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JDPA Journal of Dermatology for Physician Assistants

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From The Patient's Perspective
It's Not Just a Pink Rash

By Kevin Allen

If it had not been for a local pediatrician who was notorious for throwing outright fits in defense of his patients, I would not have received the attention needed as a child. Inability to pay, lack of insurance, and society's reluctance to assist adults in obtaining a difficult diagnosis probably would have prevented me from being diagnosed as an adult. However, my local pediatrician insisted I go to Texas Children's Hospital in Houston. As a result, I was seen by Dr. Earl Brewer Jr (a pediatric rheumatologist and founder of the American College of Rheumatology). In June 1976, Dr. Brewer diagnosed me with idiopathic juvenile rheumatoid arthritis (a.k.a., Still's disease).

Since this article is supposed to be about adult-onset Still's disease (AOSD), I should explain that children with Still's become adults with Still's. There is no cure and, although controversial, one school of thought suggests that AOSD and juvenile onset are one in the same. My experience suggests this is possible.

Some of my earliest memories are of complaining to my parents about a recurrent rash. The faint pink rash was quickly dismissed as a "heat rash." The benign nature of a heat rash meant there was no need to seek medical attention. In fact, it usually did not rate high enough to get out the calamine lotion. Little did anyone know at the time, the innocent looking rash was an ominous warning. At the same time, severe joint pain in my knees and hips at night was dismissed as "growing pains." At times, relatives even insisted the pain had to be muscle cramps. When I suggested arthritis, I was told that I was too young to have arthritis. Nighttime fever spikes were thought of as something that "just happens with children." Symptoms were repeatedly dismissed until a blood count alerted my pediatrician to a bigger problem. My blood count came back with numbers that indicated leukemia, and x-rays of my hips showed severe deformities. The results caused my local pediatrician to insist upon admission to Texas Children's Hospital; he even arranged for the Shriners organization to cover the medical expenses.

Texas Children's Hospital followed up with an endless battery of tests. I clearly remember many of them as being very painful. However, within weeks Dr. Brewer had made a diagnosis of idiopathic juvenile rheumatoid arthritis. Although the symptoms leading to my diagnosis included elevated white counts high enough to make a pediatrician concerned about leukemia and x-rays of my hips that caused concern for possible bone cancer, "arthritis" was the word my family and many medical professionals related to. Not even our family physician was educated about Still's disease. Within two years, my parents discontinued medical treatment.

Since I was so young, I did not understand what Dr. Brewer had said. Adult family members assumed warnings from Dr. Brewer about potential problems with my heart, eyes, ears, and other organs were simply an attempt to squeeze more money out of the diagnosis. "After all," they would say, "arthritis does not cause those problems." I was told, "Don't run or your legs will hurt," and "Don't play; it will make your legs hurt." My parents did not believe that the annual testing recommended by Dr. Brewer and continued medical treatments were real concerns.

Pitting edema and swollen fingers were readily dismissed, even more than ten years after diagnosis. Complaints of chest pain and fatigue were dismissed as excuses and laziness. Falling asleep immediately upon my return from school was considered cute. Feeling bad after a night of spiking fever and joint pain was looked upon as

a child being difficult. GI problems associated with Still's were thought to be "learning difficulties."

At ten years old, to teach me responsibility and a trade, I was expected to work construction. If I tried to quit, my only recreational opportunities, fishing and camping, were not allowed. Of course, as I grew older I did learn to be a better worker. In time, when I was in remission, I could out produce the collective efforts of any three carpenters. However, every few years a flare-up would strike. During flare-ups, I could barely keep up with one carpenter, if I could keep up at all. When flare-ups hit, work productivity, relationships, and social obligations all suffered. By this time, I began blaming myself for not trying hard enough. I would push even harder. Pushing harder caused my flare-ups to escalate. As flare-ups escalated, everything suffered even more. It was no use. I could not figure it out.

"Little did anyone know at the time, the innocent looking rash was an ominous warning."

