

# The EB Advocate

Supporting the EB Community

A newsletter presented by  
McKesson Patient Care Solutions Inc.



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### Featured Product: ALLEVYN



Smith & Nephew **ALLEVYN** is a soft gel adhesive that is suitable for use on fragile skin and is intended to minimize trauma and pain at dressing changes. ALLEVYN Gentle has a unique three-layer technology that actively manages exudate. An absorbent hydrocellular pad is held between a soft gel adhesive wound contact layer and a highly permeable waterproof outer film. The triple action technology provides effective fluid management to maintain a moist wound healing environment. ALLEVYN Gentle is also suitable for application under compression bandaging.

ALLEVYN is available from MPCS in the following sizes:

- 2x2
- 4x4
- 6x6
- 8x8

### Did You Know?

Our product line does not stop at wound care dressings. We also carry ostomy, tracheostomy, urology and incontinence supplies as well. If you are in need of any of these additional product lines we may be able to help, depending on your insurance coverage.

At your next reorder, let us know of any additional products you are in need of and we will advise what we can provide at that time. Please contact our office at 855.532.5463 or [EBline@McKesson.com](mailto:EBline@McKesson.com)

### Have a question about insurance? Call 855.5EB.line or email EBline@mckesson.com

### Insurance Payers News from MPCS

MPCS is a contracted supplier with hundreds of commercial insurance companies and is a participating provider with Medicare and most Medicaid plans. Our company also adds new contracts every year.

That's why a plan that was incompatible in the past may now be one that MPCS can accept.

Call the toll-free EB-line (855.5EB.line) to notify MPCS of changes in your health plan.

### EB Nurse News & Events Calendar

Tell us about your next EB-themed event! We can post it on the [EB Nurse](#) website's [News and Events calendar](#) and help you get the word out.

Email your event information to MPCS's dedicated [EB Advocate Team](#) today.

### Quick Links

**The EB Advocate page on Facebook**

**The EB Advocate on Twitter**

**EB Nurse News and Events Calendar**

### Signup



Follow us on [twitter](#)

Like us on [Facebook](#)

Like "The EB Advocate" on Facebook to learn and share information about EB, wound care products, insurance tips and events of interest to the EB community!

## Register now for 2016 debra Care Conference

### Conference

The 2016 debra Care Conference is July 24-27 at the Gaylord Texan Resort & Convention Center in Grapevine, Texas. Debra welcomes those with EB, their families, advocates and care providers to listen to and meet with medical professionals.



Wound care manufacturers and suppliers attend as exhibitors to showcase their products and services. The conference allows those with EB to connect with others from around the country that share similar circumstances. In addition, debra organizes playrooms, fun activities and social time for adults. McKesson Patient Care Solutions (MPCS) is a sponsor of the event. Visit [debra Care Conference](#) to register.

## Don't Miss 2016 Camp Wonder

McKesson Patient Care Solutions (MPCS) is a sponsor of the Children's Skin Disease Foundation's (CSDF) Camp Wonder which will be held on June 20-25 in Livermore, California. The camp provides a safe, nurturing environment filled with positive energy and acceptance.



Campers will have the chance to play sports, go swimming, climb a rock wall and make arts and crafts. For more information visit [Camp Wonder](#) website.

## 5 Questions with an EB Advocate: Christie Zink

### Christie Zink

**Name:** Christie Zink  
**Age:** 40  
**Profession:** Photography/Graphic Design and Mommy of three  
**Home State:** Minnesota  
**Something Unique about Yourself:** I have a fascination with history, including my family history; preserving the records, documents, and stories that can be passed down for generations.



#### 1. How did I first become aware of Epidermolysis Bullosa?

On a late night in 2011, the simple click of a mouse would bring me to the blog of Courtney Roth who shared the journey of her son Tripp. Tripp suffered from [Junctional EB - Herlitz](#), and it was his story, his journey that changed me and set me on this path. Courtney's words were so captivating and they compelled me take action. I began doing research to connect with others and learn everything that I could about EB. What started out as the love for one little boy turned in to a commitment to be a voice for an entire community that I have grown to care for, to call my family.

