

# Lupus News

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## Why Don't They Just Take Something?

### The Struggles of Chronic Illness

One of the first questions asked of someone with a chronic illness is, "What do the doctors' say?" You see, when we come across someone who is sick or in pain, we assume the medical community must have a handle on their condition.

Unfortunately, this often leads to thinking that they are *still suffering* because they must not be doing what their doctor is telling them to do. After all, modern medicine has come a long way! And, the doctors must have something that can take away the symptoms. Otherwise, the only other explanation is that this person must not be trying very hard to get well!

Often we drill them with questions like, "Have you tried this?" Or "have you tried that?" because it does not make sense that if they were trying, they would be better by now. It is confusing for us when we meet someone who is in horrible pain or sick. So, we ask ourselves "Can't they just take something for it?"

It is true most of us are not accustomed to the idea of illness being chronic. Usually when we get sick, we go to the doctor and then get better. We are too busy to even think about missing a moment lying in bed.....miserable. When we do feel a cold coming on, we cringe and yell, "I don't have TIME to get sick!"



So we call the doctor begging for a prescription that will make it all go away and fast! We may only be down for a few hours or maybe even a few days, but we hate every moment of it. We whine and cry to those around us, moan in pain and panic as we watch the clock wasting away our precious time. Nonetheless, soon we are back on our feet and back on track. We quickly forget how horrible it was to have to put things aside.

Yes, we are a world that is accustomed to popping some pills or vitamins and we are back in race, feeling like our determination could defeat any viral army, since we did not stay sick for long because we acted, had a positive attitude and by gosh "we were not going to let any illness keep us down!"

Conversely, when we meet up with a person who has been sick or injured for months or even years, we often assume they must be lazy or unmotivated, they must not want to work or they must not be doing what their doctor ordered.

Cont'd on pg 3



## *From Your President....*

Even as we enter the middle of summer, I see now that there is never a slow time for the Lupus Foundation. We are busy as ever with upcoming event. Check out the box below, we have a variety of events coming up that you might be interested in attending.

If you joined us for the Walk in April, you may have heard our cry for additional board members. We are actively looking for individuals who have a heart for Lupus and a desire to direct the Foundation. Do you want to have a voice on how we operate? Do you have ideas for some programs we could offer? You could be the person from which we are waiting hear! The board members meet monthly to discuss our programs and ways to fund them. You do not need to have experience of being on a board, only a yearning to have some input and a wish to help. Call the office at 520-622-9006 for more information or to contact me directly.

We are still in process of finalizing the arrangements for our Annual Meeting which is tentatively scheduled for October 5th. More information will be available soon. This year we are adding an education seminar and hope you will consider joining us.

Be careful with the sun and heat, try to stay cool and enjoy the rest of the summer.

*Joni Broussard*

## Mission Statement

To provide information, education and referrals for those affected by lupus and to promote the development and enhancement of health and social welfare services at the local level to assist lupus patients. To promote public education and increase knowledge and understanding of the disease and its ramifications. To encourage support of research programs related to the diagnosis, treatment, cure and prevention of lupus. To promote the exchange of information among health professionals and collaborate with the professional community to improve the standards of diagnosis, care and treatment of lupus patients.

### Board Officers

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## Upcoming Events

### Saturday July 27th 10A - 4P

Guadalajara Grille  
750 N. Kolb, only

Percentage of register sales will go to the Lupus Foundation - No Entertainment Book Coupons, Gift Cards or other discounts apply  
You must bring the flyer (pick up one at our office or we can e-mail it)

### Thursday August 15th 7P

"50/50 Raffle Baseball Fundraiser-Thirsty Thursday"  
Kino Stadium

Pick up discounted tickets at Lupus Office while they last

### Tuesday September 17th

Oregano's  
4900 E. Speedway Blvd  
100 W. Orange Grove Rd

20% of register sale will go to the Lupus Foundation  
Must bring the Lupus Oregano Flyer (pick up at our office or we can email it to you)

### Sunday November 17th 8AM Shotgun Start, Scramble Format

Lupus Foundation Golf Tournament  
General William Blanchard Golf Course Davis Monthan  
AFB 3465 Craycroft Road  
Entry Fee \$40, Registration includes Cart

# Why Don't They Just Take Something....cont'd from page 1

Otherwise, wouldn't they just take some medicine and get better, just like we did when we were sick? Just about anything is treatable with modern medicine, isn't it?

