

# BE Healthy™

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## Lupus: Chronic condition still a mystery

Their stories on lupus couldn't be more different.

Robin Sanzi knew from the start that something was terribly wrong.

The sudden pain and swelling in her hands and wrists were so bad that she couldn't zip her pants or open a bottle of water. "Something wasn't right," she recalled.

Tests were done, and when the results came back a little askew, Sanzi was off to a specialist. The diagnosis was fairly quick in coming: Sanzi had lupus.

"I hit the panic button," she said. "I thought I was going to die."

For Cherelle Payne, it took about two years before doctors determined she had the chronic condition. She suffered from some of the common

warning signs: fever, swelling of the feet, a rash on the face, blood problems and fatigue. She was even hospitalized at one time for kidney problems.

But for years before her diagnosis, Payne's lupus-related incidents, or "flares," appeared only during the summer months and not when she was attending school from fall to spring.

And that is part of the problem with lupus — it's very difficult to detect, and even when detected, symptoms of the disease can appear and disappear.

In a strange way, after years of going back and forth from one doctor to another, Payne admitted she was glad to hear the

words.

"I felt relieved to finally put a name on what was happening," she said.

She was 21 years old at the time.

Lupus is neither curable nor preventable. For unknown reasons, it occurs more frequently in women between the ages of 15 and 45, and is more prevalent in women of color, especially African Americans. More troubling, the complications of lupus tend to

be more severe in minorities, who also have a higher death rate than white women.

The most common and serious form of the disease is called systemic lupus erythematosus, or "lupus." It can result in kidney failure — one of the leading causes of death among people with lupus. It impacts the central nervous system and causes headaches,

dizziness and behavioral changes. It can lead to pneumonia and inflammation of the blood vessels.

Bone tissue can die due to a compromised blood supply, and pregnant women with lupus suffer a higher rate of miscarriages.

Most serious is the impact on the heart and cardiovascular system. According to the Lupus Foundation of America, women with lupus have as much as 10-times increased risk of coronary heart disease compared to the general population. Inflammation from lupus can lead to inflammation of the heart itself, the membranes surrounding the heart, as well as the arteries that feed the heart and brain.

**According to the Lupus Foundation of America, women with lupus have as much as 10-times increased risk of coronary heart disease compared to the general population.**



Cherelle Payne (right) attributes her ability to cope with lupus to the support of her husband, Daren. Payne suffered her first symptoms of lupus when she was a 19-year-old college student.

This can increase the risk of heart attack and stroke.

Despite all the damage it can cause, lupus remains one of the most difficult diseases to detect. Dr. Patricia A. Fraser, a rheumatologist with a clinical interest in lupus, is the chair of the board of directors of the Lupus Foundation of New England. Rheumatologists specialize in treating arthritis and other bone, joint and muscle disorders, including lupus.

"Lupus is a syndrome — a combination of many symptoms that, unless they occur together, are not specific for lupus," Fraser explained.

The problems don't stop there. "Unless a health care professional is thinking about the diagnosis, it can be overlooked," she said.

No one has come up with a specific test as yet.

"The antinuclear antibody test is the best screening test we have," she said.

But those test results can only "suggest" lupus; they can't confirm it. Further complicating matters, symptoms are frequently episodic. "A person might be bedridden with a symptom and by the time she gets to the

doctor, it is gone," Fraser said.

No two cases are exactly alike and the symptoms can vary widely. They can come on suddenly or slowly, be severe or mild, temporary or permanent. At times the symptoms appear so slowly that no specific pattern emerges. According to the Lupus Foundation of America, it can take as long as 10 years to accumulate enough evidence to confirm a diagnosis.

The symptoms are often attributed to other maladies. The joint pain resembles other causes of inflammatory arthritis such as rheumatoid arthritis. Recurrent fever symptoms may be mistaken for the flu. Often lupus is not diagnosed until the symptoms are severe or several manifestations occur simultaneously.

Robin Sanzi just knew she was going to die. One friend had already died from lupus. Another was disabled.

