

HSS



FOR INQUIRING TEENS WITH

Lupus

**OUR THOUGHTS,
ISSUES & CONCERNS**

FOR INQUIRING TEENS WITH

Lupus

**OUR THOUGHTS,
ISSUES & CONCERNS**

Acknowledgements

This booklet and the Charla de Lupus (Lupus Chat)[®] Program were made possible through funding by **Rheuminations, Inc.**

Special thanks to the staff and volunteers of the Charla de Lupus (Lupus Chat) Program, the Pediatric Rheumatology staff at Hospital for Special Surgery, NewYork-Presbyterian Morgan Stanley Children's Hospital, Columbia University Medical Center and The Mount Sinai Medical Center, for their valuable help and feedback. We want to also thank the United Hospital Fund for their initial support. Finally, a great big thank you to the New York City Teens 'Lupus Chat' Group for expressing their feelings, finding their strength, and inspiring us to write this booklet.

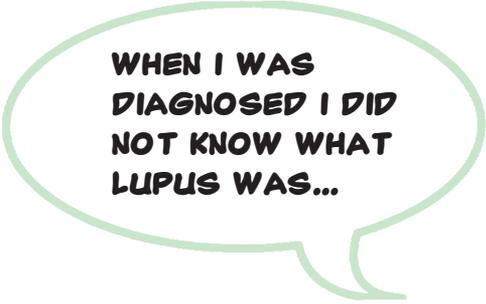
With admiration and appreciation, we thank Nichole Niles who wrote and illustrated the text. Ms. Niles is a Charla de Lupus (Lupus Chat) volunteer who was diagnosed with lupus at age 15.

The 2015 edition of this booklet is generously supported by the Victor B. and Hilda Handal Pediatric Holiday Fund.

Front/back cover, and page 20 illustrations: Winky Adam
©2003, 2006, 2009, 2015 (revised) Hospital for Special Surgery
All rights reserved.

Why this booklet?

Being diagnosed with lupus can be a scary thing for a teenager to experience. Many of us feel like no one understands what we are going through. Not only do we have to deal with the many problems and issues that teens tackle, but we also have to deal with doctors, medications, pain, and other changes that come along with lupus. When I was diagnosed, I did not even know what lupus was. That is why we created this little book. **YOU MIGHT REALIZE THAT THERE ARE OTHERS OUT THERE LIKE YOU WHO SHARE YOUR SAME THOUGHTS, FEARS, AND PROBLEMS.** This booklet might even answer some of the questions that have been on your mind.



**WHEN I WAS
DIAGNOSED I DID
NOT KNOW WHAT
LUPUS WAS...**



What's up with lupus?

Lupus is a disease that affects our **IMMUNE SYSTEM**. You've probably heard your teacher mention the word antibodies once or twice in biology class. The immune system creates antibodies, which are special substances that fight off germs and infections. For people like us with lupus, our immune system has gone haywire! We create antibodies, called autoantibodies, which get confused and attack our body's healthy cells. Lupus is also a chronic illness, which means that we'll have it for the rest of our lives.

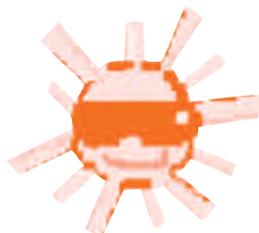
There are 3 types of lupus:

1. Systemic lupus erythematosus

It's the most common type of lupus, and it can affect your skin, joints, tendons, blood cells, and circulation. It can also affect body organs like the kidneys, brain, heart, and lungs, although many people with lupus do not experience problems with their organs. If you have this type of lupus, you may get tired pretty fast, and your joints may feel achy at times. You may also get headaches often, and experience fevers when your lupus acts up.

2. Discoid lupus

This is the lupus that affects just the skin. People with this type of lupus can get rashes on their face, scalp, ears, chest, and arms. Don't forget your sunscreen! (That goes for **EVERYONE** with lupus!) Your skin is sort of allergic to the sun, so it's best to keep in the shade, and always wear sunscreen when going out.



3. Drug-induced lupus

People get this type of lupus by taking certain kinds of medication. The good news is that drug-induced lupus goes away when you stop taking the medication that caused it.

What causes lupus?

The cause of lupus still remains a mystery, but scientists believe that things like genetic make-up, infections, major stress, ultraviolet light, antibiotics, hormones, and certain drugs may trigger our illness.

Who gets lupus?

Lupus is mostly found in women between the ages of 16-40. Lupus is also more likely to occur in African Americans, Asian Americans, Latinos, and Native Americans. But anyone, at any age, including men and boys, can get lupus.

