

Letter to the Editor

What the National Psoriasis Foundation Means to Dermatologists and Our Patients

Dear *Cutis*[®]:

The American Diabetes Association supports more than 20 million US citizens with diabetes through research, advocacy, and donations.¹ The March of Dimes Foundation funded \$24.6 million in research related to infant health and development in 2005.² The American Cancer Society (ACS) is dedicated to preventing cancer, saving lives, and diminishing effects on quality of life through research, education, advocacy, and service. Since the inception of the ACS research program in 1946, the ACS has devoted about \$3.1 billion to cancer research.³ Endocrinologists, pediatricians, and oncologists depend on these groups to facilitate communication about treatments, advance research, and provide support to patients and their families.

The National Psoriasis Foundation is dermatology's equivalent to the American Diabetes Association and the ACS. The foundation's mission is to improve the quality of life of individuals with psoriasis and psoriatic arthritis. Through education and advocacy, the psoriasis foundation promotes awareness and understanding, ensures access to treatment, and supports research that will lead to effective management and ultimately a cure.

Education

Treatment Education—Psoriasis is a chronic inflammatory disease that is characterized by an array of clinical expressions, diverse effects on quality of life, and a wide variety of treatment options. The most appropriate treatment is dependent on each patient's disease, demographics, comorbidity, and personal preferences. Educating patients about available treatment options is essential to treatment planning. The psoriasis foundation provides dermatologists and their patients ready access to a host of patient education materials covering all aspects of psoriasis treatments. Dermatologists on the foundation's medical board participate in the development of these materials and assure their accuracy. Affected patients who are members of the foundation are better informed about treatment options than nonmembers.⁴ The foundation encourages patients with psoriasis to see a dermatologist. In addition, the foundation encourages

patients to take full advantage of their dermatologist's advice, helping to improve adherence to therapy.

The educational brochures provided by the psoriasis foundation also help dermatologists treat other patients. For example, brochures on phototherapy and systemic treatments can be used to help educate patients with other diseases about their treatment options. When using drugs with many serious side effects, such as methotrexate, it is important to make sure patients have accurate written information on the side effects, regardless of whether the drug is being used to treat psoriasis or any other inflammatory skin disease.

Psychosocial Support—A critical element of educating patients with psoriasis is to help address the psychosocial needs of patients. Psoriasis broadly affects patients' quality of life.^{5,6} The lack of cure is frustrating, and patients with psoriasis often are depressed and embarrassed by their appearance. They commonly encounter individuals with various misconceptions about the disease, exclusion from public facilities, and isolation. Patients with psoriasis report difficulties in the workplace and getting a job, impact on interpersonal relationships, and suicidal ideation.⁷ Emotional stress may precipitate flares of the disease in some patients.⁸

The psoriasis foundation helps both the dermatologist and the patient to manage these issues. Membership in the foundation helps patients reduce their sense of isolation. The foundation's print materials, Web site, chat groups, local support groups, and national meetings help patients learn how to handle the many social and interpersonal situations they encounter by communicating with other patients with psoriasis. The message boards provide an online community of support and connection to others with the disease. The foundation reduces patients' sense of ignorance and isolation and helps correct misunderstandings about the disease. Patients who are members of the psoriasis foundation have a lower burden of disease and a better quality of life.⁴

Physician Education—The American Academy of Dermatology is a primary source for dermatologists' postresidency education. When educational gaps and needs have emerged, the psoriasis foundation

has acted in a timely manner with educational programs targeting these needs. Since 1999, the foundation has held national meetings to educate dermatology chief residents, helping improve the psoriasis treatment knowledge of nearly 100 dermatology residents a year.⁹ In the early 1990s, the foundation held a meeting to educate dermatologists about new and existing systemic treatment options. The meeting resulted in a practical textbook entitled, *Therapy of Moderate-to-Severe Psoriasis*, now in its second edition.¹⁰ The success of this book led to the development of the companion text, *Mild-to-Moderate Psoriasis*.¹¹ The foundation also developed a book of psoriasis treatment algorithms to help dermatologists.¹² Most recently, the foundation has collaborated with the American Academy of Dermatology in physician education efforts, such as combined efforts for the chief residents' meeting as well as a number of regional psoriasis treatment education meetings. The foundation publishes *Psoriasis Forum*, a peer-reviewed medical journal with research, news, and practical treatment information.

