



Allergy & Anaphylaxis Australia

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On behalf of people with severe eczema, Allergy & Anaphylaxis Australia (A&AA) welcomed the PBS listing of Dupixent in early 2021. Until the registration and then PBS listing of Dupixent, people with severe eczema had lost hope and many actively removed themselves from work, social activities and importantly, from the care of dermatologists and/or clinical immunology/allergy specialists. Many had given up on there ever being a treatment that really worked for eczema and lived to manage each day, often in isolation as they felt nobody truly understood the burden of severe eczema on their lives.

Family members contacted A&AA asking for assistance as the mental and physical health of their family member with eczema declined. A&AA health educators did their best to encourage disillusioned people to remain connected with health professionals and assisted in getting psychological and medical help as needed. Many families spoke of their exhaustion and helplessness in trying to care for the family member with severe eczema.

Whilst people with severe eczema sometimes contacted our 1300 helpline themselves, it was more often a family member that reached out. See below:

- The parent of the 34-year-old mother of two children who could not pick up her little children or cuddle them because her eczema was so severe contacted us desperately wanting to help her daughter.
- The father of a 28-year-old university student who hadn't stepped out of the house for weeks contacted us because of yet another eczema flare. He heard about Dupixent being registered with the TGA and then contacted us every two to three weeks over 12 months to ask if it had been PBS listed. Each time he called he asked what we could do as an organisation to make the medication accessible to his son.
- The parent of a 17yr old called us because her daughter was unable to wear clothes as the eczema was so bad. She was concerned for her daughter's mental health as she wouldn't come out of her room even to eat. She was in her room, naked and not concerned that her teen brother was bringing food to her each day. This mother was desperate for help as she feared for her daughter's life.

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This snapshot of just three calls helps communicate the burden of this illness on people with severe eczema and their family. The PBS listing of Dupixent has not only changed people's lives, it has given them life. Many people with severe eczema had lost hope that there would ever be a treatment for them. The rollercoaster of a severe flare would throw them harshly into a spiral as they knew they would treat their eczema aggressively with even more emollients, steroid creams/ointments/ bleach baths and sometimes wet dressings knowing they'd work for weeks to improve their skin, only to have another flare soon after.

The PBAC needs to understand that this biologic has changed the life trajectory of so many people who had given up hope. People with severe eczema are in disbelief that their skin is now so much better since commencing Dupixent. While some were so used to the restrictions of life with eczema, many are now understanding just how much more they can do. People are engaged in life once again and this is wonderful for them and importantly, their family who also suffer with the diagnosis of severe eczema.

Over the last 12 months, A&AA has not received phone calls from distressed family members or individuals with severe eczema. We have had heartening phone calls from people who are now being treated with this life changing (and in some cases, even life-saving) biologic treatment.

A grandfather with severe eczema expressed the changes to his life and shared his joy and relief. He does not have to wash his bloodstained bedsheets every day. He is no longer embarrassed to see people as he no longer sheds flaky skin. He can get down on the floor and play with his grandchildren who love the rough and tumble play with granddad. There was a time he could not have them sit on his lap.

Another mother has reported her 17-year-old went to the beach several times last summer. The teen actually went shopping herself and bought three different swimming costumes. She is no longer ashamed to show her body. Her body does not sting as she steps into the ocean, and she cannot believe she can swim again.

Another young woman who had locked herself away because of the severity of her eczema is now thriving. She is engaged in the world, is able to work, started dating and has found love.

These people are grateful for medication that has literally changed their lives – many share it has given them back their life. Their skin does not control who they are and what they do. We ask that you consider the changed lives of people with severe eczema who are now taking Dupixent in the July 2022 PBAC meeting. People are utilising the medication because there has been a huge need for a treatment that works without the need for immunosuppressive medication. People are sharing their stories and those who were disengaged are now re engaging with health professionals that can review their health condition and offer those with severe eczema this new treatment.

Thank you for the opportunity to communicate on behalf of people with severe eczema.

Yours sincerely,

Maria Said
Chief Executive Officer
Allergy & Anaphylaxis Australia

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