Fortunately Sanzi, 48, was diagnosed with a relatively mild case. Her most common symptom is photosensitivity, or reaction to the sun.

"My skin becomes very red," she said.

*Sanzi, continued to page 4*

## Hope for a lupus patient

Say this about Hope White.

For the last 20 years, lupus and all its complications have altered her life in devastating ways. But one thing remains constant: her parents named her right.

"They named me that for a reason," White explained.

"Hope" is an understatement. Since her diagnosis, White, 44, has had one complication after another. As it is now, she takes 16 different medications, and is in and out of doctor's offices almost every week.

Still, White considers herself blessed. She is still working as the manager for health and wellness programs at the YWCA Boston. She sits on eight community boards and has her hands full with a relatively new addition — a 20-month-old baby boy.

In her mind, her battle with one of the most mysterious diseases has been a good thing. "Lupus has opened a lot of doors for me," she said.



Hope White, who manages the health and wellness programs at YWCA Boston, has lived with lupus for 20 years.

It all started when White had recently graduated from Northeastern University. She was working two jobs to repay her college loans.

At first, she said, she thought she was simply tired from all the hours of work. She had other symptoms as well

— aches and pains in her joints, fever and night sweats. But more than anything else, she was fatigued.

"I had to sit down to brush my teeth," she recalled. "I thought it was a really bad case of the flu."

Her condition got worse, and she finally went to the doctor about two months later. Their initial diagnosis was that she probably had mononucleosis — a

common blood disease among young adults. She was given antibiotics.

When White's condition persisted, doctors thought that she had Epstein-Barr

virus, a very common affliction that can cause mononucleosis. She was told to eat vegetables, get plenty of rest and take vitamins. The doctors increased the dosage of antibiotics, but, again, the problems didn't go away.

In fact, they got worse. Her joints began to swell. "My elbows actually locked and I was unable to extend my arm," said White.

Now alarmed, White's family took her to an emergency room and demanded answers.

"We'll keep Hope here until you find out what's wrong," they told the doctors.

They tested her for everything under the sun, including HIV. One lone female doctor suggested they test for lupus. When the results of her antinuclear antibody test were positive, her doctors eventually confirmed the diagnosis — after a year of deliberation.

Lupus is a chronic autoimmune inflammatory disease that causes the body to attack itself. In healthy bodies, the immune system produces antibodies

*White, continued to page 4*



# Lupus: An unpredictable rocky road

Lupus is an autoimmune disease that affects an estimated 1.5 million to 2 million people in the United States, according to the Lupus Foundation of America.

The majority of lupus patients are women who develop the disease between the ages of 15 and 45. Minorities, such as Latinos, African Americans, Asians and Native Americans, are also at a higher risk for developing the disease. If you belong to an at-risk group, it is important to be educated about lupus, its symptoms and treatment options.



## What is lupus?

In lupus — short for systemic lupus erythematosus, the most common form of the disease — the body's immune system, which normally defends against viruses and bacteria, attacks healthy tissue. This self-inflicted attack results in inflammation, which can be painful and damaging to the tissue. The organs most affected are the kidneys, heart, lungs, nervous system or blood cells, though all areas of the body are at risk.

The symptoms of lupus tend to come and go. Most commonly you will experience pain and swelling in your joints, a fever, skin rash and exhaustion. If these symptoms occur on a regular basis, you should ask your doctor to test you for lupus.

## Testing and diagnosis

No single test can determine if a person has lupus. The diagnosis will depend on a complete medical history, physical examination and several laboratory tests.

One significant test is the antinuclear antibody (ANA) test, which looks for antibodies the body makes against itself. Although a positive ANA test is highly indicative of lupus, it is not conclusive. Drugs, infections and other diseases can also cause a positive result.

Other laboratory tests are important — complete blood count, urinalysis, chest X-ray and electrocardiogram. The erythrocyte sedimentation rate, which measures inflammation in the body, is essential, as are biopsies of the kidney and skin.

## Treatment

There are several drugs that your doctor may prescribe to control your symptoms. Steroids are commonly used to reduce swelling, tenderness and pain. These steroids are different from those used by some people who play sports or lift weights. Steroid creams are applied to the skin to cause a rash to subside. Steroids are also taken by mouth or injections.

