YOU TELL THEM: IT'S IN THEIR HEAD DR. JAMES SCALA, Ph.D.

Lupus

CRYSTAL'S STORY

A young, healthy, active girl usually has her share of scratches and bruises. Crystal wasn't any different, but her scratches and bruises became infected more easily. Frequent bladder infections, a related problem, made her life difficult. As a young girl she had frequent visits to the doctor, and only once did he say to her mother, "Something is wrong with Crystal's blood. She gets too many infections." However, that was more of an observation than a diagnosis and they didn't follow up.

As a young mother, Crystal noticed that she'd get lumps or "knots" on various parts of her body, usually around her muscles. After a week or so they would disappear, so she just lived with them. At 23 years of age, a lump appeared on her abdomen and seemed to stay longer. "This seemed more serious, so I went to the doctor. He recommended a hysterectomy. Since I was 23 and wanted more children, I refused." The lump just disappeared after several months.

Crystal started having headaches and noticed that sometimes one of her joints would swell during the headache. One time the swelling would be in her fingers on one hand, and the next time it would be in a knee or an elbow. She sought the advice of an internist. "I asked him if there was a type of arthritis that could go from one joint to another and could be related to headaches?" At the time of her medical appointment, the swelling had gone down. It's like asking a talkative little child to show your friends how well they speak and all you get is silence!

After some questioning, the doctor decided her headaches were from birth-control pills. However, he concluded her joint swelling was not from birth-control pills, so he tested her for arthritis. This test, which looks for a protein called the "inflammation factor," requires a blood sample. The results of this finding are usually expressed as sedimentation rate, or "sea rate" for short. Crystal's arthritis test came back negative. The doctor said, "You don't have arthritis."

Now what should she do? She got headaches, knots or bumps in her muscles from time to time, and inflamed joints that seemed to come and go. By this time she, her friends, and family noticed that she always felt tired. She had been a person with lots of energy, but now she seemed to let her housework slide and took daily naps. Fatigue creeps up, so you don't really notice it. Crystal was taking a nap every morning and afternoon, but to make matters worse, she woke up tired even after a good night's sleep.

As the fatigue progressed, her eating habits became worse. She needed energy, so she ate candy. She was too tired to cook, so she ate food that came in boxes. Slowly, without realizing it, her diet shifted to sweets, packaged foods, and processed meat such as hot dogs. These eating habits didn't help whatever her health problem was.

Attacks became regular during a particularly traumatic period in her life. Her husband, a welder, had a work related accident that required surgery and he couldn't work. Consequently, Crystal had to care for her three children and hold down a job in order to put food on the table. To add fuel to the fire, some friends who were in tough financial shape moved in with them to "get back on their feet"! Even though the friends did their share around the house, it was a tough, stressful way to live. Crystal was unable to get any quiet time.

Once her son was hurt in sports and required a trip to the doctor. When the doctor finished with her son, who was alright, she asked him to look at her inflamed hand. It hurt so much that she couldn't even hold a comb. The doctor thought it looked like active rheumatoid arthritis, so he took a blood test. It was negative! Crystal didn't have rheumatoid arthritis no matter how her hands looked and felt.

Before long, all her joints became swollen, and she couldn't hold eating utensils, open bottles, or comb her hair with her hands. It even hurt to walk. Something had to be done. Crystal and her husband packed into the car and went to a clinic that specialized in arthritis. By the time they arrived, most of the swelling had gone down and only her ankles were swollen. They were bad enough, so the clinic doctors took more blood tests. Once again, they were negative.

Even if the tests were negative, the doctors recognized the swelling and discomfort she was suffering, so they gave her prescriptions for a steroid, Butazolidin, a tranquilizer, Stelazine, and an antibiotic, Tetracycline. She decided not to take them. These prescriptions focused on what the doctors had concluded. They realized there was some inflammation, so they prescribed a steroid to make it stop. Since inflammation is stress related, they probably felt the tranquilizer would make things easier for her. Tetracycline knocks out a number of microorganisms, so the doctors probably thought she had a persistent low-grade infection, possibly in her digestive system, that caused the inflammation. Her decision not to take the drugs was wise.

Tetracycline can have serious side effects on a lupus patient. Since lupus hadn't been diagnosed, she could have died, because the doctors wouldn't have known what was happening. The Stelazine might have relaxed her, but it wouldn't have removed the stress, and Butazolidin isn't the correct steroid. If she lifted weights, she might have developed bigger muscles, but that's about all. The drugs alone would have increased her need for vitamins, but her diet had also become very poor by this time. Consequently, she was falling short nutritionally because of both her medication and diet.

Shortly after her visit to the clinic, the inflammation subsided, but something else took its place. One day she found it difficult to speak. Her next series of knots and bumps seemed to develop on her vocal cords. The doctors were at a similar loss to explain these symptoms and recommended speech therapy. They said the therapy would help her use what she had left. Speech therapy was like offering bottled water to someone whose house is on fire.

When rashes developed that would come and go on any part of her body, Crystal decided to consult with a new doctor in a larger city. She felt that doctors in large metropolitan areas treated more patients, so they would probably see things differently and be more apt to confer with each other.