But what about all of the recent breakthroughs in medicine? Aren't we getting a handle on curing diseases and learning how to repair the human body? Yes and No. Many experts conclude the number of people suffering from chronic illness is actually increasing because of the improvement in diagnostic medicine.

With past medical care many people died from a variety of illnesses and injuries. Today they are kept alive with drugs, surgeries and treatments. Yet for many, the improvements have not been sufficient to cure them or make them well enough to live without debilitating symptoms.

"The fundamental issue is that contemporary medicine is often able to delay death but not restore health, so that the more breakthroughs of modern medicine we have, the more sick people we have. I say this without sarcasm and without cynicism. In other words, modern medicine may be saving the lives of millions, but many of these people are still left with great limitations. Suddenly we have a growing group of people who have chronic illnesses and pain. For many, treatments do help enough for the person to function again, but for others they do not. This leaves millions of people living an entire life, ill, in pain, frustrated, searching and at a loss for how to deal with an ongoing disease or injury that may not improve.

Yes, most do "take something." In fact, most have gone from doctor to doctor, trying medication, after medication. Even for those who do find relief through medications, it is often a long, slow process.

Finding the right medication takes time, because patients may exchange one benefit for one condition, for a side effect in another. This of course may well include a gamut of tests, procedures, physical therapies, surgeries, special diets, supplements, and alternative treatments.

For some, their limitations are mild and manageable with medications, treatments, therapies and learning the skill of pacing themselves. For others, it takes a huge effort to try to keep up with careers, hobbies, children and housework, and still others find it a great struggle just to get through a day of work or raising kids, with no energy left for anything else.

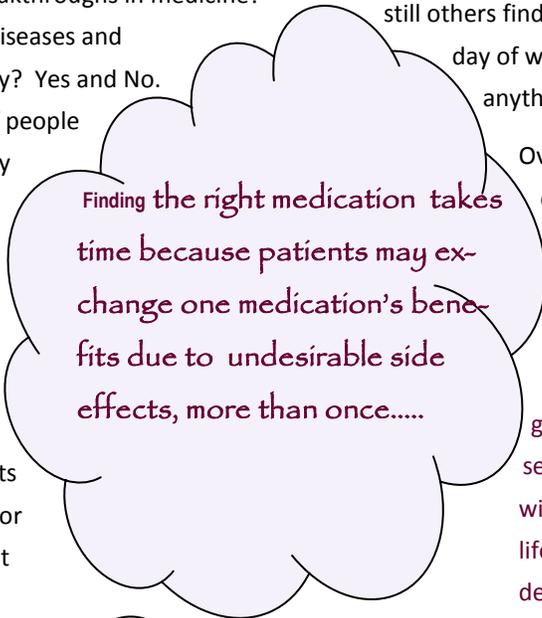
Over a period of time some may well become disabled, and no longer able to work and it takes all they have just to complete a few daily tasks such as daily grooming or visiting their physician.

Those with chronic illness could easily give up, but they keep battling and keep searching for an answer or something that will at least help them to get some of their life back. Many have even fought the face of death and have won. They may still be living

with limitations, but they often do not get the credit for the war they did win.

Therefore, isn't it time for our society to realize that people with disabling conditions are not weak and unassertive? Instead, let us recognize their courage and strength for living a life of loss, struggle, and perseverance. After all, that is an incredible accomplishment in and of itself that most will never know!

Thanks to The Lupus Newslink, Lupus Alliance of America, Inc, References: Dr. Jeffrey Boyd "But You Look Good: A Guide to Understanding and Encouraging People with Chronic Debilitating Illness and Pain!"



*"Attitude is the mind's paintbrush, let your brush paint a positive end to each day"*



By Paul Howard, M.D.

**Imagine** a glimpse into a physician's office that specializes in diagnosis and care of children and families with rheumatic diseases. In my office, the following typical scene surprises and dismays normal families:

**Mother and Father, nearly in unison:** "My child has WHAT?"  
 Physician: "She has lupus. It is really called systemic lupus erythematosus. Lupus for short."

**Mother:** "I never knew children could get lupus. In fact, I hadn't heard of lupus until a few years ago when my sister was diagnosed with it. How could my daughter Becky, ever get such a thing?"

