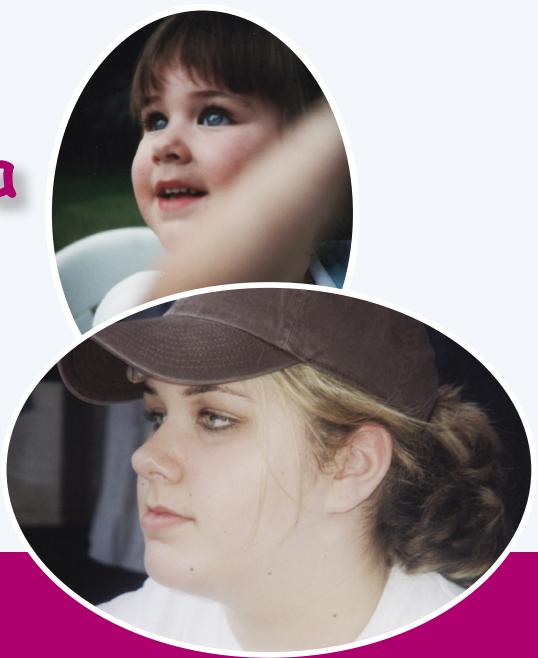


Challenges and Issues for a Child Living with Scleroderma

(Pt. 2 of 2) By Linda Murray

There have been numerous challenges and issues related to scleroderma during my granddaughter Samantha's 16 years. Although we do not have the answers to them all, we felt our family's experiences might be beneficial to other parents and caregivers of children living with scleroderma, so we wanted to share some of them with you.



GROWING UP

As Samantha has matured over the years, many physical changes have become more obvious. The right side of her body is much smaller than her left. This is the result of her skin being so much tighter on the right side, causing

stunted bone growth in her early development. Samantha's right foot is a woman's size 4 or 5, while her left foot is a size 9. Her right leg is shorter by $\frac{3}{4}$ -inch, her right breast is smaller, her right buttock is smaller and flatter, and her right index finger is non-functional and severely deformed. The teenage years are tough enough for a young woman, but they can be devastating when you don't measure up to what today's society thinks you should look like.

Samantha was raised like any other child. As long as it was not a threat to her health, she was allowed to take part in all the activities she wanted. She may not have always done as well as others, but she always wanted to try, and no one stopped her. She has grown up secure in her physical appearance and isn't ashamed or embarrassed about the way her body looks. She is confident and outgoing, and jumps at the opportunity to educate those who question why her skin looks the way it does.

As comfortable as she is in her own skin, there may come a day when she may be self-conscious about her physical appearance. Should that day ever arise, she is aware of the many options out there for her. Retailers make underwear and bras with padding so she could even out her right side. She has the option of surgery on her right index finger to make it more cosmetically appealing, or she could have a removable orthotic finger custom designed to make the existing finger look normal.

She shops at department stores such as Nordstrom for her footwear. This store chain pairs two different shoe sizes for no extra charge – just as if it were any other pair of shoes. Before learning about the store's policy, we were forced to buy two pairs of shoes in different sizes and then throw the odd shoes away. It was expensive and wasteful. Now, Samantha finds all the latest styles in boots, sneakers and athletic shoes, at comparable prices to other department stores.

They even have makeup to help blend any skin pigmentation your child may have. You can learn more about using make-up in a workshop titled "The Art of Camouflage Makeup" at the National Patient Education Conference offered each year by the Foundation.

Through all of these challenges, be sure to let your child know that there are options out there so he or she may feel less self-conscious in his or her appearance.

THE TEENAGE YEARS

How time flies! Samantha is nearing 17. In my last article, I told you about her dressing up Barbie dolls, and now I'm telling you she has her license and a job! With every new milestone comes a new challenge.

When looking for a job as a teenager, many of the only places hiring are in the food industry or retail. These positions require employees to stand on their feet for an entire shift, averaging about four hours. In Samantha's case, she experiences backaches and sore feet during her shifts at work.

Not only are there physical demands from a job, getting the job was

no easy task. Since she has morphea, which affects the pigmentation of her skin due to the lesions, it appears to the uneducated public that Samantha has dirty skin or burn scars. Some employers feel that this is not attractive to customers and may leave some people uncomfortable. While it is difficult to prove that someone didn't land a job because of his or her physical appearance, the thought crosses your mind. Samantha was turned down a handful of times when she began her job search. Was it Samantha's interview that did not go well? Her personality? Her appearance? We will never know the reason.

She doesn't want special treatment such as a chair or extra breaks. She has never taken advantage of her disease. We have tried padded inserts in her right shoe to help even out her leg lengths to ease her backaches. Yet, we haven't been able to find one that works well. Her doctor suggests that orthotics may be the way to go and we will explore that at her next appointment.

Children, teens and young adults want and need to be accepted as normal. However, with the added burden of scleroderma, it can be tough.

Peer pressure is brutal, and being different than one's peers can be a nightmare. Your child may not always be willing to talk about peer pressure or what he or she is feeling. Remember, a young patient's thought process is different from ours – after all, they think they know it all! By listening to your child and letting him or her know about resources, you help raise his or her self-esteem and confidence – giving them unlimited possibilities for the future.



HINTS FOR PARENTS

Linda Murray suggests doing the following things to help your child live with scleroderma and beat the challenges that he or she may face:

- Be there for your child.
- Listen to what he or she says.
- Read between the lines. Listen to what he or she may not be saying.
- Work closely with your child's healthcare team and teachers.
- If an activity causes no physical harm, let them spread their wings and try new things.

Editor's Note: This is the second part of Ms. Murray's piece on living with a child who has scleroderma. The first segment appeared in the Fall 2011 issue of "Scleroderma Voice."