Crystal went through another series of blood tests. This time the doctor had a hypotheses. He was looking for either rheumatoid arthritis or lupus and said jokingly: "Which would you rather have?" As if she had a choice and wasn't already frightened enough.

SYSTEMIC LUPUS ERYTHEMATOSUS

In 1960, lupus was one of those rare diseases that only a few specialists would talk about. Very few nonmedical people had ever heard of it. Now, in 1991, most people over the age of 55 have heard of lupus and many know someone who has it.

Lupus, more specifically, systemic lupus erythematosus, or SLE for short, means "the wolf." It's named the wolf because you can't predict what organ the disease will attack, and the flare-ups are savage.

BACK TO CRYSTAL

In the spring of 1981, Crystal was told that she had systemic lupus erythematosus (SLE). Right after being diagnosed, she got a serious kidney infection, along with a flare-up that totally immobilized her hand. Now that she knew what she had, she took the medication that the doctor prescribed and the flare-ups stopped.

It's important to realize that once a flare-up of lupus starts, it must be stopped. A runaway flare-up can be fatal. For example, consider Kay, who isn't with us any longer, even though she would be only 44 today. Her lupus flare-up got going, and by the time the doctors got started treating her, it was too late. Lupus is a big-league disease.

On a typical day, she might take four short naps and 24 aspirin, which caused ringing in her ears and stomach pain. Finally, when the pain became constant, she was put on Prednisone, an anti-inflammatory steroid. It stopped the inflammation, but the side effects were ferocious.

Crystal joined the Lupus Foundation, which sent her many booklets filled with lots of information about lupus. After reading them, she realized that all the symptoms she had experienced, and no one could diagnose, were typical for the disease. She also learned that the disease was called lupus (the wolf) because it can attack anywhere. The problems Crystal encountered, all came to mind:

- Kidney problems and infections
- Muscle lumps that come and go
- Inflamed joints that seem to come and go
- Headaches that make you want to die
- Voice problems due to inflammation in her voice box
- Fatigue that drugs, coffee, and candy make worse

As its final statement, the Lupus Foundation said: "It's a fatal illness." Great! She could expect to die from lupus.

By December of 1981, Crystal was in so much pain she called her husband to her bedside and put her physical condition in two words: "I'm dying." Her husband's reaction was, "No way!" He called the Shaklee distributor because he had heard some tapes that said good nutrition seemed to help people with lupus. At least they felt better.

Her initial nutrition program included Instant Protein, which made her gag, Vita-lea, which gave her a queasy stomach, Vita-C, B-Complex, and up to seven Herb-Lax a day to start. She noticed two things: protein gave her energy, and Herb-Lax gave her regularity. This proves she reacts normally to some things.

After a few week she noticed that she was not only regular, but was taking only one daily nap in the afternoon. Besides that, she was doing more of the cleaning and daily household chores rather than just sitting around. She felt better than she had ever felt. After listening to some tapes on nutrition, she became so motivated, that she told the doctor she was going off the drugs. He laughed and said, "Okay, but let's do it slowly." She did it gradually and, much to his surprise, succeeded.

About two years later, during a particularly stressful time, Crystal had a flare-up of the lupus, along with some typical female problems that necessitated surgery. In spite of telling the doctor she didn't want any more steroids, she woke up from the surgery and was put on 40 milligrams of Prednisone daily. Crystal felt she was starting all over again. But this time she had built her reserves with a good nutrition program and, with the doctor's help, got off Prednisone once again.

Unfortunately, lupus waited a couple more years and attacked her kidneys. Kidney problems are not minor league; they're always serious. You can't live without working kidneys. Consequently, Crystal required medication to keep her kidneys working, but by sticking with her good diet and supplement program, she was soon able to get off that medication as well.

About this time Crystal was regularly listening to tapes on nutrition, and began to develop a Shaklee business. At first it paid for her prodigious product use, but she also saw people get results and started to feel the joy that comes to people who help others. As she got more into her business, she started listening to motivational tapes, which started her on the road to positive thinking. Pretty soon she was attending motivational seminars by such leaders as Nevena Christi and Rick Hill. Her life changed. Besides feeling good about herself, her family, and the world, she had also found satisfaction.

A year ago she went for a complete checkup by a specialist in rheumatology. He gave her a thorough evaluation, including blood tests, x-rays, and everything he could think of that might be relevant. First he told her she didn't look her age, 60. Then he said the best words of all: "I can't find any evidence of lupus right now." But Crystal knows, and all the experts confirm, that the lupus is simply sleeping. Like its name suggests, it will attack if she provokes it and lets her guard down for an instant.

Her "guard" includes an excellent diet that is based on the following:

- No red meat
- No sugar or white flour
- Lots of cranberry juice
- No dairy products
- Foods that cause a flare-up for her are avoided. These include citrus fruits.
- A supplement program that includes Instant Protein, Vita Lea, Vita-C, B-Complex, EPA, vitamin E, and alfalfa tablets.