**As** I explain systemic lupus erythematosus and how this disease, with so many different faces can affect a child, Becky's mother gazes through me. She fights back tears, not wanting to cry or show fear in front of her daughter. Her mind races with thoughts of how this will affect her beautiful young daughter. "When she's older, will Becky be able to be part of the cheerleading team? Will she be able to complete junior and senior high school? Will she even graduate from high school" She thinks, "No, wait, I can't ask that in front of Becky. Will she be able to have children? *Should* she have children?"

Years ago, I started treating children with lupus. I would begin with a lengthy discussion of the disease, emphasizing how lupus differs in adults and children. I would explain how lupus affects children of any age and often can be a more serious disease with frequent kidney involvement. Simply, I was trained to diagnose the disease called lupus and treat its untoward effects. I did not consider the importance of a personal approach with the child or family. As I matured as a physician, however, I realized the family must be included in the treatment plan. It is not simply treating lupus in the child but rather treating the whole child affected by lupus and the family of the child that is important. Instead of offering long explanations about the disease, I now wait to have the parents and child ask the first questions similar to how we respond to a child's wanting to know about any difficult topic while growing up.

Initial questions often reveal families' fears and worries mothers and fathers want to know what this means to their child's future. After traveling this road many times, I have learned not to predict or anticipate the future. In spite of uncertainty, we look ahead and proceed with optimism. It is frequently a long road with many highs and lows. Fundamental principles provide a solid foundation for successful treatment, note the following highlighted areas:

#### **Taking care of children with lupus is making the correct diagnosis.**

It is critical to make a proper diagnosis. To wrongly label someone with systemic lupus erythematosus can lead to physical and emotional setbacks. In certain situations, I prefer to make a diagnosis of an undefined autoimmune process until the diagnosis becomes more clear. This can be difficult for parents and the children to understand. A mere blood test will not confirm a diagnosis of lupus; a blood test is a tool used along with discussions and clinical examinations to insure an accurate diagnosis. Time may be required to allow different symptoms to manifest before establishing a definite diagnosis.

#### **Taking care of lupus in children is more than caring for an altered immune system.**

The difficulties in caring for the child with juvenile lupus are two-fold. First, the immune system is different in children. Second, there may be alteration of the child's normal growth and development into a mature young adult. From a purely medical viewpoint, the main problem in juvenile lupus is an intolerant immune system and its inability to recognize things foreign to itself. The immune system consisting of the specialized cells and antibodies, attacks the organs and tissues it is designed to protect. The attack is often generalized, affecting many parts of the body, especially the skin, joints, lungs, heart, blood, kidney and brain. Damage to these last two organs, kidney and brain, can most severely diminish quality of life.

There also is the need to care for that developing person, the child in the process of becoming a young adult. That process may be altered, changed, and possibly even derailed for a time due to the emotional disruption an illness such as lupus can provoke.

#### **Taking care of lupus in children is more complex than prescribing medications to suppress uncontrolled inflammation in multiple organs.**

It is critical to design a treatment plan that includes medications to suppress and correct the underlying defects in lupus. Prevention of damage to internal organs, skin and joints is necessary if excellent control is to be achieved.

More importantly, the physician must provide different therapies to treat particular forms of lupus that attack different areas of the body. The appropriate treatment plan is considerate of the risks and benefits for long-term management.

This treatment plan is balanced in light of the child's disease manifestations, the family's overall understanding of lupus, their religious convictions, and their concerns about the possible side effects of the treatment. Some parents will not allow a child to be treated with chemotherapy to prevent kidney damage. Others will refuse or severely limit the use of corticosteroids such as Prednisone or Medrol due to fears of side effects. Only through a strong foundation of education and the development of a trusting relationship with their doctor can they see the future and weigh potential harm of the treatment against harm from uncontrolled lupus....



# Pharmacy Assistance Programs

## [Partnership for Prescription Assistance \(http://www.pparx.org\)](http://www.pparx.org)

Brings American's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many people will be provided with free or drastically reduced medication through this program.

## [Together RX \(http://www.togetherrxaccess.com\)](http://www.togetherrxaccess.com)

A FREE prescription savings card for eligible residents of the U.S. and Puerto Rico who have no prescription drug coverage. This public service program was created and sponsored by a group of the world's largest pharmaceutical companies.