Nearly thirty years after my diagnosis, while attending graduate school, I had another flare-up. This time, the doctor kept uncovering autoimmune issues. I vaguely remembered that the juvenile rheumatoid arthritis diagnosis was considered to be an autoimmune disease. So, finally armed with an education and the Internet, I began researching idiopathic juvenile rheumatoid arthritis (idiopathic JRA). I discovered that idiopathic JRA is also known by several other names and is divided into two classes (juvenile onset and adult onset), all of which adds to the difficulty in locating information. Even JRA is differentiated into pauciarticular JRA, polyarticular JRA, and idiopathic (a.k.a. systemic) JRA. Idiopathic JRA is the specific subset of JRA known as Still's. Eventually, the pieces fell into place. Still's disease, as I learned it was called, explained every symptom of mine to the minute detail.

In time, I found the International Still's Disease Foundation (ISDF) support group. There I met others with similar stories. For example, Jamie, was not diagnosed until she was a teen, and she suffers from severe joint damage. Others were not diagnosed until they became adults. By the time I became educated about Still's, I had gone untreated for nearly three decades. Typical symptoms of Still's disease (e.g., pain, swelling, pitting edema, rash, fevers, etc.) were trivialized, or dismissed altogether, and were the same that I had experienced with pulmonary emboli, pleural effusions, splenomegaly, liver problems, vision problems, and critically low blood pressure. There are also Still's related dermatological issues such as photosensitivity and possibly discoloration of the lower extremities (if associated with Felty's syndrome).

Even after becoming educated about Still's, proper testing and treatment for flare-ups is difficult. My own parents still do not understand that Still's disease and JRA are the same. I have had licensed physicians ask, "What is Still's disease?" On one occasion while working out of town, I began to not feel well and was unable to see my regular physician. Even with me explaining Still's and suggesting that the new doctor look it up on the Internet, the doctor would not listen. He denied the possibility of an early stage pleural effusion and suggested that I had asthma. Within days, the flare-up was full blown. My temperature spiked to 105.8 F and breathing was nearly impossible. I could not get transportation to a medical facility for three days. When I did, the same doctor again denied the possibility of a pleural effusion due to a Still's flare-up. Because standing chest x-rays only show pleural effusions of 300ml or greater, I asked him to repeat a chest x-ray. He refused. He insisted I was having an asthma attack. This is something I have experienced many times before I understood Still's disease well enough to advocate for myself. I was shocked it was happening again, especially with me telling a trained physician what I was dealing with. In the following weeks, my blood pressure dropped to 60/30, pitting edema and breathing problems remained, fevers continued to spike, and acid reflux became unmanageable. I became so pale that a neighbor would frequently ask if I needed a ride to the doctor. However, my insurance (after initialization of the Affordable Care Act) would not cover a pre-existing diagnosis of Still's. I could not afford tests that would not lead to treatment. I decided to wait until I got home to my own physician.

When I arrived in my hometown, eight months later, I was recovering some. I worked construction two more months before I could save enough money to see my physician. The PA who had been involved in treating me in the past listened to my lungs and conducted a physical exam that revealed itching, bronzing and inflammation of the skin over my knees, and an enlarged liver and spleen. She immediately ordered a chest x-ray and blood chemistries. I explained I had done some web research and suspected Felty's syndrome. I asked that she add a CBC to the blood tests, which she did. The chest x-ray indicated an enlarged heart and pulmonary infiltrates. The liver profile came back with bilirubin levels so high that the physician called me at home that evening to ask

me to come in the next day. The CBC came back showing neutropenia and anemia. Treatment with steroids, anti-inflammatories, hydrocodone, and a newly released acid blocker helped with the symptoms, but it was months before they subsided. Treatment with methotrexate was not performed, because my physician was uncomfortable prescribing the medication. However, he did offer to refer me to a rheumatologist for treatment, but it was not something I could afford at the time.

What you should learn from my story is not how Still's disease can negatively affect one's life, but rather remember that identifying early symptoms, making an early diagnosis, and patient/family education are critical in the management of Still's disease. I know this is a professional audience, but my experience demands that I be blunt. That pink rash one might see on the next patient could be a sign of something devastating – even life threatening. However, the rash alone does not make a diagnosis. All factors, even those considered insignificant by patients and/or family members, need to be identified. It is up to the medical professional to ask the questions that will identify the symptoms. If a patient knows of an existing diagnosis, please listen. Once a diagnosis is made, appropriate action is imperative.