You may also take nonsteroidal anti-inflammatory drugs, such as aspirin and ibuprofen, to treat joint pain and stiffness. Anti-malarial medications are also used to treat joint pain, skin rashes and mouth sores.

More severe cases of lupus are treated with immunosuppressive agents and chemotherapy.

While treatments help control the symptoms, they take their toll in other ways. Steroids can result in osteoporosis, or weakening of the bones, and you may need to take calcium and vitamin D to counter those effects. Immunosuppressants also leave you much more susceptible to disease and infection.

## Pregnancy

Because lupus affects primarily women of childbearing age, women with lupus should understand the risks involved with pregnancy. Experts agree that women with lupus can now safely become pregnant and

suffer few or no flares, especially if the disease is under control or in remission for a period of time.

However, complications can arise. According to rheumatologists at the Johns Hopkins Arthritis Center, about 10 percent of pregnancies end in miscarriage. Miscarriages that occur after the first trimester are more associated with signs of active lupus. In addition, about 20 percent of pregnant women with lupus develop pre-eclampsia, a sudden rise in blood pressure. Pre-eclampsia, a critical condition that requires immediate attention, often results in preterm births.

Because of the risks associated with lupus and pregnancy, it is important to talk to your doctor about how best to keep symptoms down throughout your pregnancy. It is also recommended to find an obstetrician that specializes in high-risk pregnancies who can more efficiently monitor your progress.

## Coping

Lupus is a chronic condition that requires full-time maintenance. Those with lupus are encouraged to practice a healthy lifestyle to avoid flares and complications. Tips on healthy living include:

- Rest to reduce stress;
- Avoid the sun, and wear sunscreen and protective clothing when outside;
- Exercise regularly to prevent joint stiffness, fatigue and depression;
- Stop smoking. Tobacco increases inflammation of the arteries;
- Learn as much as you can about lupus; and
- Work closely with your doctor.

In general, the best thing you can do, if you've been diagnosed with lupus, is to maintain your treatment regimen and visit your doctor on a regular basis. Because the types of lupus and the affected areas can vary so greatly, only your doctor can create a truly effective treatment plan. You will also begin to recognize the activities and behaviors that cause your symptoms to flare up and you'll learn to avoid them. You should also check with your health insurance company to see which treatment options are covered by your health plan.

There's no such thing as a silly question. Especially in health care.

At Blue Cross Blue Shield of Massachusetts, we are committed to working with hospitals and physicians to improve health care quality and safety. Patients, too, can play an important role by following these guidelines from the U.S. Agency for Healthcare Research and Quality:

1. Ask questions if anything is unclear.
2. Keep a list of medications that you take.
3. Get the results of any tests or procedures.
4. Ask questions about your surgery.



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## Living with lupus

Although it is not possible to prevent or cure lupus, there are steps you can take to minimize flares and cope with the disease.



Get plenty of rest and actual sleep.

Wear sun block every day and avoid excessive sun exposure.



Exercise regularly to maintain joint flexibility and prevent cardiovascular complications.

Don't smoke. Smoking increases your risk of cardiovascular disease.



Follow a healthy eating plan.

Join a support group.



Take your medications as directed.

Get regular checkups and maintain a good doctor-patient relationship.





## Questions & Answers

### 1. If a woman has lupus when she gives birth, is her baby born with the disease?

About 3 percent of babies born to mothers with lupus are born with a special type of lupus called neonatal lupus. Different from regular lupus, neonatal lupus is temporary (lasting only a few months) and characterized by a rash and blood count abnormalities. By 3 to 6 months old, the baby usually no longer shows any signs of neonatal lupus. Sometimes, a baby born to a mother with lupus can be born with an abnormal heartbeat. This special type of heartbeat is permanent, but can be treated with a pacemaker and usually results in no other complications. Overall, though, the chance of the baby developing lupus is very low.