## [RxAssist—Patient Assistance Center \(http://www.rxassist.org\)](http://www.rxassist.org)

RxAssist offers a comprehensive database of patient assistance programs as well as practical tools, news, and articles so that health care professionals and patients can find the information they need.

## [RxHope \(https://www.rxhope.com/home.aspx\)](https://www.rxhope.com/home.aspx)

RxHope is exactly what its name implies, a helping hand to people in need in obtaining critical medications that they would normally have trouble affording. They act as your advocate in making the patient assistance program journey easier and faster by supplying vital information and help. RxHope is the only internet patient assistance initiative financially supported by PhRMA (Pharmaceutical and Research Manufacturers of America) and participating pharmaceutical companies.

## [NeedyMeds.org \(http://www.needymeds.org\)](http://www.needymeds.org)

NeedyMeds provides information for people who need help with the cost of medicine and other health care expense.

## [Wal-Mart Prescriptions \(http://www.walmart.com/cp/1078664\)](http://www.walmart.com/cp/1078664)

Wal-Mart Pharmacies offer \$4 prescriptions for a 30 day supply of 300 generic drugs. Follow the links to the Pharmacy and the \$4 Prescription program for additional information.

## [Access2wellness\(http://www.access2wellness.com\)](http://www.access2wellness.com)

A Johnson & Johnson sponsored program designed to assist people with limited or no health insurance get the help they need to lead healthier lives. Through access2wellness, people can learn about a variety of assistance programs that, combined, offer more than 1,000 prescription medicines and medical products for free or at a discount to qualified individuals. Special sections have been developed to address the specific needs of patients, caregivers, healthcare professionals, hospital administrators, and advocate organizations; and the exclusive access2wellness Online Eligibility Tool offers a quick and easy way to find out which assistance programs are available and who qualifies for them.

## [AARP State by State, Plan by Plan List of Pharmacy Assistance Programs \(http://www.aarp.org/health/drugs-supplements\)](http://www.aarp.org/health/drugs-supplements)

This is a handy tool through the AARP website that provides information about medications and savings programs available in your area. Once on this website, click on the "Save on Prescriptions" link, which is located on the right side of the AARP Health, drug and Supplements website. Then click on the "Drug Savings Tool."

## [HealthCare Connect \(http://www.healthcareconnect.org/qualification.html\)](http://www.healthcareconnect.org/qualification.html)

The Healthcare Connect program is a resource for residents of Maricopa County who do not qualify for other programs (Medicaid, Medicare, employer-based) Members of HealthCare Connect pay their enrollment fee and then choose a primary care physician who oversees all of their care, ensuring complete, coordinated services. Members also pay very low fees at the time they receive medical services. Participating physicians, hospitals, facilities and health centers that are committed to caring for uninsured Maricopa County residents provide these medical services.

## [Patient Assistance \(http://www.patientassistance.com/programs.html\)](http://www.patientassistance.com/programs.html)

This non-profit organization helps patients to identify the many patient assistance programs to help with the costs of medication. The website is easy to use and searches multiple assistance programs simply by entering the drug name and/or pharmaceutical company into the search boxes.

## [INDIVIDUAL PHARMACEUTICAL COMPANY PATIENT ASSISTANCE PROGRAMS](#)

### [Abbott](#)

(Type Abbott Patient Assistance in your search engine)

The Abbott Patient Assistance Program (PAP) PROVIDES Abbott medications, at no cost to patients in financial need.

### [AstraZeneca \(http://www.astrazeneca-us.com/help-affording-your-medicines\)](http://www.astrazeneca-us.com/help-affording-your-medicines)

Provides information about AstraZeneca's assistance programs.

### [Bristol-Myers Squibb \(http://www.bms.com/products/Pages/programs.aspx\)](http://www.bms.com/products/Pages/programs.aspx)

This website provides information about Bristol-Myers Squibb Patient Assistance Foundation and other programs that provide access to BMS products to eligible individuals.



# Pharmacy Assistance Programs cont'd from page 5



## [Bridge to Access through GlaxoSmithKline \(http://www.bridgestoaccess.com\)](http://www.bridgestoaccess.com)

GlaxoSmithKline's patient assistance program for non-oncology medicines provides GSK prescription medicines to eligible low-income patients without prescription drug benefits.

