without her.

The mother who pushes herself so much to try and be a 'normal' mom, you know the ones that actually take showers and drive to a full time job they are passionate about. Like the ones who are able to make it to every school program and PTO meeting. The ones who always seem to have their shit together.

But lupus doesn't care about any of that. In fact, it feeds

off destroying our body from the inside out. But we are lucky to be lupus mothers because we know that many of our fellow lupus warriors have struggled with pregnancy and loss. You see, lupus can rob us of our chance to successfully carry a baby, especially if the mom is experiencing significant health issues. So the guilt of it all sets in...because we grieve with them too. So we try to remind ourselves to be grateful, that the life and children we have is a blessing.

But I want that one lupus mom who is struggling today to see this. To see that there are many of us out here. A lot of people do not like to talk about how hard it is to raise children and fight a chronic illness because maybe they don't want to come off as being unappreciative, or seem like they don't love their children as much as any other mom, or that they simply can't get it together. I want you to see what we see.

I see you waking up after a few hours of constant interrupted sleep nightly. I see you trying to remember every last lupus medication, every last class party at school, every doctor's appointment, and every favorite Fortnite dance. I see you remembering all those things while being physically in pain. I see you out there still getting things done while trying to maintain what's left of your mental state.

I see you waking up to a new day that you already know will be filled with physical pain and maybe even depression. I see the person you once were and the person you have become. I see all the dreams and goals you once prayed about.

They may not see your limp when you wake up in the mornings, they may not see all of your ER visits, the tears that fell earlier, or the hours of dialysis...but I see you fighting the good fight. Every. Single. Day.

You are not alone in your fight and we see the amazing love and determination you have for your family. Understand that

we KNOW what it's like, even when most will never understand. So pick yourself off of the floor and wipe the tears from your eyes. You are a warrior and you are worthy. Your babies love you and they need you, even if you don't believe it today.

We need you.

Let's end the cycle of not talking about our parenting struggles with other lupus moms. It's almost like a stigma, that many don't want to talk about. Honestly, it's one that should be broken, because girl, you are not broken.

You are a warrior. You are a fighter. You are lupus mom strong.