Debra PCC unites EB families

Debra of America's Patient Care Conference united families from across North America last month and gave them opportunities to learn about the latest in EB research, wound care products and patient care.

People who have EB, their parents, siblings and caregivers traveled to Orlando, Florida's Gaylord Palms Resort from as far away as New York, Oregon, California, Canada and Mexico. National Rehab (NR) served as a PCC sponsor.

NR EB Advocate Team members Danielle Malchano, Bill Cornman, Michelle Graham and Christine Hartz enjoyed meeting people and learning more about EB. Michelle spoke about insurance advocacy. Danielle spoke about camp opportunities for children and teens that have EB.

"I feel fortunate to have attended the patient conference again," said Michelle, the team's insurance expert. "It is wonderful to be able to help people and know that what we do may be life-changing for them."

Representatives from wound care manufacturers also attended the PCC and handed out product samples. Families appreciated the chance to try new products.

"We get in the habit of using the same dressings over and over on the same wounds, and the products may no longer be working," said Faye Dilgen, whose son John Hudson has Recessive Dystrophic EB. "Seeing new products makes me think "what else can I use?' At that point, I usually call NR to see if any new products are available."

Product samples that were given out by Coloplast, Hollister, Ferris (PolyMem), Systagenix and Keraplast at the PCC can be ordered from NR. Call Bill Cornman at 1-877-567-8468, extension 5318 to order these products or any other wound care supplies.
Researchers and healthcare providers also spoke about advancements in patient care. Jakob Tolar, a leading EB researcher and associate professor at the University of Minnesota, talked about the "steep mountain to climb" to cure EB.

PCC presentations were recorded and are now available on the Debra website.

Learn About Alginate Dressings

In each issue of "the eb advocate," we highlight a different category of wound care products that may be suitable for EB skin. We do this to help educate the EB community about product properties, application and precautions.

In this issue, we highlight alginate dressings. Alginates are made of soft non-woven fibers which are derived from seaweed. These dressings are capable of absorbing large amounts of wound drainage. Alginates are available with or without silver. Learn more about alginates on the EB Nurse website's Wound Care Products page.

Watch EB Dental Program on ebnurse.org

We have heard from members of the EB community about the struggle to find a dentist who is familiar with EB. That is why the NR EB Advocate Team produced the program "Dental Care and Epidermolysis Bullosa."

Sponsored by NR, the program features guest speaker, Dr. Mark Cannon. Dr. Cannon specializes in dentistry for special needs children in the Chicago, Illinois, area. He has treated patients who have EB for many years.

Watch the program on the EB Nurse website to learn more.

Inspired by EB, kindergarten teacher wins blog contest

Less than two years after starting a blog about adventures in her kindergarten classroom, Illinois teacher Katie Mense can add two honors to her resume: award-winning blogger and accomplished fundraiser.

NR Insurance Partners News

NR can work with hundreds of private insurance companies as well as Medicare and select Medicaid plans.

"Like" the eb advocate Facebook page to learn when we announce a new insurance plan that NR accepts.

To order this product or other wound care supplies, call NR EB Product Expert Bill Corman at 1-877-567-8468, ext. 5318, or email him at bcornman@nationalrehab.com.

Insurance Tip

Open enrollment for many insurance plans happens at the end of the year. Even if you are not changing plans, take this time to understand your coverage.

Usually a month before your re-enrollment start date, a summary of the covered benefits and an explanation of plan changes are mailed to the member’s home or distributed at the member’s place of employment.

Read through the materials and discuss your questions with your human resources department or insurance company. You may find your plan has benefits of which you were not aware.

If you need advice or have questions, call NR Insurance Consultant Michelle Graham at 1-877-567-8468, ext. 5319, or email her at mgraham@nationalrehab.com.

EB Nurse News & Events Calendar
That's because her blog, "Little Warriors," was recently named Top Education Blog by insurance company California Casualty. She won a $200 prize and donated it to Debra of America in honor of New Baden Elementary student Mareyna McCaughtry. Mareyna, now 8 years old and a third-grader, has EB Simplex Koebner (EBS-K).

Katie, 32, met Mareyna three years ago. This was the first time she had ever heard of EB.

"Meeting Mareyna was so eye-opening," the teacher said. "She taught me a lot. She is in pain everyday but never complains. She might have a huge blister on her hand from writing. She works through it and keeps on going."

The more Katie learned about EB, the more she wanted to help people like Mareyna who endure so much. That is why she decided to share her winnings with Debra.

"When I got to reading about EB and learning what these kids go through on a daily basis -- the pain and the bandaging to heal wounds and protect skin -- I knew I had to do something," Katie said.

She created the blog in early 2011 as a means to share tips with other teachers. Soon, she began educating educators about EB. Her blog was nominated for the nationwide contest in May. Voting took place online and ended July 8. She learned in late July that she won.

"A lot of teachers from different places read my blog because I share a lot of freebies that can be incorporated into their lesson plans," she said. "They commented that they had never heard of EB either and thanked me for doing this."

Mareyna and her mother Jennifer were ecstatic to learn "Little Warriors" won and was able to shine a light on EB.

"Katie has helped other kids and adults see that yes, Mareyna has special skin, but that deep down, she is just like every other kid," Jennifer McCaughtry said. "She is capable of so many things."

Katie credits Jennifer with educating people at school about Mareyna's condition. Jennifer accomplishes this by speaking with her daughter's new teacher before the start of every school year. She also sends letters about EB home to students' parents so they understand how EB is managed and that EB is not contagious.

Jennifer also keeps the New Baden, Illinois, community aware of EB by hosting the EB Awareness Walk during International EB Awareness Week. This year's walk is scheduled for 3:30 p.m. on Saturday, October 27 at New Baden Community Park.

Read the "Little Warriors" blog post about why Katie chose Debra of America.
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"There were many opportunities for campers to try new things," Danielle said. "One of the highlights for me was helping one camper ride a bike for the very first time."

Please Note
National Rehab 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.

About “the eb advocate” newsletter
"The eb advocate" contains helpful information about 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@nationalrehab.com.

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