Is there a cure?

No, there is no cure for lupus, but the docs are working on it. Until they find a cure, lupus is a disease that lasts a lifetime.

Can I give lupus to someone else?

Lupus is not contagious. This means you cannot catch or give lupus to another teen by kissing, coughing, sexual contact, or any other way your imaginative mind can think of.

Is lupus like AIDS or Cancer?

Lupus is definitely not like AIDS or cancer. AIDS is the breakdown of someone's immune system, but people with lupus have an overactive immune system. Plus, the AIDS virus can be passed on from one person to the next through the exchange of body fluids. And we know that it is impossible for someone to give or get lupus from another person.



Key point to remember:

You are unique. Everyone's lupus is different. What you might experience with your lupus might be totally different from what another person with lupus experiences. So, as an individualist, get to know your lupus. See your doctor regularly for checkups to find out what's happening on the inside.

NO WAY!

Talking about your lupus can be like therapy. So share your feelings with...

Family

Yeah, yeah... I know that the **FAM** can be hard to talk to sometimes. Parents especially can seem like they belong to a totally different species. You might have noticed that your parents' strangeness has become even stranger since you were diagnosed. Parents may seem like broken records, constantly asking: "Did you take your medication? How are you feeling today? Do you have any pain?" Other times it may look like Mom and Dad are too scared to even mention the word lupus. It may even seem as if they are trying to pretend things are OK when they really aren't.



Remember that you are not the only one going through changes. Because our parents care about us, they sometimes become overprotective, or may even have a hard time accepting the fact that we have lupus. But, guess what... the best way to face difficult and uncertain times is to go through them with the ones we love. Although they can be hard to talk to sometimes, deep down we know we love them. Sharing our feelings with mom, dad, brothers and sisters can help them understand what we are going through. In return, they can help us by giving us the support we need. Work along with your parents and doctor as a team to figure out what method of treatment is best for you.



THE BEST WAY TO FACE DIFFICULT AND UNCERTAIN TIMES IS TO GO THROUGH THEM WITH THE ONES WE LOVE.

So share your feelings with...

Friends

It's understandable if you don't want to **BROADCAST** your lupus on the loud speakers at school. You may even feel a little embarrassed to tell certain people that you have lupus. Not everyone is going to accept you for who you are. You might bump into a few teens who find it hard to understand what lupus is all about. Because people are sometimes afraid of what they don't understand, there might be some who try to avoid you, and you could lose a friend or two. This does not mean that you should hide the fact that you have lupus, it just means that you have to find out who your real friends are. Good friends are there for us during the smooth and the rough times. Telling a good friend about your lupus can give you a shoulder to lean on, and may bring the two of you closer together.

Doc

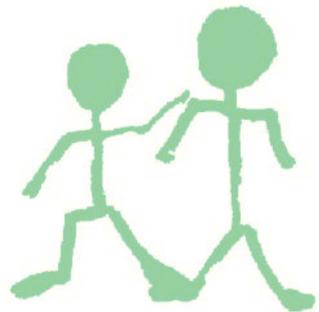
If you have lupus, you should see a doctor regularly. Your doctor may refer you to a pediatric rheumatologist, who will know more about the specific needs of teens with lupus. Since lupus is different for everyone, it is best to keep in touch with your doctor, so that he/she can get to know **YOUR** lupus. Your doctor is the one who will organize the best treatment plan to control your symptoms. Plus, your doctor is the best person to answer any questions you might have about lupus. I know sometimes doctors get all **TECHNICAL** with their big, scientific words. At times it seems as if they speak a completely different language from the rest of us. But don't let that stop you from finding out what you need to know. Just ask your doc to break it down for you. Discuss your concerns, and tell your doctor about health problems that might pop up. And I mean **YOU**. Don't let mom and dad do all the talking. Yeah, they can help, but learn to speak up for yourself. Hey... this is your body we're talking about.

What's on your mind?

Hmm... Let me guess. Is it school... friends... dating... or maybe that upcoming party?

When I was first diagnosed with lupus, I missed a lot of **SCHOOL**. As a result of being under the weather, your class attendance may go downhill. You might find it difficult to complete class assignments, and you may even miss a test. This is why your teachers should know about your illness. You can even have your teacher speak with your doctor, or have your doctor write your teacher a note, explaining to him/her the difficulties your lupus might bring about. Allow your school doctor and parents to work together to make your school experience a good one. It is also a good idea to let a classmate that you trust know about your lupus. He/she can fill you in on what you've missed while you were out of class. This friend can give you a copy of their class notes, bring you the homework, and he/she can even stop by your home to help you study.

