

2014 VSI Achievements and Highlights

Just a few of our initiatives, projects, and events!

Education and Awareness

- Recruited vitiligo patients for national media, including ABC's TV program *What Would You Do?*
- Co-authored a chapter for a Wiley-Blackwell medical text entitled **Management of Vitiligo**
- Quoted in the highly regarded journal *Derm World* for an article entitled "Dermatologists share insights, strategies to enhance patient relationships," published in October 2014
- Teamed up with physicians and researchers as a key partner of the international collaborative Vitiligo Working Group (VWG) to strategize ways to draw more attention to vitiligo, improve treatments and increase research
- Presented to the VWG on challenges faced by vitiligo patients in garnering understanding of the emotional, financial, and access-to-treatment burdens faced by patients
- Ensured attention for vitiligo and that the voice of the vitiligo patient was heard at the American Academy of Dermatology Annual Meeting
- Provided cutting edge news and information on vitiligo management, treatment and research via quarterly electronic newsletter
- Invited by an international research group to collaborate on a 2015 vitiligo patient conference

Advocacy

- Participated in a national task force to abolish discrimination against vitiligo patients by the insurance industry
- Provided sample letters and tips for patients seeking insurance reimbursement for treatments
- Joined dermatologists, residents, patient advocates and dermatology nurses to meet with nearly 200 members of Congress as part of the American Academy of Dermatology Association (AADA) Legislative Conference
- Promoted access to care for vitiligo patients on Capitol Hill to ensure that patients can access knowledgeable dermatologists and that specialists are available through insurance networks

Research

- Cultivated relationship with the U.S. National Institutes of Health (NIH), the world's largest source of medical and scientific research funding, to encourage support of vitiligo research. In 2014 alone, new research funding increased dramatically for vitiligo across the NIH with \$6.3 million awarded to vitiligo-related research
- Facilitated research recruitment for surveys such as "How does vitiligo affect your life?" resulting in greater understanding and awareness of vitiligo
- Publicized clinical trials to increase recruitment so that new therapies in vitiligo are investigated
- Tested samples and provided feedback on new vitiligo products still in development to improve availability and quality of vitiligo-related goods

Organizational Governance and Growth

- Met with nonprofit leadership consulting firm to obtain input on VSI's strategic plan and ideas for improving organizational effectiveness and development to meet the growing needs of VSI stakeholders