



## Common Drug Review *Patient Group Input Submissions*

### **ivermectin (Rosiver) for rosacea**

**Patient group input submissions were received from the following patient groups. Those with permission to post are included in this document.**

Canadian Skin Patient Alliance — permission granted to post.

### **CADTH received patient group input for this review on or before May 20, 2015**

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## Canadian Skin Patient Alliance

### Section 1 — General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	ivermectin for rosacea
<b>Name of the patient group</b>	Canadian Skin Patient Alliance
<b>Name of the primary contact for this submission:</b>	[REDACTED]
Position or title with patient group	[REDACTED]
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<b>Name of author (if different)</b>	
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Website	<a href="http://www.canadianskin.ca">www.canadianskin.ca</a>
<b>Permission is granted to post this submission</b>	Yes

#### 1.1 Submitting Organization

The Canadian Skin Patient Alliance is a non-profit, for patients, by patients organization that serves individuals living with dermatological conditions in Canada. We focus on education, support and advocacy for patients as well as our 21 Affiliate disease-specific organizations in Canada, including the Acne and Rosacea Society of Canada.

#### 1.2 Conflict of Interest Declarations

We have the following declaration(s) of conflict of interest: Abbvie, Amgen, Celgene, GSK, Leo Pharma, Janssen, Merck, Roche and Valeant have provided funding support over the past 12 months. Most of the funding is provided to us for project-specific grants while some are unrestricted grants.

We have recently received funding from Galderma, the manufacturer of Ivermectin for projects related to rosacea.

### Section 2 — Condition and Current Therapy Information

#### 2.1 Information Gathering

We used a variety of methods to gather information on what it is like to live with rosacea. We developed a one-week Facebook campaign inviting individuals living with rosacea to complete a questionnaire. This was a very effective tool, garnering 184 completed surveys.

We also approached some dermatologists to assist us with sending out the same questionnaire to patients who had been involved in the Ivermectin clinical trial. This approach was less successful only resulting in 20 questionnaires submitted.

### 2.2 Impact of Condition on Patients

Rosacea can range from mild to severe, and every person's experience is different. It is also a systemic disease which can affect the whole body and can cause internal, as well as external, symptoms, which include:

- Skin redness, usually in the centre of the face, covering the cheeks, nose, forehead and chin
- Dry, thick or scaly skin
- Pimples, which can be inflamed, hard, red or filled with pus
- Red lines which appear when small blood vessels get larger and show through the skin
- Knobby bumps on the nose and eventual enlargement of the nose due to excess tissue build-up
- Eye inflammation, resulting in swollen eyelids, styes, burning, stinging or irritation and a watery or bloodshot appearance
- Vascular dysfunction in the face, extremities and bowels

The majority of respondents to our questionnaire stated that the redness and bumps were the most important symptom for them to control.

The noticeable skin changes on the face common in rosacea can have a profound long-term effect on a person's quality of life by causing low self-esteem, embarrassment, frustration and sadness. Many respondents reported shame, depression and inability to participate in day-to-day activities.

*"Clients, friends, co-workers, family, etc. are always commenting on my skin, people sometimes stare at me when I am out and am having an episode and am looking like a boiled lobster. It really makes me self-conscious about myself and appearance. Sometimes people whisper thinking I can't hear them."*

The flushing associated with rosacea can be especially embarrassing since it can be unpredictable and severe, and the permanent reddening of the face can make patients worry that they are perceived as heavy drinkers.

*"It has gotten worse over the last year and people seem to think that it is from drinking. I have no alcohol not even wine so it is embarrassing."*

### 2.3 Patients' Experiences With Current Therapy

Forty-five percent of the respondents to our questionnaire have been living with rosacea for well over 10 years so had a lot to offer in terms of current treatment options.

The most common responses for the use of current therapies were 1% metrogel, finecea, a variety of prescription creams, over the counter acne medication. Many also reported that they did not use anything.

*"I could not use anything without a red sore reaction."*

Others opted to try laser therapy with limited results.

*“Made me red and itchy, extremely sensitive.”*

Others expressed how expensive it is to treat, going from one therapy to another to try to find relief for their rosacea symptoms.