FRIENDSHIPS might suffer, since you may not be able to chill with your friends as much as you would like. At times you might have to cancel plans on short notice, because of your lupus. This is where telling certain friends about your illness can help. They will understand if you don't show up to the party this weekend, or if you cannot make it to the movies. You might feel better knowing that you have a friend who is aware of what you are going through.



What's on your mind?

If you go out on dates, you know that **DATING** is already complicated without the additional complications of an illness. Having lupus may affect the way you feel about yourself, and the way you feel about yourself can affect your relationship. It is best to tell the



person you are dating that you have lupus. Explain the illness to him or her. Let them know that at times you may not feel or look your best due to sickness. Try to answer their questions the best way you know how. You can even give them this booklet. Let him or her get to know the **WHOLE** you by not keeping your lupus, or your feelings about your lupus a secret.



Yeah, there might be days when you just want to stay in bed. But, on those days that you do feel better, **GET UP** and have some **FUN**. Continue to do the things you loved doing before you were diagnosed with lupus. Just because you have lupus does not mean you can't enjoy life. In other words, be a **TEEN**.



Lupus and changes

For many of us, the onset of lupus brought about many changes. These changes can be physical, emotional, or just changes in our regular routine.

As you've probably already experienced, looks and image are very important to teens. One reason for this is because we are often judged by our peers on the basis of how we look. Looks can also define part of who we are. That is why many of us go through a tough time when we experience **BODY CHANGES** because of our lupus. Feeling sick can make you not only feel bummed out, but look bummed out as well. Some of the medications we take can also change the way we look. After I was diagnosed with lupus, I noticed that my face became rounder and chubbier. This is one of the common side effects of taking corticosteroids like Prednisone, which is a medication taken by many people with lupus. Weight gain and increased acne are some of the other possible side effects of corticosteroids. Some medications can even cause hair loss.



The important thing to remember is that these medications do more good than harm.

So, if you have any problems with your meds, or if you don't want to take a medication, talk to your doctor about it. Stopping our meds would be like abandoning our baby brother in the woods... you never know what could happen! Our medications help control joint pain, rashes, fevers, headaches, and other symptoms of our lupus. They also reduce the risk of **FLARES**, which are periods when our lupus gets worse. So, take your meds to stay out of bed.

Lupus and changes

Our **LIFESTYLE** might have to change after developing lupus. We may not be able to stay up late and watch our favorite shows, because we need our rest. We might have to lighten our workload to give our mind and bodies time to relax. We also might have to change the type of activities we do, like going to the beach, because our doctors tell us to avoid sunlight. I know some of us love to get our groove on down on the dance floor, or kick butt in our favorite sport. But, there might be times when hanging out, partying, and playing ball is just not possible for us to do when tiredness and achy joints get in the way. It's all about knowing your limitations, and respecting your body. Hey... you can take this chance to try new things to keep yourself entertained. Instead of thinking about the things you can no longer do, focus on the many other things you **CAN** do.

Lupus can also affect our **MOOD**. Feeling sick and being unable to be out there with our friends can make us kind of depressed. The pressures of school, grades, and making friends can also leave us feeling down in the dumps. I know there were times when I just didn't want to be bothered, didn't want to talk to anyone, and didn't feel like getting out of bed, or even leaving the house. It is understandable if you even feel angry that you have lupus. But, being angry, isolating ourselves, and letting sadness take over is not going to help us. Letting these feelings rule us would be like giving into the illness. Put up a good fight by keeping a **POSITIVE ATTITUDE**. Tell yourself, "**I am not going to let lupus change who I am.**"



Lupus and changes



Remember “You have lupus, but lupus is not you.”

Check out what’s happening in your neck of the woods by calling up your local Lupus Foundation or Arthritis Foundation and seeing what’s available for teens with lupus.

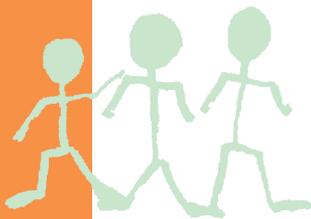
Talking to young minds like ourselves, who are going through some of the same things you are going through, can help us get through our difficult moments. You can **GET CONNECTED** to others with lupus by calling Charla de Lupus (Lupus Chat) to talk with a peer health educator in English or Spanish. If you live nearby, you can also join the Teens Lupus Chat Group in New York City. Phone us at 212-606-1958 (within NYC) or 866-812-4494 toll-free (outside NYC).

