

# DebRA Currents

THE QUARTERLY NEWSLETTER OF THE DYSTROPHIC EIPERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

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## Wound Healing Study Still Recruiting Participants; Adds Locations

*As part of DebRA's ongoing commitment to keep patients apprised of the latest information, DebRA has agreed to provide the following for information purposes only.*

RegeneRx Biopharmaceuticals, Inc. ([www.regenerx.com](http://www.regenerx.com)) is still recruiting participants for its Phase 2 clinical trial to test the safety and wound healing properties of Thymosin Beta 4 (TB4) in EB wounds. In addition, RegeneRx has expanded the number of clinical trial sites. The official title of the study is: *A Randomized, Double-Blind, Placebo-Controlled, Dose-Response Study of the Safety and Efficacy of Thymosin Beta 4 in the Treatment of Patients with Epidermolysis Bullosa.*

A total of 36 patients will be enrolled under the direction of the following physicians:

**JO-DAVID FINE MD, MPH**, Vanderbilt University, Nashville, Tennessee

**ANNA BRUCKNER MD**, Stanford University, Stanford, CA

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## Scientists Meet in Dublin to Plan Next Steps of EB Research

Within the past two decades or so, there has been tremendous progress towards understanding the molecular basis of major forms of EB.

*By Jouni Uitto, MD, PhD  
DebRA of America Scientific Advisory Board Member  
Chairman, Department of Dermatology and Cutaneous Biology, Jefferson Medical College*

Within the past two decades or so, there has been tremendous progress towards understanding the molecular basis of major forms of EB. It is now known that mutations in as many as 10 different genes can underlie EB. Identification of mutations in these genes has been extremely helpful in providing more accurate diagnosis and subclassification of EB, with the ability to

prognosticate the severity of the disease in the future. Mutation analysis has also provided a means for accurate genetic counseling for the risk of recurrence in future generations, and has provided the basis for prenatal testing at early stages of pregnancy, if requested by the parents. Yet, there has been relatively little progress in finding new treatments to counteract the blistering tendency in affected individuals.

### SCIENTISTS MEET IN DUBLIN

The leading scientists from all around the world working on different aspects of EB

*continued on page 2*



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## Conference

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It was recognized that science is moving forward at a very rapid pace, and some of the techniques that were at the leading edge of research four years ago seem now somewhat outdated.

met in Dublin this past October to identify new research directions and explore new opportunities towards development of clinical solutions for EB. In other words, what are the barriers that prevent us from translating the fundamental science progress in EB to improved clinical care and perhaps a cure? This conference was initiated by DebRA Ireland with organizational help from DebRA International and financial support from the global EB network, including DebRA of America. The participants represented a spectrum of basic scientists, geneticists, clinicians and other healthcare providers involved in research and treatment of EB, and they represented several European countries, US, Japan, and Singapore, among others.

### **NOVEL MOLECULAR THERAPEUTICS**

The focus of the meeting was on development of novel molecular therapeutics. It was recognized that science is moving forward at a very rapid pace, and some of the techniques that were at the leading edge of research four years ago seem now somewhat outdated. In fact, the emphasis of molecular therapies is shifting from replacement of genes in the skin to introducing cells, particularly stem cells isolated from bone marrow or umbilical

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## Conference continued from page 2

vein, to the patients. It is expected that the stem cells differentiate into skin cells and then synthesize normal skin components that are defective in the patient's skin. As an extension of this approach, it has been suggested that delivery of purified protein, such as type VII collagen in dystrophic forms of EB, directly to the skin would be the most effective way of correcting the fragility and counteracting the blistering tendency. In fact, a number of clinical trials exploring the feasibility of cell- and protein-based molecular therapies to counteract different forms of EB are at planning stages.

### SKIN CANCER IN EB

An emerging clinical problem is skin cancer development in patients with the recessive dystrophic subtype of EB. These skin cancers are exceptionally aggressive and tend to rapidly metastasize to the neighboring tissues and elsewhere in the body. A considerable amount of

