What Happens At A Sickle Cell Convention

October 30, 2014 By Cyntra Scott

This was my third year attending the Sickle Cell Disease Association of America's Convention--its 42nd--and like the previous two, this year's convention was on point. Held in the heart of Baltimore's inner harbor, the vibe was high-energy, encouraging, and inspiring. The workshops offered ranged in topics from SCD: Young Adult Transition to Nursing Perspectives on patients with SCD. This year's Lonzie Lee Jones Patient Advocacy Symposium featured a panel of individuals including comedian Kier "Junior" Spates of The Steve Harvey Morning Show, model Jourdan Dunn, actress La'Veda Wallace-Page, Ms. New York, Patrice Hamilton and Reverend Violet L.D. Lee, PhD.

These individuals shared their experiences with either having SCD or having a child with SCD. There was a patient empowerment luncheon which allowed us, as participants, to have the rare opportunity to engage in conversations with a cross-section of people (with SCD or within the SCD community) from different regions and who have had a variety of experiences.

Overall, I think the convention was a success. One great aspect of the event that I always find helpful is to be able to be around others who understand and relate to what people living with SCD deal with. Often, individuals with sickle cell don't know many, if any, other people living with the illness. That's why when we finally have the opportunity to be in the midst of others with SCD we feel connected and understood.

In addition, the convention is a great venue for networking, gaining knowledge and exchanging ideas. I encourage each of you to consider attending the convention next year!

Having a support system can be very important for individuals living with SCD. First, you should let your family and friends know what you are going through and what your needs are. Often family and friends want to help but don't know how.

There are two other main avenues of support listed below:
1) A local SCD support group. You can locate one in your area by contacting your local hospital; or click here to contact the Sickle Cell Disease Association to find the chapter in your state; or be proactive and start one yourself through your local hospital or health care center.
2) The Internet. There are SCD support groups available online. Click on the links you see for some you might like to contact and /or join: Sickle Cell Warriors and Health Unlocked. (Search Sickle Cell Society)
Facebook groups:
Sickle Cell Unite
Sickle Cell Anemia Disease
If you know of any sickle cell disease support groups, please list them in a post in the comments section.

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