Hmm... But what if talking to just family and friends isn’t doing the trick? Sure, everybody feels blue every now and then. But sadness that won’t go away, anxiety, feelings of worthlessness and hopelessness, anger, loss of appetite or overeating, oversleeping or an inability to sleep are all signs of depression, and can mean that you need just a little extra help. **DEPRESSION** can affect our grades in school, stop us from enjoying the things that



make us happy, cause us to lose friends, and can disconnect us from our families. Do not feel alone, because help is out there. Talking about your feelings with a professional counselor can help you work through difficult times and open up your eyes to the many good things you’ve got going for

you. Yeah, professionals can be scary, but you’ll find that when your problems seem too high and you’re feeling down and low, talking about it really helps. Just give it a try.



What about the future?

When we hear words like **DISEASE** and **CHRONIC ILLNESS** we tend to wonder, and even worry a little about the **FUTURE**. All kinds of questions popped into my head when I was diagnosed.

Can I have children?



Since lupus is a disease that affects **both young women and men**, pregnancy and childbearing is a subject that pops up a lot. **Teens** who have just been diagnosed with lupus often wonder if it is possible for them to have a family. This is a good and sensible question. Women with lupus can become pregnant, and most women with lupus have successful deliveries. **Men with lupus are also able to have children.** This does not mean that pregnancy is OK for everyone with lupus. There is an increased risk of a miscarriage for women like us. Doctors say that if our lupus is very active, becoming pregnant is not a good idea. When doctors say that our lupus is **“ACTIVE,”** they could mean that our bloodwork does not look too good, or there might be a problem with an organ in our body, which can put us at risk.

**BE RESPONSIBLE
AND RESPECT
YOUR BODY.**



Our lupus symptoms can also increase during and after pregnancy. This is why it is important for pregnant women with lupus to be monitored closely by their doctors. Also, some teens enter into more intimate relationships at this time of their lives. It is important to be responsible and respect your body. So learn about your needs and get the facts up front from your doctor, school counselors, and mom and dad.

What about the future?

Will my children have lupus?

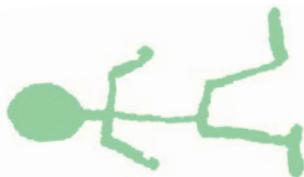
Lupus is not hereditary, even though there are some people with lupus who have other family members with lupus. If you are like me, no one else in your family has lupus. Just because we have lupus does not mean that we will have children who develop lupus. **LESS THAN 5%** of parents with lupus have children who develop lupus.

Can I go away to college, camp or vacation?

Since you were diagnosed with lupus, you probably wonder if you are still going to be able to go on those yearly family vacations, or go to camp, or go away to college. Having lupus does not mean that you have to leave behind your future plans and dreams. It might just mean that you have to be more careful when it comes to making certain decisions. If you plan on going away, let your doctor know so that he or she can help you prepare.

Am I going to die?

When my doctor told me I had lupus, I was scared out of my mind. Since I did not know anything about lupus, I automatically thought the worst. "Will I die from lupus?" I pictured myself in a hospital bed, with all kinds of wires and tubes connected to my body.



I never thought that I would be going to college, planning for the future, and living a normal life like I am now.

No one can say what will happen to us in the future. Lupus is different for everyone. What I can tell you is that doctors have gotten better at treating lupus. The medications we take have allowed people with lupus to enjoy life, and to live until we are old and gray.

You've got 1 body... take care of it!

Whether you have lupus or not, there are certain steps people can take to improve their health. **EXERCISE, EATING RIGHT,** and getting plenty of **REST** are ways to help control our lupus.

I bet you are saying, "I'm too tired to exercise." But, once you get started, you will find that exercise actually energizes you. Exercise is also one way we can help loosen up our stiff joints. Remember to check in with your doc before starting an exercise routine. He or she may be able to suggest and recommend some exercises too. Be careful not to overdo it and pace yourself.

You gotta eat your veggies! **EATING RIGHT CAN HELP PREVENT HEALTH PROBLEMS DOWN THE ROAD, AND CAN BOOST YOUR ENERGY LEVEL.** You might also want to ask your doctor about any vitamins you can take. Doctors suggest that teens who take corticosteroids also take calcium supplements with Vitamin D, because corticosteroids can weaken our bones.

Regular exercise and a balanced diet along with plenty of rest will not only help control our lupus, but will also help us feel better about ourselves. And of course... don't forget to take your meds!



You are not alone!

If you would like to connect more with others like yourself, or if you just want to know even more about lupus and teens, check out the resources listed below. We are providing these to you for general information only. If you have any questions regarding your health,

ALWAYS CONSULT YOUR PERSONAL QUALIFIED HEALTHCARE PROVIDER.

