

Help Young People Tackle the Problem of Psoriasis

Sheri Decker, BS, MAT

Nanette B. Silverberg, MD

"I am 10 years old, and I look at my psoriasis and cry. I feel lonely because I don't have anyone to talk to, and I am embarrassed to go to the store."—Excerpt from youth message board, National Psoriasis Foundation (NPF) Web site.

"I am 12 years old, and I wear jeans and long sleeves all the time because of my psoriasis. I fainted one time 'cause I was so hot."—Excerpt from youth message board, NPF Web site.

Healthcare providers play a pivotal role in the overall well-being of young psoriasis patients. Just as the therapy of psoriasis is challenging, quality-of-life issues for young psoriasis patients don't have easy answers either. The unsightly lesions, sloughing skin, itching, and uncertainty of treatments are troublesome, but the social stigma linked to psoriasis is extremely distressing, especially for children and teens.

To assist medical professionals in addressing quality-of-life issues, the NPF created its first educational initiative aimed at youth. This program, which was launched earlier this year, attends to the social and emotional concerns facing young people with psoriasis. The program is designed to help children and teens with psoriasis develop a healthy self-esteem and a sense of belonging. It also provides a sound education in psoriasis treatments and stresses the young person's role in caring for his or her skin.

The NPF youth program is specifically designed for children and teens, their parents, and caregivers (eg, babysitters, teachers, coaches, employers). It offers tools such as Web site activities, information, and educational booklets that make it possible to live successfully with psoriasis through education, emotional support, and communication. The educational booklets have enjoyable stories that engage children while promoting their knowledge of the

disease. The feedback from patients and parents has been positive. Young people with psoriasis and their parents are encouraged to learn that many other children and teens experience the same daily trials and tribulations of living with the disease and have many of the same questions.

Some of the resources available to young psoriasis patients are:

- *www.psoriasis.org*—This NPF Web site for children and teens provides appropriate age-related educational information. Monitored message boards offer methods for young people to communicate and learn about psoriasis. These message boards are active and worth a visit to explore how young psoriasis patients cope with their disease.
- *Educational Booklets*—The NPF publishes 4 booklets specifically for multiple age groups to facilitate understanding of psoriasis, develop skills to educate others, and reinforce acceptance by the public. The titles include *Bernie's Secret*, a book for children aged 5 to 8 years; *The Adventures of G. Wow*, an illustrated adventure for children aged 9 to 12 years; *A Handbook for Teens With Psoriasis*; *A Parent Guide*; and a handout for young people to distribute to adults who spend time with them (eg, coaches, babysitters).

Young people and their parents are welcome to request booklets at no cost by calling the NPF at 800-723-9166 or 503-244-7404. Medical professionals also may request a copy of the booklets to preview. For more information, contact the National Psoriasis Foundation at 6600 SW 92nd Ave, Suite 300, Portland, OR 97223-7195; Telephone: 503-244-7404 (toll free: 800-723-9166); Fax: 503-245-0626; E-mail: getinfo@npfusa.org; Web site: www.psoriasis.org.

Ms. Decker is from the National Psoriasis Foundation, Portland, Oregon. Dr. Silverberg is from St. Luke's-Roosevelt Hospital Center, New York, New York.