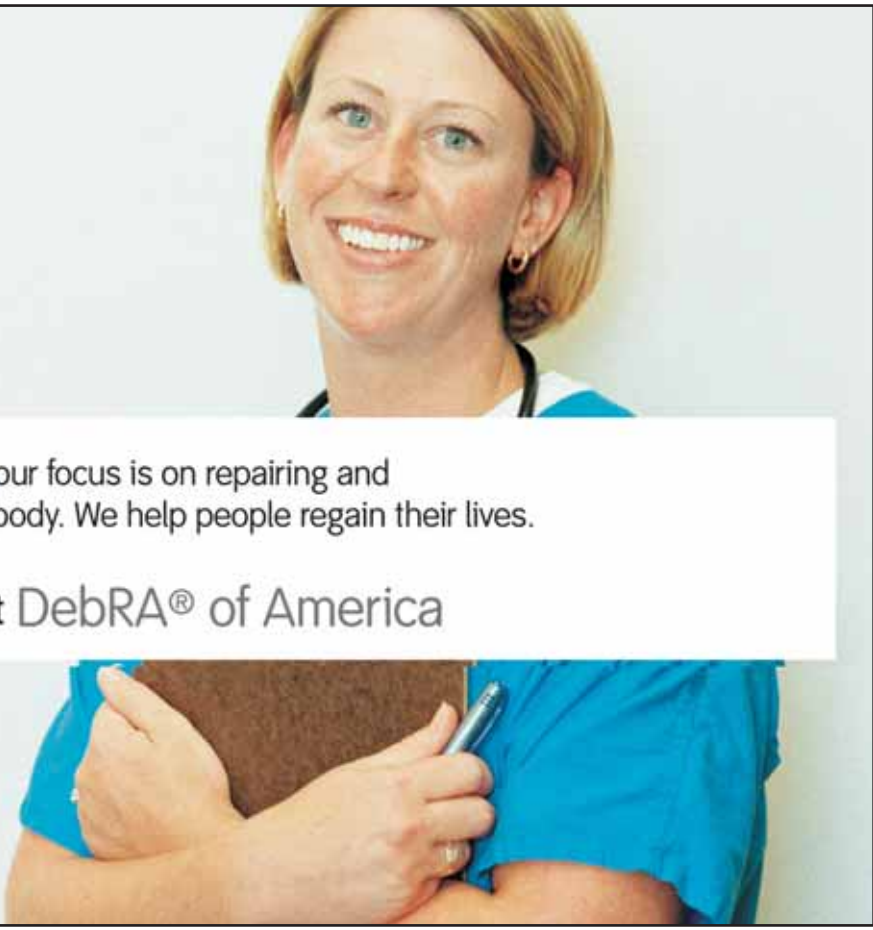
information is known from various forms of skin cancer, not related to EB. The major question of discussion is to what extent the EB-associated skin cancer is similar to or different from those frequently encountered in general


A picture is clearly emerging that the skin cancer associated with recessive dystrophic EB has its own pathways and biological requirements that may explain its unusually aggressive nature.

population, particularly in the elderly. In other words, is the knowledge of the development, invasion, and metastasis of "garden variety" skin cancers applicable to EB-associated malignancies? A picture is clearly emerging that the skin cancer associated with recessive dystrophic EB has its own pathways and biological requirements that may explain its unusually aggressive nature. At the same time, identification of characteristic pathways and signal transduction mechanisms in the latter tumors now provide potential opportunities to disrupt the malignant behavior and counteract the development of these lesions.

### SUMMARY

EB 2006 in Dublin was an extremely successful scientific get-together allowing the research community to derive a consensus on developmental priorities in EB research, towards improved treatments and perhaps a cure in the foreseeable future.



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# National Awareness Effort Reaches First Goal

*Editor's note: This article was prepared by Gena (Brumitt) Gruschovnik, a lead volunteer in the effort to bring a National EB Awareness Week to fruition. Her connection to EB is through her mother, Pat Barbrey, who had RDEB HS. The following is her summary of these advocacy efforts to date. In addition to Gena, the following volunteers have been crucial to the success of the effort—Don Peshkur, Barbara Stowe, Shirley Jones, Dennise Joseph, Allyson Anderson, Robin Eckworth, and Madeline Weiner, RN.*

For people who have been in the EB community a long time, the recent effort to declare the last week in October "National EB Awareness Week" may seem like déjà vu. In fact, President Ronald Reagan proclaimed "National EB Awareness Week" in 1984 and 1986, but those proclamations were only for a one-year period.

In June 2005, Sen. Charles Schumer and Rep. Timothy Bishop answered a call-to-action from the Peshkur family, and sponsored resolutions S.RES.180 / H.RES.335 to make "our week" an enduring reality.

The objectives of the Bills are to:

- Increase EB awareness in society
- Foster understanding of the impact EB has on patients and families
- Stimulate the designation of research funds for EB

Our community's efforts thus far include:

- Disseminating press releases from DebRA and EBMRF in 2005/2006 to promote the Bills, working in harmony on this important endeavor;
- Asking citizens to persuade Members of Congress and Senators to co-sponsor; and
- Assembling a group of volunteers to implement a writing campaign to contact every Congressperson and Senator

**The community can help by petitioning the current leadership to vote on H.RES.335.**

Contact information can be found at [http://www.house.gov/house/orgs\\_pub\\_hse\\_ldr\\_www.shtml](http://www.house.gov/house/orgs_pub_hse_ldr_www.shtml).