## [Genentech Patient Access Programs \(http://www.gene.com/gene/products/access\)](http://www.gene.com/gene/products/access)

Patient assistance support is for eligible patients in the United States who do not have insurance coverage or who cannot afford their out-of-pocket co-pay costs. There are several different patient assistance programs available through Genentech.

## [Eli Lilly and Company Patient Assistance Program \(http://www.lilly.com/responsibility/servingpatients/programs\)](http://www.lilly.com/responsibility/servingpatients/programs)

Eli Lilly and Company programs assist patients with prescription drug costs. Eli Lilly and Company recently lowered the income eligibility requirements for their assistance programs. Many different programs are available through Eli Lilly.

## [MerckHelps \(http://www.merck.com/merckhelps\)](http://www.merck.com/merckhelps)

Merck&Company provides its medicines and adult vaccines for free or at discounts to people who do not have prescription drug or health insurance coverage and who, without our assistance, cannot afford their Merck medicine and vaccines.

## [Novartis \(type Novartis Patient Assistance Program in your search engine\)](#)

Novartis is committed to providing access to their medications for those most in need through the Novartis Patient Assistance Foundation, Inc. (PAF). PAF provides assistance to patients experiencing financial hardship who have no third party insurance coverage for their medicines.

## [Ortho-McNeil, Inc. Patient Assistance Program \(http://www.ortho-mcneil.com/ortho-mcneil/company\\_pap.html\)](http://www.ortho-mcneil.com/ortho-mcneil/company_pap.html)

Ortho-McNeil provides assistance to patients through the access2wellness website who because of financial burden and lack of prescription drug coverage, may have difficulty paying for their treatment.

## [Pfizer Patient Assistance \(http://www.pfizer.com/responsibility\)](http://www.pfizer.com/responsibility)

Pfizer believes that everyone should have access to the medicines they need. Pfizer Helpful Answers is a family of assistance programs for the uninsured and underinsured who need help getting Pfizer medicines. These programs provide Pfizer medicines for free or at a savings to patients who qualify. Some programs also offer reimbursement support services for people with insurance. Whether you are prescribed a Pfizer or a Wyeth medicine. Pfizer is committed to helping patients in need get access to their medicines. Visit PfizerHelpfulAnswers.com to learn more about the Pfizer and Wyeth Patient Assistance Programs.

## [Roche U.S. Pharmaceuticals Assistance Programs \(http://www.gene.com/gene/products/access\)](http://www.gene.com/gene/products/access)

Roche in partnership with Genentech is committed to patients having access to their therapies through its Genentech Access Solutions program the company provides patients and healthcare providers coverage and reimbursement support, patient assistance and informational resources. Patient assistance support is for those eligible patients in the United States who do not have insurance coverage or who cannot afford their out-of-pocket co-pay costs. (Roche and Genentech merged companies)

## [Schering-Plough \(http://www.patientassistance.com/profile/merckscheringplough-17\)](http://www.patientassistance.com/profile/merckscheringplough-17)

Schering-Plough in partnership with Merck assists patients in securing drug reimbursement as well as providing lifesaving drugs at no cost to people with low incomes through their patient assistance program. Schering-Plough-Merck uses the non-profit organization "Patient Assistance" to identify programs available to the patient based on the name of the medication needed.

## [Wyeth Pharmaceuticals in Partnership with Pfizer \(http://www.pfizerhelpfulanswers.com/pages/Misc/PfizerWyethDetails.aspx\)](http://www.pfizerhelpfulanswers.com/pages/Misc/PfizerWyethDetails.aspx)

Wyeth medicines are now available through the Pfizer helpful Answers family of patient assistance programs which strive to ensure eligible patients receive meds at no cost and in a timely manner.

# When A Child Has Lupus

Continued from page 4

Involvement of the skin is often best treated with sun avoidance, sun blocking agents and topical steroids, arthritis pain and inflammation sometimes can be controlled with anti-inflammatory medications such as aspirin or non-steroidal anti-inflammatory drugs (NSAIDS) approved for use in children (Naprosyn, Tolectin and Ibuprofen). When skin or joint involvement is more severe and is not controlled by these measures, hydroxychloroquine (Plaquenil) often is an effective alternative.

When an inflammation is severe in vital organs or tissues, steroids often are required to bring the damaging inflammation under control. Inflammation of the lining of the lungs and heart (pleurisy and pericarditis), blood cells or nerves, and skin and joints are all of particular concern.