Kevin Allen holds a BA in Public Relations Journalism and a MS in Resource Interpretation. His experience with Still's disease has led him to become an advocate for other patients with Still's disease. He serves as the Systemic Onset Juvenile Idiopathic Arthritis (SOJIA) Representative for the International Still's Disease Foundation (ISDF) Board of Directors. He still works construction and enjoys writing peace stories and other literary works, including a variety of Christian resources. His most successful written work was dramatized at the 2009 International Forum for Literature and Culture of Peace's, International Peace Stories Festival in Haifa, Israel. A few of his literary works are geared toward provoking awareness and appreciation of Still's disease.

The International Still's Disease Foundation, Inc. (ISDF) is participating in a patient centered study led by the International Foundation for Autoimmune Arthritis. The study, funded by Janssen Global, Inc., involves a patient survey to identify early onset symptoms of five autoimmune diseases, including adult-onset Still's disease (AOSD). To participate in this study AOSD patients may go to: http://fluidsurveys.com/s/early-symptoms-autoimmune-arthritis-study/. The deadline to participate in this study is August 30th, 2014.

Take Home Points for Derm PAs:

By Steven K. Shama, MD, MPH, FAAD

1. *When an author writes well, writes about himself and his disorder, and is a passionate advocate to educate the public on a particular disease, we should all listen. But in another sense, it really doesn't matter who is writing about his or her disorder and how eloquent he or she writes. As clinicians we should listen to all our patients when they say something doesn't make sense, something is wrong, and I'm still hurting. It took nearly one third of Kevin Allen's life for someone to make a proper diagnosis and in the mean time many other clinicians simply dismissed his symptoms as "heat rash," "growing pains," and the like.*

We must follow our patients, sometimes for years and sometimes for a lifetime, and never give up looking for that specific diagnosis amidst the seemingly nonspecific symptoms. One day it may all make sense. Never give up on your patients. Perhaps one day you'll discover a new disorder amidst a lifetime of nonspecific symptoms and signs and make that patient whole again.

2. *Kevin Allen makes another excellent point. Sometimes family members can sway the clinician's thoughts regarding a proper diagnosis. My own feeling is that the patient, no matter how young or old he/she may be, somehow knows that all is not well. Once you have found the exact diagnosis and hopefully the best treatment, there will be relief in the patient's demeanor. Until then you, as the clinician in charge, should sense that something is not complete. Keep all your senses open for what a disease, through the patient, is telling you. Only as a seasoned clinician will you know when it's time to write that proper, final prescription or when you must continue to wonder about something else you are missing.*

Dermatology Physician Assistants

Physician Assistants (PAs) in dermatology play a number of varied and vital roles.

PAs are medical providers licensed to practice medicine with physician supervision. From patient care and education, to skin surgery, treatment of chronic skin conditions, and cosmetic procedures, PAs are dynamic members of the healthcare team. PAs practice in every medical and surgical specialty and have been collaborating with dermatologists for 30 years, providing a wide variety of services. These include diagnosing, prescribing medications, ordering and interpreting lab tests, wound suturing, and medical or surgical treatment of a wide variety of clinical diseases. As with all PAs, dermatology PAs are legally and ethically bound to practice only under physician supervision.

PAs are trained in intensive, accredited education programs.

Because of the close working relationship that PAs have with physicians, PAs are educated in the medical model designed to mirror and complement physician training. PAs take a national certification examination and to maintain their certification, they must complete 100 hours of continuing medical education every two years and take a recertification exam every six years. Graduation from an accredited PA program and passage of the national certifying exam are required for state licensure.

How a PA practices dermatology varies with training, experience, and state law. In addition, the scope of the PA's responsibilities corresponds to the supervising physician's scope of practice. In general, a PA will see many of the same types of patients as the physician. Referral to the physician, or close consultation between the PA and physician, is based on the dynamic relationship between the physician and PA.

The Society of Dermatology Physician Assistants (SDPA) is a non-profit professional organization, composed of members who provide dermatologic care or have an interest in the medical specialty of dermatology. Fellow members provide medical services under the supervision of a board certified dermatologist.

More information can be found at **www.dermpa.org** and **www.aapa.org**.