#### 2. What do I do to advocate for the EB community?

I have used social media as a platform to share information, raise awareness, help families, and support research. In early 2012, I launched [irefuseEB.org](#) in an effort to inspire others to take action and to be a voice for those who are affected, in essence, to "refuse" to do nothing. I participate in many race events with my young son Ethan to help raise awareness and research funding for the work being done by Dr. Jakub Tolar; I have also hosted the Wings of Hope event that supports the University of Minnesota. In 2014, [irefuseEB.org](#) partnered directly with the University of Minnesota Foundation and created a fund dedicated to EB research. It is very important for me to cultivate an attitude of love and compassion; therefore I often try to engage my children and community in projects and events that make a difference. Projects like the Secret Stocking Project where we help coordinate gift giving to families over the Christmas holiday and Ethan's Butterfly Bandage project to help those affected by EB that lack insurance. I have found that there are so many ways to help make a difference, and I take advantage of each opportunity. Being a voice is important and I make the most of every chance that I can to help educate others about EB and hopefully inspire them to get involved. I often wear something associated with the cause that hopefully will incite conversation...it is very rare that I do not have a butterfly somewhere on me.

#### 3. Which fact about EB do I share most often?

Although I talk about the tragedy of EB, I also talk about how those with EB have this amazing spirit about them. It is rather incredible despite the suffering that they endure that they still smile and have an infectious effervescence about them. I always emphasize there is no known cure for EB and it will not get better or go away; that the research into effective treatments is vital in providing those with EB a chance for a better life, a life with less pain. I talk about the amazing hope that is on the horizon in the ongoing and new clinical trials because that hope is so incredible.

#### 4. What do I want people to do after you tell them about EB?

I am passionate and it is my hope that I would ignite a little of the same passion into the hearts of those I talk to; that they would feel compelled in to action, to do something to help make a difference. I would hope that they would see the benefit in the current research and that they would be enthusiastic about supporting it in any way that they can. I just want people to be involved any way that they can because each ripple caused by a simple act of compassion can ultimately create huge waves. It only takes one...

#### 5. What motivates me to accomplish my goals?

The people, they are my family and I love them dearly; and we fight for those we love. Every conversation, every interaction, every smile reminds me why I do what I do. With each new milestone in research, I am motivated to continue and help in the progress of this research through the fundraising that is vital for its success. I recently gave a talk at an EB benefit in New Hampshire and I spoke about hope. Hope is a powerful thing and once you choose hope, anything is possible. I see the hope in this community and I see the hope in the research that is being done, this hope motivates me, it drives me.

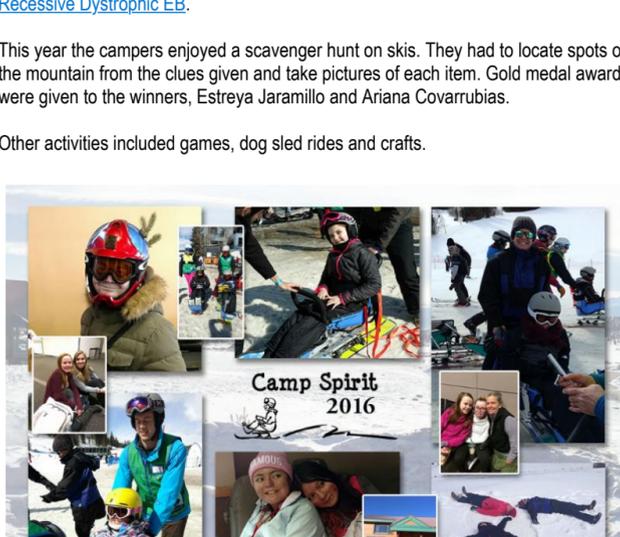
Read more on the [EB Nurse website](#).

## MPCS Enjoyed Winter Adventure with Camp Spirit

Danielle Malchano of the McKesson Patient Care Solutions (MPCS) EB Advocate Team recently returned from [Camp Spirit](#), a five-day winter adventure camp in Winter Park, Colorado. MPCS sponsored the camp, which is for children ages 9-18 who have [Recessive Dystrophic EB](#).

This year the campers enjoyed a scavenger hunt on skis. They had to locate spots on the mountain from the clues given and take pictures of each item. Gold medal awards were given to the winners, Estreya Jaramillo and Ariana Covarrubias.

Other activities included games, dog sled rides and crafts.



## Call our Dedicated EB-line

Call the toll-free dedicated phone number to order wound care supplies for EB. The number is **easy** to remember:

**855.5EB.line** (855.532.5463)

A product specialist is available Monday-Friday from 8:30 a.m.-5 p.m. ET to take orders and answer questions about products or insurance guidelines.



## Please Note

McKesson Patient Care Solutions Inc. does not recommend or endorse any specific test, products or procedures that may be mentioned. Always consult your own physician or healthcare provider about the applicability of any opinions or recommendations.

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## About "The EB Advocate" newsletter

"The EB Advocate" contains helpful information for people living with EB, special events, featured products and tips for dealing with insurance coverage issues. If you would like to contribute to future newsletters, please email [ebadvocate@mckesson.com](mailto:ebadvocate@mckesson.com).

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