Severe, damaging inflammation of the kidney and rarely, the brain, often requires intensive therapy with combinations of steroids and cytotoxic agents (such as cyclophosphamide and azathioprine).

It is important to realize that how lupus presents in a child now can be quite different from how it may present in the future. In fact, I have often seen severe lupus in a child at the beginning of their disease enter remission (a symptom-free period) with treatment and time. My goal in treating children is, once remission is achieved, to remove the very treatment that helped get the child to that state.

A treatment plan is necessary if lupus is to be brought under proper control. Parents need to know what to expect, how long treatments and therapies will continue, how rapidly improvements can be anticipated, and what changes will occur if the desired effects are not achieved. Certainly all of the possible outcomes cannot be predicted, but an outline of expectations will help the doctor and family be partners in the process of treating and controlling lupus.

## **Taking care of lupus children is more than monitoring laboratory test results.**

Careful monitoring and follow-up help ensure a minimum of side effects from the disease or its treatment. Often the use of medications is not simple and straightforward. Parents must be consistent in how they give medications. They should also have knowledge of the possible side effects from medication, so they can recognize a problem early. As the child matures and becomes involved in the treatment, the child becomes increasingly responsible for taking medications regularly, eating properly, getting needed rest and exercise, and avoiding fatigue which can lead to flare-ups of the disease.

## **Caring for children with lupus involves the child's other healthcare professionals.**

The physician who treats children with lupus must be constantly mindful of communication with the child and parents. Interactions must be clear, logical and honest. This will help when treatments become more difficult, or if frustrations concerning the disease or its complications develop. The office visit can become a place where parents or children vent their frustrations in dealing with lupus. These moments can occur when discussing the direction of therapy or

interpreting laboratory tests. The trusting relationship can be strained but eventually will grow stronger if it is based on honesty and hopefulness.

## **Caring for children with lupus involves the child's other healthcare professionals.**

Promoting teamwork and facilitating communication between the different people involved in the child's care is another important goal. As mentioned, healthcare professionals such as the other doctors, nurses, physical therapists and psychologists who are involved in the child's care need to be supportive of the treatment plan and demonstrate understanding and patience with the child.

## **Taking care of children with lupus is educating parents and child about the disease, the treatment and how it may affect them.**

Parents and their child must become actively engaged in day to day decisions concerning lupus and its treatment. The physician's role is to provide education. By talking directly with the family, providing pertinent and up-to-date literature and referring them to resources such as the Lupus Foundation, doctors can help families gain a sense of hope and optimism.

In addition the physician's role is to encourage parents to allow a child with lupus to grow self-reliant and independent. Children must learn the relationship they have with lupus. Successful families and consequently successful children develop and grow in the face of lupus. These children actually become more extraordinary because they have been faced with challenges unfamiliar to most of their peers.

## **Caring for children with lupus may include contacting the school and educating the teachers.**

Teachers, counselors, coaches, and other leaders of the child's activities may need additional information regarding the child's condition. The child may have special needs, and special understanding and sensitivity is needed. Children may be embarrassed or fear rejection because they are perceived as different from their peers. They may find it difficult to concentrate and complete academic requirements, accomplish physical tasks, compete in sporting activities or deal with unstable and fragile emotions. They will need their parents' love, understanding and compassion.

## **Caring for children with lupus means helping the child to continue to grow and develop.**

The primary goal is to nurture and create an environment of growth and positive development for the child with lupus. The family provides the foundation; everyone else aids the process. Family and physician together impact the child's quality of growth and development toward maturity. Successful children are not necessarily those with the most quiet or controlled disease, rather, they are the children who look at tomorrow with the bright eyes of youth in spite of or even because of the challenges they face today.



FOUNDATION

RESOURCES

After- Hours Telephone Support Line - 520-622-9006

Bi-Lingual Information & Support

Support Groups: Tucson - 3rd Weds. 10AM our office

Personal Support - Call Office

Youth Support Group - 331-2997

Douglas Support Group - 364-5028

Community Speakers

Emergency Medical Need Assistance

Information and Referral Services

Information for Visually Impaired

Lending Library

Medical Articles Library included Research Articles

Quarterly Newsletter & A Newsletter for the Newly Diagnosed

Website - [www.lupus-az.org](http://www.lupus-az.org) and Toll free = 1-877-822-9006



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