On September 21, 2006, the Senate gave S.RES.180 unanimous approval. Now, Congress must approve H.RES.335.

With Barbara Stowe, a writing campaign volunteer and grandmother of a child with JEB, I commenced a new campaign in October – I requested letters from EB families, assisted everyone who needed help, and forwarded letters I received to Barbara. She set up appointments on Capitol Hill and donned her walking shoes, educating politicians and aides as she hand-delivered the letters. We've obtained 10 more co-sponsors this way!

Most recently, letters from DebRA, EBMRF, and EB families were hand-delivered to Majority/Minority Leaders and Whips, and to the Speaker of the House, who have greater authority to

place a Bill on the suspension calendar. Few weeks remain in the tenure of the 109th Congress. We will persevere, in spite of a crowded agenda in the House of Representatives.

The community can help by petitioning the current leadership to vote on H.RES.335. Contact information can be found at [http://www.house.gov/house/orgs\\_pub\\_hse\\_ldr\\_www.shtml](http://www.house.gov/house/orgs_pub_hse_ldr_www.shtml). Rep. Bishop is committed to taking the Bill to the 110th Congress if needed, and our little team of volunteers will see this undertaking through to the end! Whether we win the support of the 109th Congress or the 110th, I have every confidence that our community efforts will prevail.

**Have you remembered  
DebRA in your will?**

# • Ask the DebRA Nurse Educators •

Dear DebRA Nurse:

**My daughter has EB and is expecting her first child. We were discussing her plans with the new baby and she would like to breastfeed. Will my daughter be able to or will the friction of nursing cause her to develop blisters on her breasts? And are there ways to treat this to make it more bearable?**

—Concerned Grandmother

Dear Concerned Grandmother:

Your daughter should certainly try breastfeeding if it is her desire. It is possible that she might do as well with breastfeeding as a non-EB mom.

The experience of breastfeeding varies widely in the EB population. Very few EB moms have successfully breast-fed their babies without any problems. Most have difficulty because when a baby suckles blisters tend to form around the nipple area.

I would suggest that your daughter ask her OB/GYN doctor to recommend a lubricant that is baby-safe. She can apply this to her nipples prior to feeding the baby. If that alone does not help to reduce/prevent blistering, she can try a silicone nipple shield

on her lubricated nipple. This may offer her some additional protection as the baby feeds.

If these methods are problematic, she can consider using a breast pump on her well-lubricated nipple. This will widen the diameter of pressure on her nipple. The pumped breast milk can then be bottle-fed to her baby. It is also possible that hand expression of her breast milk will be less traumatic to her breast tissue.

Not every technique works for every woman. It is important to remember that some EB moms are not successful when it comes to breast feeding and/or pumping their breast milk. Your daughter needs to know it is okay to bottle-feed the baby with formula if necessary. If she is not able to breastfeed, her pediatrician can recommend a good formula for her child.

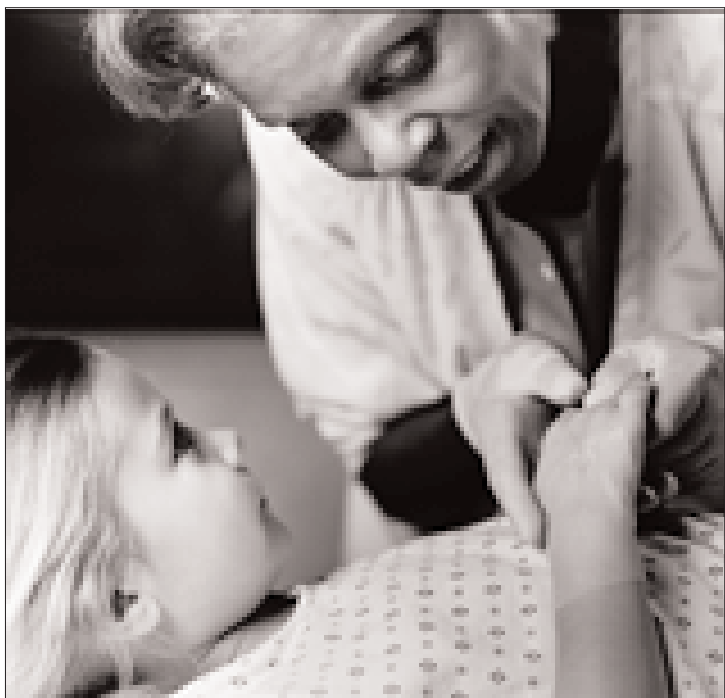
There is often concern expressed that bonding occurs during breastfeeding and that the inability to breastfeed may prevent bonding between mother and child. The truth is that the acts of cradling the baby, making eye contact and talking or singing to the baby will allow a mom to bond with her child, even when bottle-fed.