**Joseph R. Betancourt, M.D.**  
Director of the Disparities Solutions Center, Massachusetts General Hospital

### 2. How can a person determine if joint pain is due to arthritis or lupus?

Many with lupus experience joint pain at some point in their life, but unlike arthritis, the joint pain caused by lupus is usually temporary. If you have arthritis, you experience constant swelling of the joints and joint pain that is less severe than what is seen with lupus. Determining the difference can get confusing and is best left to your doctor. If you are experiencing any pains in your joints, talk to your doctor and ask about the best ways to take care of your joints.

### 3. Can lupus cause osteoporosis?

Osteoporosis or bone loss occurs when the bones become less dense and less strong, making it easier for them to fracture or break. If you have lupus, you are more at risk for developing osteoporosis, but you can take steps to prevent increased bone loss. Individuals with lupus have an increased risk for osteoporosis for two important reasons. First, certain medications used to treat lupus (glucocorticoids) can cause the bones to decrease the amount of calcium they absorb, making them weaker over time. Second, because lupus can cause fatigue, those with lupus are less likely to engage in important physical exercises that can increase bone strength. If you have lupus, talk to your doctor about your medication dosage and about finding an exercise plan that is right for you.

### 4. Why is it important for a person with lupus to closely monitor blood pressure and cholesterol levels?

Individuals with lupus are at increased risk for heart disease, so it is important to make sure your blood pressure and cholesterol levels are within healthy ranges. Lupus can cause arteries to swell, raising blood pressure, and patients with lupus more commonly have plaque (cholesterol from fats) buildup in their arteries, both of which can increase your risk of heart disease.

### 5. Can children and men also get lupus?

Although lupus is most common in women between the ages of 15 and 45, lupus can occur at any age and in both males and females. The symptoms are the same in both adults and children — fatigue, rash and/or achy joints. Similarly, a diagnosis is made based on the presentation of symptoms and lab tests done by your doctor. Although there is no cure for lupus, the disease can be successfully managed and complications can be minimized with proper treatment. Treatment, regardless of age and gender, will vary depending on how much the disease has progressed.

### 6. Should people with lupus refrain from exercise?

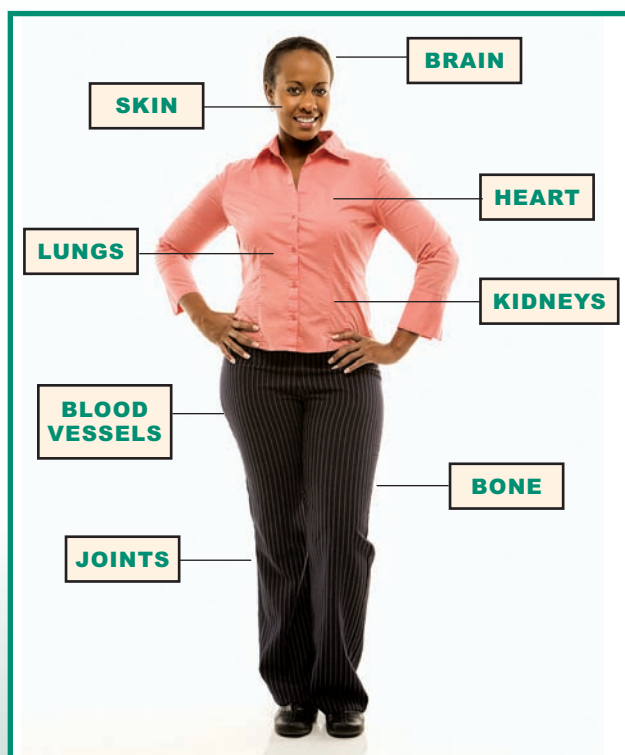
Exercise is an important part of maintaining a healthy lifestyle, especially for those with lupus. Although exercise can be difficult for individuals with lupus because of fatigue and joint pain, studies have shown that regular exercise can actually alleviate some of the symptoms. For example, regular exercise (like walking and stretching) can reduce fatigue, improve your range of motion, help with arthritis and help slow the onset of complications associated with lupus-like osteoporosis. Begin by talking to your doctor about which exercises are best for you.

