



# Skin patients and online support

By Jennifer De Freitas

Today's skin patients have the opportunity to seek social support online. I have been sharing my vitiligo experience on social-networking sites for those with skin conditions for more than two years.

I am a member of Skinergy.ca, the online community of the CSPA. Skinergy.ca is a friendly online space where skin patients in Canada can discuss skin issues, get help, and share stories and pictures. I'm also a member of Vitiligo Friends—a network where “vitiligans” and their families and friends can build relationships, share healing ideas and inspire hope. Both of these online support groups are safe, secure and free, and conversations are closely moderated.

## Virtual therapy

Skin conditions can negatively impair many aspects of an individual's well-being. By participating in a virtual community, people can receive psychological and social support. Such communities can also be a valuable educational resource for friends and family. Since joining Skinergy and Vitiligo Friends, I have developed a greater acceptance of my skin condition because people understand what I'm dealing with. It's therapeutic!

Skin patients facing difficulties with real-world networking can turn to online communities, where the

relative anonymity makes it easier to discuss challenges.

## Benefits

The Internet is a great place to raise awareness about skin issues. There are 1.2 billion Internet users worldwide, and research has shown that social networking is the most popular online activity in the world.

When someone like me joins an online community, I am not the only person to benefit. Being a member means having the opportunity to connect with an advocacy group such as the CSPA and speak up. By joining together, we expand our clout with politicians and decision-makers.

The conversations we have within online support groups should not end there—we can carry them forward to mainstream social-networking sites such as Facebook and Twitter. This allows us to learn from each other, improve awareness and support, and change the way people think about skin diseases.

Being a member of an online patient group also means having the opportunity to talk with researchers, physicians and members of other professional organizations working in the dermatological community. This can help you stay up to date with the latest research findings, possible new treatments, fundraising opportunities and clinical trials.

Although social-networking sites give us the freedom to express ourselves, it is important to stay safe. Unsuitable content, such as someone claiming to have found a “cure,” using the space to advertise or posting threatening messages, should be reported.

While being a member of a patient group is a step in the right direction to psychological and emotional support, we should not allow another member's misery or negative attitude to dampen our spirits. In addition, conversations between members should never replace consultations with a dermatologist or psychologist.

## Social commitment

Lack of time shouldn't stop you from joining an online support group. Unlike traditional patient groups, there is no day or time when you must sign in. You can chat or catch up with other members at your convenience.

Feeling connected is wonderful. Online social support groups bring skin patients together. And it is when we are together that we can forge ahead and create change in our lives. **CS**

*Jennifer De Freitas is 24 years young. She lives in Quebec and has been a vitiligo patient since she was 18. She is a koga (yoga-kickboxing) fitness instructor and the editor of Touching Base, an English Montreal School Board publication.*