

September 8, 2008

I wanted to give you an update on Jonathan and the cream. His skin has improved - it looks softer and less red. The wounds we have used it on seem to look cleaner, have less drainage and heal faster than previously. I am almost out of the second jar. Will I be able to get more? I hate to have started this and now I am seeing wonderful results (he seems to like it too) and I'm worried that I can't get any more. Please let me know if I will be able to get more and when. If you need more input on how it is helping him let me know. I know his nurse is very impressed. She loves how the wounds just look cleaner to her.

September 11, 2008

We use the cream every bandage change which is 3 times a week. We apply a very generous amount to the more severe areas (such as his feet, legs and arms mostly). With more cream I would apply it to the entire body as it does help soften the scar tissue. We put the cream directly on a bandage like xeroform, mepilex or mepilex transfer then place on skin including wounds. He doesn't like cream applied directly to his skin - he prefers it to be put on a bandage first.

You had sent me 2 jars about 3 or 4 weeks ago and we have been using it sparingly because I wasn't sure how much, if any more, I would be able to get. Ideally I would say for my son a good amount would be about 1 1/2 jars a week equaling about 6 jars a month. The total optimal amount I would estimate to be able to put on his entire body I would say 7 to 8 jars a month.

May 5, 2009

Jonathan has eczema on top of the RDEB. I have noticed a huge help with his eczema. Alwyn Cream helps to reduce the redness his eczema causes and the itching. The improvement with eczema has been a great benefit because it in turn also helps with the EB. Less itching means more comfort and less blistering.

In my opinion the Alwyn Cream has been a great help to my son. It has greatly improved his comfort and has helped his skin. It is not a cure all but anything that helps EB in any way is a small little miracle in my book.