Advocacy

Psoriasis and psoriasis treatment are not well-understood by insurers. The psoriasis foundation has developed an educational brochure designed for insurers to help educate them on psoriasis treatment. This brochure can be used by dermatologists in their struggle to obtain the medications their patients need. A new CD-ROM is available for physicians with strategies to improve access to treatment, including sample letters for insurers. The foundation also provides tools and resources to patients navigating complex insurance systems and provides letters to insurers on their behalf. This online advocacy resource for patients is available at <http://www.psoriasis.org>. There have been extensive efforts by the foundation to assure reasonable access to biologic treatment for patients with severe disease. Many of these efforts have been successful at changing insurers' policies.¹³

The psoriasis foundation also has had success in assuring that patients have access to phototherapy services. The foundation noted with concern the decreasing availability of phototherapy in the late 1990s due to poor reimbursement and high co-payments. In 2002, the foundation successfully lobbied Medicare for a doubling in phototherapy reimbursement and continues to work to reduce the co-payment burden some insurers place on phototherapy treatment.¹⁴

The psoriasis foundation is the largest organization of laypeople who understand the importance of the dermatology specialty.¹⁴ Not surprisingly, and not as appreciated as it should be, the foundation is a strong partner in dermatologists' efforts for direct access, which was well-illustrated in the 1990s

when Medicare coding documentation guidelines were introduced.¹⁴ The initial guidelines proposed a single physical examination "bullet" for the entire skin examination, which would have had the practical effect of limiting dermatologists to level 1 new office visits. Knowing the complexity of psoriasis evaluation and management, the foundation realized that a single bullet for the skin examination was inappropriate and could limit patient access to care. The president of the foundation, Gail Zimmerman, contacted the Health Care Financing Administration and explained that scalp psoriasis is evaluated and managed differently than elbow/knee psoriasis, which is different than genital psoriasis, palm and sole psoriasis, nail psoriasis, and others. Her efforts directly resulted in the multiple bullets dermatologists have today for documenting the skin examination, not only for psoriasis but for all skin diseases.¹⁴

Research

The psoriasis foundation has generated and awarded hundreds of thousands of dollars for research on psoriasis. In 2006, four \$30,000 seed grants were awarded to psoriasis researchers across the country. Recently, the foundation embarked on a bold capital campaign, "Finding a Cure," aiming to raise \$5 million for research and advocacy for psoriasis. To achieve this goal of finding a cure, the foundation has focused much of its research resources on the search for genes that cause psoriasis. The National Psoriasis Victor Henschel BioBank is an initiative of the psoriasis foundation to provide researchers with valuable genetic samples and clinical information that will facilitate finding a cure for psoriasis and psoriatic arthritis. The National Psoriasis Victor Henschel BioBank is recruiting 1000 cases and 1000 controls for the study in 2007.

The psoriasis foundation conducts regular surveys of patients to ascertain the needs of their constituency. Past surveys have provided dermatologists important data on the prevalence of psoriasis and its impact on patients' lives.¹⁵ The foundation supports research in other ways. It encourages pharmaceutical companies to focus research on treatments for psoriasis, educating them on patient needs; further facilitates drug development by defining measures used in psoriasis clinical trials^{16,17}; and lobbies on behalf of increased federal funding of psoriasis research.

Conclusion

Since its inception in the mid-1960s, the psoriasis foundation has been a partner to dermatologists in the care of patients with psoriasis. The foundation now plays a key role in educating patients with psoriasis about their condition and its treatment. Advocacy efforts of the foundation facilitate access to

medication and dermatologists' services. The foundation's support of research strengthens the future of our specialty. The psoriasis foundation needs the support of dermatologists. Patients with psoriasis should be told about the foundation and encouraged to join. Most members learned about the foundation from their dermatologists. The psoriasis foundation has materials that make this process very easy.

There are many ways for dermatologists to be involved with the foundation, such as speaking at local or national meetings, helping review educational materials, participating in lobbying efforts, and maintaining an updated physician listing on the psoriasis foundation Web site. The show of support from the dermatology community helps encourage further participation from patients, major donors, and pharmaceutical companies. We hope dermatologists will consider making a donation to the psoriasis foundation, an investment that will provide dividends for both our patients and the future of our specialty. While the psoriasis foundation serves nearly 1 million individuals each year, currently less than 1% of individuals with psoriasis are members.⁴ Dermatologists should strongly encourage patients with psoriasis and their families to join the psoriasis foundation and utilize its many resources.

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The Center for Dermatology Research, Wake Forest University School of Medicine, Winston-Salem, North Carolina, is supported by an educational grant from Galderma Laboratories, LP. Drs. Kaufman, Krueger, and Feldman report no conflict of interest. Dr. Lebwohl is chairman and Ms. Zimmerman and Dr. Horn were employees of the National Psoriasis Foundation.

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