Websites

www.abilityonline.org
www.girlshealth.gov
www.goldscout.com
www.kidshealth.org

Helpful Organizations



Arthritis Foundation
www.arthritis.org
800-283-7800 toll-free



Arthritis Foundation, New York Chapter
www.arthritis.org
212-984-8700



Lupus Foundation of America, Inc.,
New York Chapter
www.lupus.org
202-349-1155 or
800-558-0121 toll-free

You are not alone!

Helpful Organizations (con't)



The S.L.E. Lupus Foundation
www.lupusny.org
212-685-4118 or 800-745-8787 toll-free



The Starbright Foundation
www.starbrightworld.org
310-479-1212 or 800-315-2580 toll-free



Lupus Alliance of America
Long Island/Queens Affiliate
www.lupusliqueens.org
516-783-3370 or 800-850-9000 toll-free



Make-A-Wish Foundation
www.wish.org
www.metrony.wish.org
212-957-9474

You are not alone!

Good Books (con't)

Anderson, T. (2010). *Lupus Love*. USA: Moral Literature, Inc.

Culbert, T., & Kajander, R. (2007). *Be the Boss of Your Pain: Self-Care for Kids*. Minneapolis, MN: Free Spirit Publishing Inc.

Huegel, K. (1998). *Young People and Chronic Illness: True Stories, Help and Hope*. Minneapolis, MN: Free Spirit Publishing Inc.

Kaufman, M. (1995). *Easy for You to Say: Q & A's for Teens Living with Chronic Illness or Disability*. Toronto: Key Porter Books.

Kehret, P. (2002). *My Brother Made Me Do It*. New York, NY: Alladin Paperbacks.

Lehman, J. T. (2004). *It's Not Just Growing Pains*. New York, NY: Oxford University Press, Inc.

Murphy-Melas, E. (2001). *Keeping A Secret: A Story About Juvenile Rheumatoid Arthritis*. USA: Aventis Pharmaceutical, Inc.

O'Loughlin, W. (2010). *What's Lupus, Mama?* Washington, D.C.: Lupus Foundation of America, Inc.

Phillips, R., & Lahita, R. (2014). *Lupus Q&A, Everything You Need to Know*. New York, N.Y.: Penguin Group LLC.



You are not alone!

Cool group

There is also a cool group, Charla de Lupus (Lupus Chat), just for teens with lupus in the NYC area. It is sponsored by Hospital for Special Surgery.

Teens like us meet monthly to talk and share experiences with lupus. We haven't forgotten about parents, either. At the same day and time that the teen group meets, we also have a support group for your parents, which meets separately.

Lend an ear

The Charla de Lupus (Lupus Chat)[®] program can also provide support and education by phone by our trained peer volunteers and staff with lupus.

More info

For more info on the Teens and Parents **"LUPUS CHAT" GROUPS** or to speak with a staff member or volunteer, please call **THE CHARLA DE LUPUS (LUPUS CHAT) PROGRAM** at:

212-606-1958 (within NYC)

866-812-4494 toll-free (outside NYC)

You can also visit us at: www.hss.edu/CharladeLupus



You are not alone!

We would like to know your comments and **IDEAS** about this booklet and about how we can continue to provide you with information and support about lupus. We also would love to hear how you, as a teen, cope with lupus.

Please email us your comments.

Provide your name, complete mailing address (Street, City, State, Zip Code) and email address to:

Charla@hss.edu



Wait! Before you go, some teens want to let you know how they cope...

LUPUS IS JUST ONE PART OF ME. IT'S NOT WHO I AM.

- Rosa, age 18



THINKING POSITIVE...

- Samantha, age 17



I COPE WITH MY LUPUS BY PRAYING. THIS GIVES ME COMFORT.

- Jose, age 18



I WRITE POETRY AND LET OUT ANYTHING I MAY FEEL.

- Octavia, age 18



TALKING WITH FAMILY AND FRIENDS I GET THE COMFORT I NEED!

- Annette, age 15





**DISCOVER THERE ARE OTHER
TEENS WITH LUPUS WHO KNOW
WHAT YOU ARE GOING THROUGH.
LEARN HOW THEY COPE.**



**WANNA KNOW MORE
ABOUT LUPUS?**



**GET TIPS ON HOW YOU CAN
TALK TO YOUR DOC, FAMILY
AND FRIENDS ABOUT YOUR
LUPUS.**



**GET THE FACTS
STRAIGHT, AND SOME
QUESTIONS ABOUT
LUPUS ANSWERED.**



**FIND OUT HOW YOU
CAN CONNECT WITH
OTHER TEENS WITH
LUPUS.**



GOOD IDEAS!