### 7. Is lupus hereditary?

Doctors believe that lupus results from an interaction between our genes and our environment, but the exact cause is not known. Although lupus tends to appear in certain families, it can develop in individuals with no family history of the disease. If you have any concerns or are experiencing some common symptoms associated with lupus, such as a large butterfly-shaped rash on your face, fatigue, or joint pains or stiffness, speak with your doctor as soon as possible.

*Marina C. Cervantes of the Disparities Solutions Center participated in the preparation of these responses.*

## The face of lupus



Lupus is a chronic, inflammatory autoimmune disease that can result in complications affecting the skin, central nervous system, kidneys, heart and blood vessels, lungs, joints and bones. Lupus is more common in black women than any other group, occurs at a younger age and tends to be more severe in blacks. There is no cure for lupus, but the treatment has improved over the years so that those affected can often live long and productive lives.

## Signs and Symptoms

- Painful or swollen joints
- Fever with no known cause
- Fatigue
- Skin rashes
- Anemia
- Trouble thinking, memory problems, confusion
- Kidney problems with no known cause
- Chest pain when taking a deep breath
- Butterfly rash across nose and cheeks
- Sun or light sensitivity
- Hair loss
- Blood clots
- Purple or pale fingers and toes from cold or stress
- Seizures
- Mouth sores
- Severe headache
- Dizziness
- Swelling of hands and feet
- Depression
- Strokes

*Healing the racial divide in health care*

## Dr. Joseph Betancourt wrote the book on health care disparities. Now he's trying to erase them.

When Joseph Betancourt was in medical school, he often saw children acting as interpreters for family members who did not speak English. Originally from Puerto Rico, and as the only Spanish-speaking medical student on his team, he had to interpret for hospitalized patients.

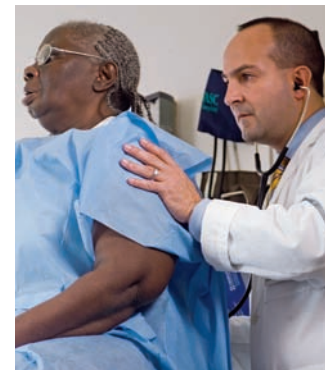
Years later, Joseph Betancourt, MD, MPH, co-authored a landmark study by the Institute of Medicine that found striking inequities in health and health care for racial and ethnic minorities across the US.

When Massachusetts General Hospital president Peter Slavin, MD created the Disparities Solutions Center at MGH, he chose Dr. Betancourt to lead it. "It is time to move from diagnosing the problem to treating it," said Dr. Slavin.

The MGH Center is the first hospital-based Disparities Solutions Center in the country to move disparities beyond research into policy and practice. It has \$3 million in support from MGH and Partners HealthCare.

The Disparities Solutions Center will:

- advise MGH in its efforts to identify and address racial and ethnic disparities in care;
- develop and evaluate customized solutions to



eliminate disparities in the health care community in Boston and beyond;

- educate, train and expand the number of leaders working to end disparities nationwide.

Perhaps most important, the center will transfer what it learns to hospitals and health centers, community groups, insurers, medical schools, educators, government officials, and of course, physicians and nurses across the country.

One of the Center's first efforts is the new Diabetes Management Program at the MGH Chelsea Health Care Center, where more than 50 percent of patients are Latino. Latinos are more likely than whites to die from diabetes complications including kidney failure, blindness, heart disease, and amputations.

MGH Chelsea health professionals will help patients control their diabetes, get regular screenings, and prevent complications through telephone outreach, individual coaching, and group education sessions in English — and Spanish.

Translating talk into action is what Dr. Betancourt has been doing all his life.

*More information at Boston Public Health Commission at [www.bphc.org](http://www.bphc.org)*

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Yet, that seemingly minor affliction interferes with Sanzi's job, which requires her to work outside, even in the heat of August. At times she merely covers up, wearing a hat and long sleeves. Other times she is forced to take medical leave.

There are other symptoms. She notices that she bruises easily and that the bruises don't go away quickly.

