

Let's Talk!

By Trudie Mitschang

If your life depends on immune globulin, this column is for you! Here, we have an opportunity to network and share our experiences about all of the ramifications of our illnesses, and to learn from one another. If you have a question, comment or experience to share for a future column, email it to us at editor@IGLiving.com.



In this issue, we chat with John Crawford, 65, and Debbie Crawford, 52, who both suffer from stiff person syndrome (SPS), a rare disorder affecting only one in one million people. Prior to the advent of the Internet, the odds of John and Debbie meeting, much less falling in love, were on par with contracting the disease — one in a million. But thanks to technology, John and Debbie will celebrate their second wedding anniversary this year. Their story will be featured in the latest edition of the popular Chicken Soup for the Soul series titled "True Love."

In the story "Go For It," Debbie shares her thoughts about how to be disabled without letting disability define you.

Trudie: What are the symptoms of SPS and how is it treated?

John: SPS is a rare disease of the nervous system. The symptoms include progressively severe muscle stiffness in the spine and lower extremities and painful episodic muscle spasms that can come on suddenly. Most people with SPS have other autoimmune disorders as well.

Debbie: There are variances in the symptoms of SPS. Treatments

include intravenous immune globulin (IVIG) and plasmapheresis, as well as pharmacological therapy. Some also may benefit from behavioral and physical therapy.

Trudie: Tell me how the two of you met.

John: I was widowed shortly after I was diagnosed with SPS; doctors had given me two years to live. I began treatment with IVIG and miraculously began to get better. I met Debbie when I was searching online for support groups and came across her website. Her story moved me and I sent her an email with my phone number. A few weeks later, she contacted me and we became very close friends.

Debbie: When I met John, we had an instant rapport and shared a lot of things besides our SPS — it wasn't just commiserating and complaining. We have a similar "gallows" sense of humor, and we were friends for four years before finally meeting face to face in August 2007. My previous marriage had failed, and I was cautious about a new relationship. Plus, we really had to come to terms with the fact that both of us having SPS could be a tremendous challenge; we didn't want to be a burden to one another.

Trudie: Since both of you have

chronic illnesses, who is the caregiver in your relationship?

John: We take turns. In addition to SPS, Debbie is a type 1 diabetic and I have chronic inflammatory polyneuropathy (CIDP). I also have heart problems, so we don't know what the future holds. But we are committed to making the most of every moment.

Debbie: Between the two of us, our calendar is peppered with doctors' appointments, which we turn into lunch dates! I help him button his shirt, and he helps me put on my pantyhose; so it's give and take all the way. With our combined ailments, we buy our medications in bulk, and then there's all of our medical equipment, gait aids and handicapped placards. We understand our reality and limitations, but our motto is: "The only future is the day." We make the most of each one.

Trudie: SPS can be very debilitating. Tell me about some of the issues and how you have overcome them.

John: People look at us and assume we are so in love because we are always holding hands. The truth is: We are holding each other up!

Debbie: Fear of open spaces is a common concern. With SPS, your muscles can just lock up unexpectedly, which can be terrifying if you are crossing a busy intersection or riding an escalator. For me, it was a matter



of facing the issues head on.

Trudie: How do you pay it forward?

John: I always look for opportunities to help others. We're very involved in our church, and we have a nursing home ministry where we visit the seniors once a month.

Debbie: I pay it forward through my website outreach with information, a personal perspective and hope. I love to post silly pages that make people laugh. Sharing a smile with others is such an easy thing to do, but it can make a huge difference in someone's day.

Trudie: You both have a great sense of humor. What makes you laugh?

John: SPS is a bizarre syndrome. Finding humor in some of my quirky situations is a positive way I cope. Laughing at yourself helps you become better, not bitter.

Debbie: I find humor in children and reality. Like John, I look for the laughter instead of tears with my SPS. We find humor in each other.

Trudie: How has IVIG helped you?

John: I'm just starting with IVIG again, and it's been a tremendous help to me. Now I am able to walk around the block.

Debbie: IVIG has helped us tremendously. Even though it's not a cure, it can really improve your quality of life and should be available to anyone who needs it.

Trudie: What are you looking forward to?

John: Loving Debbie as long as I can. I never dreamed I would remarry, so I'm very fortunate. One thing I said many years ago is it's not what kills you that amazes me, but it's what you can live with and still survive. Here I am with five illnesses and able to do as much as I do; Debbie has made me a stronger, more vital human being.

Debbie: I want as blessed and full a future as I can have. I have been encouraged to write. I want to enjoy my children and grandchildren. John and I know our lifetime is just a season. We choose to make it Christmas. ■

Resources

To learn more about John and Debbie and SPS, visit their websites.

John's: www.stiffpersonsyndrome.com

Debbie's: livingwithsps.com/index.html



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