When we asked rosacea patients how well other treatments have helped them control their symptoms:

- Over 50% of patients responded that the treatment either “didn’t work at all” or “somewhat” in regards to controlling redness, pimples, dry thick scales and red lines.
- Over 40% of patients responded that the treatment either “didn’t work at all” or “somewhat” in regards to controlling knobby bumps on nose, eye inflammation or vascular dysfunction.
- Almost 20% said they had never treated their rosacea in the past.

## **2.4 Impact on Caregivers**

Although we did not ask specifically about the impact on caregivers in this questionnaire, skin diseases that affect one’s physical appearance and self-esteem can have a significant impact on close family members. Not wanting to participate in social and family activities (hiding from public) is the most common concern expressed by caregivers, followed by a loss of self-esteem/depression and an impact on intimacy.

## **Section 3 — Information about the Drug Being Reviewed**

### **3.1 Information Gathering**

We used a variety of methods to gather information on what it is like to live with rosacea. We developed a one-week Facebook campaign inviting individuals living with rosacea to complete a questionnaire. This was a very effective tool, garnering 184 completed surveys.

We also approached some dermatologists to assist us with sending out the same questionnaire to patients who had been involved in the Ivermectin clinical trial. This approach was less successful only resulting in 20 questionnaires submitted.

### **3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?**

Of the patients questioned who had tried Ivermectin, we received an overwhelming majority of positive feedback regarding the effects of the new drug. Here are some of the responses we captured:

*“My confidence returned and I felt better physically and emotionally.”*

*“Totally got rid of rosacea plus it never came back. So happy I tried the study.”*

*“I am now more confident about my facial appearance.”*

*“Enjoyed more being with friends and taking pictures. Skin was very normal.”*

*“No more redness, more confidence.”*

*“It completely cleared up skin. I was no longer afraid to go out in public. Everything the rosacea impacted was improved.”*

*“I am less embarrassed about skin. More confidence.”*

*“Changed how I felt about the look of my rosacea.”*

*“I felt less embarrassed and more confident after my redness disappeared. It was great.”*

Most importantly, 93% of the respondents had no side-effects. For those who had negative side-effects, 100% still supported the availability of Ivermectin on the market and to rosacea patients because the positive outweighed the negative effects.

The impact of a proper treatment is huge on patients living with rosacea. Of the patients that responded to our questionnaire, when their rosacea isn't under control, over 70% of those asked said that they felt embarrassed or felt the need to hide their skin. Over 50% felt depressed, ashamed and had a drop in their self-confidence. As well, 38% expressed that their skin condition affected their ability to sleep and daily activities. Finally, over 20% admitted it affect their level of sexual intimacy.

Patients taking Ivermectin expressed positive improvements in their condition. In our questionnaire, we listed the common complaints of rosacea patients. Patients were then asked to rate any previous treatments compared to Ivermectin:

- 80% reported a “very good” reduction in the redness (very good being the highest score) with Ivermectin vs 22% using an existing treatment
- 73% reported a “good” or “very good” results in treating pimples with Ivermectin vs 24% using an existing treatment
- 66% reported a “good” or “very good” results in treating dry scaly skin with Ivermectin vs 11% using an existing treatment
- 60% reported a “good” or “very good” results in treating red lines with Ivermectin vs 11% using an existing treatment
- 47% reported a “good” or “very good” results in treating knobby bumps on nose with Ivermectin vs 10% using an existing treatment.

These patients expressed life-changing comments about Ivermectin:

*“My life changed 100% for the better.”*

*“I felt good about my skin/face for the first time in years. Before the trial, I was trying to cover my skin with makeup. After, I didn't need makeup at all.”*

*“This is a miracle drug ... not only did it work while I was using it but I have had much less flare ups since I stopped. Prior to this study, I had concluded that I would just have to live with it and it was embarrassing to go out in public...”*

Over 90% reported in the questionnaire that they would like to see Ivermectin available via a public or private drug plan as soon as possible. Some have started calling their dermatologist asking when they can be prescribed the drug!

## Section 4 — Additional Information

I believe that there is some overlap in the questions (2.1 and 3.1.) Patient groups do not have the time nor the resources to do separate information gathering.