"Sometimes they can linger for over a year," she said. "Even people touching you can cause a bruise."

For the most part, Sanzi controls her condition well. She is on medication and gets a checkup every three months. She visits the dentist every four months to have her teeth cleaned and her gums checked. People with lupus are prone to inflammation of the gums and mouth sores.

She gets her eyes examined every year, since the medication she is on may damage the retina. She keeps track of her blood pressure and cholesterol, and exercises regularly to ward off the cardiovascular problems so common with lupus.

Payne has a more severe case of lupus. But after her diagnosis, she went through a fairly innocuous period for three years.

That changed in 2005 when she traveled to Mexico. She got a pain in her hip

that she thought was the result of walking too much. Although the pain got worse, she stayed in Mexico and promised to tell her doctor during a regularly scheduled appointment back in Boston.

She made it back to Boston, but not to her appointment.

"I went to the emergency room instead," she said. The doctors discovered a blood clot. According to Payne, a small piece had entered her lungs. Patients with lupus sometimes make antibodies that enhance the body's tendency to form blood clots. Payne spent two weeks in the hospital and was given blood thinners, which she still takes.

For the next three years, Payne's condition was manageable. She still suffered the usual headaches and joint pain that come with lupus. And fatigue. "Lupus makes you so tired you don't even want to get up to go to the bathroom," she said.

Then, in 2008, she suffered a stroke.

Fortunately, the stroke has left no permanent damage, but Payne has been unable to work since then.

Payne is 29 years old and considers herself blessed. She married her high school sweetheart and has the support of a loving family and friends. Wise beyond her years, she says she takes everything in stride.

She is on lots of medication, including steroids and blood thinners. And has the side effects to prove it — puffy face, fluctuating weight and stretch marks that she refers to as "tiger stripes."

One thing is certain — lupus has not dampened her spirit.

"You can live with lupus," Payne said. "Don't let this stupid illness scare you. ... I'm going to deal with it. It's not going to deal with me."



Patricia A. Fraser, M.D., M.P.H.  
Chair, Board of Directors  
Lupus Foundation of New England



Photosensitivity, or reaction to the sun, is Robin Sanzi's major complication with lupus.

## What increases your risk of lupus?

- **Age** — although lupus can occur at any age, it is more common between the ages of 15 and 45
- **Gender** — 90 percent of the people with lupus are females
- **Race** — African Americans are three times more likely to get lupus than white people
- **Exposure to sunlight**
- **Certain medications** — some medications for psychoses, heart disease and tuberculosis can trigger lupus
- **Family history of lupus**
- **Exposure to chemicals** — those who work with mercury and silica may have an increased risk



## It's hard to tell ...

It is difficult to diagnose lupus because the symptoms vary widely from person to person, may change over time and overlap with other disorders. According to the

American College of Rheumatology, if you have four of the following 11 criteria — documented by a physician — you probably have lupus. The four criteria can occur together or individually over time.

- **Face rash** — especially butterfly shaped on the nose and cheeks
- **Scaly rash** characterized by raised, scaly patches
- **Sun-related rash**
- **Painless mouth sores**
- **Joint pain and swelling in two or more joints**
- **Inflammation of the membranes lining the heart or lungs**
- **Kidney disorder**
- **Seizures or psychosis**
- **Low blood counts, such as anemia**
- **Positive antinuclear antibody test**
- **Immunologic disorder** — presence of certain antibodies

Source: American College of Rheumatology

## Stay connected

Talking to other people with lupus and sharing experiences and information can help reduce the stress of living with the disease. Below are three support groups in the Boston area.



Name of Group	Address	Date	Time	Facilitator	Tel. No.
Arthritis and Lupus Support Group	New England Baptist Hospital 125 Parker Hill Avenue, Roxbury	2nd Tuesday of the month	6 p.m.	Denice Garrett	617-825-1225
Women of Courage	Codman Square Health Center 637 Washington Street, Dorchester	3rd Thursday of the month	6 p.m.	Gail Granville	617-825-6010
Daughters of Comfort	Morning Star Baptist Church 1257 Blue Hill Avenue, Mattapan	2nd Tuesday of the month	7 p.m.	Lorraine Hector Deanna Gross	617-282-4919

## White

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that ward off bacteria and viruses. But in patients suffering from lupus, the immune system cannot distinguish between healthy and bad cells. As a result, it attacks everything, including healthy tissues and organs.