Stress control is also part of her "guard," along with a good nutrition program that gives her body a strong foundation, so all its needs are met. Along with nutrition, stress control calls for a positive outlook and the ability to let problems roll off you, like water off a duck's back. Crystal has become a positive woman who radiates good cheer and self confidence.

IS THIS IN CRYSTAL'S HEAD?

No way! About 85 percent of lupus victims are women. It's inherited and often passed to men by their mothers. Crystal's story is quite typical.

It's not uncommon for victims of lupus to bounce from one doctor to another without a diagnosis, just as Crystal had done. Often the diagnosis will include kidney infection, the result of food poisoning, or a lingering systemic infection. Only after everything seems to be ruled out, lupus is diagnosed. In 1992, it's not as confusing as it was in 1962.

It's typical for the victim to be tired. This tiredness isn't relieved by either a good night's sleep or naps during the day. It's as if the body can't get its energy back.

WHAT DOES NUTRITION DO FOR LUPUS?

A chronic illness produces many side effects that can be overcome by a good diet and good nutrition. Having irregular bowel movements and being tired are typical.

The lack of a bowel movement every 36 hours or less is usually indicative of a poor diet. Recall how Crystal drifted to eating lots of processed foods, especially candy. Many drugs, including steroids, often cause constipation or make it worse. Consequently, the Herb-Lax helped to make her regular again.

Regularity helped her body eliminate the same toxins that kept a flare-up going. Add Alfalfa, and you increase a special type of fiber that is especially good at binding the materials excreted through the gall bladder. So, Herb-Lax and alfalfa worked together to bring on regularity and eliminate toxins.

Instant Protein, though Crystal didn't like it at first, was the best energy source she could use. Instant Protein provides sustained energy without calling on the body to produce insulin. When insulin is put into the blood, it causes blood sugar to drop. When blood sugar drops, it leads to the desire for more sugar, usually in the form of candy. Candy quickly elevates blood sugar and makes you sleepy. Sound like Crystal's symptoms? By using Instant Protein, she eliminated all those complexities and had a good sustained-energy source.

Her supplement program was excellent. A body under the stress of a a chronic illness needs more nourishment. One added benefit of Crystal's program is the EPA. EPA helps shift the body's metabolic processes in favor of the prostaglandins that modulate and reduce inflammation.

An additional benefit is the elimination of headaches. These headaches seem to be part of the inflammatory symptoms. In some clinical studies, EPA was shown to be effective in reducing and eliminating headaches.

Finally, Crystal noticed that by using lots of cranberry juice, she eliminated bladder infections. This practice goes back to Finnish folklore as a therapeutic or preventive side-effect of cloudberries. Cloudberries are similar to cranberries, although they are yellow in color. Clinical research has proven that a substance in the juice of these berries prevents bacteria from holding on to the bladder membranes. If the bacteria can't attach, the infection can't get started or keep going. So, using cranberry juice regularly eliminates many bladder infections, and is a common preventive program for people confined to wheelchairs.

WILL NUTRITION CURE LUPUS?

Absolutely not! But it can make life much better. Any chronic illness is a constant stress on the body and causes all

of the body's systems to be vulnerable. No one really knows what a chronically ill body requires.

Nutritional needs are unknown because it would be almost impossible to do the right nutrient-balance studies. When a person is chronically ill, you can't ask them to volunteer for additional research, so the only recourse is to increase their nutrition program sensibly and observe. In most cases, positive nutrition produces an improvement in health.

A POSITIVE OUTLOOK

Crystal noticed that she felt better when she worked her Shaklee business, and when she attended motivational seminars. This wonderful response falls into the category I call "positive outlook."

A Shaklee direct-selling business can't be built without a positive outlook. You have to see the good side of things. A "no" isn't a negative to you; it's a person depriving themselves of an opportunity. Motivational seminars are dripping with positive energy. A good leader guides you to acquiring a positive outlook.

People with a positive outlook live longer. In a clinic study, Stanford Medical School divided terminally ill people with cancer into two groups. One was given regular, motivational programs by an experienced leader. The other group was given books to read on a positive outlook, without the guidance of a leader. The people with the motivated leader lived 18 months longer, on average.

Similar studies have been conducted to show that an optimistic outlook improves sleep, energy, work efficiency, and family life. Crystal's experience was typical. As an aside, young people with an optimistic outlook are likely to not use drugs or get into trouble.

ABOUT THE AUTHOR

James Scala was educated at Columbia (B.A.), Cornell (Ph.D.), and Harvard (Post-doctoral studies) Universities.

He has spent his career in research, research management, and teaching. His accomplishments include over fifty published papers on research in nutrition, biochemistry, and biology. His teaching includes courses for undergraduate, graduate, medical, and dental school students.

As a research manager, Dr. Scala held positions at Procter and Gamble, Owens-Illinois, Unilever, General Foods, and was the Senior Vice-President of Scientific Affairs for the Shaklee Corporation. He now devotes his energies to writing and speaking for the general public.

Dr. Scala lives with his wife Nancy in Lafayette, California. For recreation, they sail the ketch La Scala from its home port on San Francisco Bay.