There are several different types of lupus. The most common and serious form of the disease is systemic lupus erythematosus, commonly referred to as "lupus." Other kinds include discoid lupus, which impacts just the skin and is characterized by a red raised rash on the face, scalp and other parts of the body; drug-induced lupus, caused by certain medications, which is reversed with discontinuation of the medication; and neonatal lupus, linked to the mother's autoimmune disease, which usually disappears shortly after birth.

The cause of lupus is unknown, but theories abound on the reasons that incidences of lupus are higher in communities of color. Recent studies suggest that genetics and environmental factors play a major part.

One such recent study — the Roxbury Lupus Project — was conducted by experts at Brigham and Women's Hospital in collaboration with the Women of Courage, a lupus support group, the Massachusetts Department of Public Health and investigators at the National Institute of Environmental Health Sciences. The purpose of the study was to test the theory that chemical wastes and other environmental factors prevalent in Roxbury, Mattapan and Dorchester might trigger the disease earlier than



Hope White (left) shown with her 20-month-old son, Narai, has suffered many complications of lupus over the years. White is currently on a kidney transplant list.

expected in people with certain patterns of genes.

Dr. Patricia A. Fraser was one of the experts who participated in that study. Fraser is the chair of the board of directors of the Lupus Foundation of New England.

The study did provide an estimate of how many people have lupus in Roxbury, Mattapan and Dorchester, but did not conclusively show a link between residential exposure to hazardous waste sites and lupus. Fraser explained that the study also increased awareness of lupus among the residents of these neighborhoods. This consciousness raising is essential — among providers as well as consumers.

"Get fully informed," she said. "Especially if you have a family history of lupus."

For White, the complications from her case of lupus are mind-numbing.

When she was initially diagnosed, doctors prescribed steroids to reduce the symptoms. They worked, but not without side effects such as weight gain and swelling in her legs.

Two years later, without warning, White learned she had another problem — hemolytic anemia, a condition that results from premature destruction of red blood cells. Her hematocrit, which measures the number and size of red blood cells, fell rapidly.

A low hematocrit indicates that the body is being robbed of much-needed oxygen. She was admitted through the emergency room and received a blood transfusion to restore her blood to normal levels.

The next lupus-related incident, or "flare," caused minor kidney problems, a common consequence. Even now, she has her urine tested regularly to monitor the amount of protein — a strong indication of kidney dysfunction.

Then came yet another diagnosis. White already had the most common form of lupus. Doctors later determined that she also had discoid lupus, a less common type of the disease.

"I got rashes similar to [those of] eczema," she said.

According to the Lupus Foundation of America, approximately 20-30 percent of patients with the most common form will develop discoid lesions at some time during

the course of their disease.

But by now, doctors had determined that White also had a third form — bullous systemic lupus erythematosus — which is characterized by blisters that contain a clear fluid.

"I broke out in blisters from head to toe," said White, who was hospitalized as a result.

Even treatments caused problems. Chemotherapy, for instance, helped, but brought with it an unhappy side effect. It caused temporary osteoporosis and early menopause — what White calls "the most heartbreaking part of the disease." The chemotherapy also led to bacterial meningitis.

It came on suddenly, as White recalls. "I went out to dinner and a movie, came home and woke up with a 105-degree fever," she said. She was hospitalized for two weeks.

More problems followed. One time her blood pressure suddenly soared. "I saw colors of the rainbow everywhere I looked," she said.

Again she went to the emergency room and, while being transported by wheelchair, passed out.

White is now in stage 5 renal failure. So far she has been able to escape dialysis, but had a shunt inserted for dialysis just in case. She is now on a transplant list.

In spite of all she's been through, White said she keeps a positive outlook. And she falls back on her name.

"They named me Hope for a reason," she said.