Geraldine Kelly-Mancuso, RN

DebRA EB Nurse Educator

Cincinnati Children's Hospital Medical Center

## Tailormade wound care



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# DeBRA Events

EVENTS AROUND THE COUNTRY SUPPORT DEBRA'S MISSION

The programs and services of DeBRA are made possible in large part to the generosity of the individuals who support its mission. Throughout the year, many people hold events from which the proceeds benefit DeBRA. The following is a round-up of recent events. If you plan to hold an event to benefit DeBRA, the staff is happy to assist you. If you would like your event included in a future newsletter, please send information to Current Newsletter, DeBRA of America, 5 West 36th Street, Suite 404 or via email to [staff@debra.org](mailto:staff@debra.org).



Michael Tavani

## RUNNING FOR A CURE

Michael Tavani completed two challenges by running in this October's Chicago Marathon—conquering the more than 26 mile course and more than tripling his initial fundraising goal. Tavani ran in honor of his niece, Ellie, who has EB. The funds

raised are designated to the DeBRA International Research Grants Program. Tavani is continuing his efforts to raise funds for DeBRA via the website [www.do26.com](http://www.do26.com)



Jessica Simpson, Rachel Nasuti (RDEB), and Ken Paves promote awareness of Epidermolysis Bullosa at the opening of the Ken Paves Salon in Beverly Hills in September.

## TEEN SHINES AT STAR FILLED EVENT

Salon owner Ken Paves, famous for styling the tresses of stars like Jessica Simpson and Eva Longoria held a benefit in conjunction with the opening of his Beverly Hills salon this fall. Paves developed the benefit to support EB organizations because of his friendship with Rachel Nasuti, a teen with RDEB. Rachel was the guest of honor and was featured in *People's* coverage of the event.

## GOLFING FOR EB

Two families held fall golf events to benefit DeBRA. Don Furjes helmed the fourth annual golf tournament in honor of his daughter, Ella, who has EB Simplex-Dowling-Meara. The event was held at Sunset Lakes in Fenton, MO with proceeds benefiting the DeBRA International Research Grants Program.

Lindsey and Jason Gregg of Ohio held their second golf tournament in honor of their three-year-old son Maxx, who has

[continued on next page](#)



Lindsey Gregg & Friends raise funds for DebRA of America

Dominant Dystrophic EB. Proceeds of the event are designated to support the Nurse Educator Program.

### DEBRA TRUSTEES GO TO THE "MATS" FOR DEBRA

Two DebRA Trustees held fall events to benefit DebRA. Dr. Robert Meirowitz used a treasured auction item he won to develop a fundraising event for DebRA. Dr. Meirowitz had won a famed "School of Mats" tennis lesson with Mats Wilander at a DebRA event. He decided to turn the private lesson into a group lesson as a fundraiser in the Princeton, NJ area. Guests got the opportunity to get one-on-one pointers from the Tennis Hall of Famer.

Mats and his wife, Sonya, held their own fundraising event at their Idaho home. Guests enjoyed a lobster dinner before being entertained by a comedian.

## Wound Healing Study continued from page 1

**MOISE LEVY MD**, Texas Children's Hospital, Houston, TX

**KIM MOREL MD**, Columbia University, New York, NY

**TOR SHWAYDER MD**, Henry Ford Medical Center, Detroit, MI

**KAREN WISS MD AND AMIT GARG MD**, University of Mass at Hahnemann Campus, Worcester, MA

**ELIZABETH ALVAREZ CONNELLY MD**, University of Miami, Miami, FL

**AMY PALLER MD**, Children's Memorial Hospital, Chicago, IL

The study medication (TB4 or Placebo) will be supplied as a gel and will be applied once daily to a single lesion (a sore selected by the physician investigator for treatment evaluation). Study medication will be applied daily until the lesion completely heals or for up to fifty-six days, whichever comes first. Visits will be required weekly for the first month of the study and then biweekly.

TB4 is a naturally occurring substance present in virtually all human cells. It represents a new class of wound healing drug. A key mechanism of action is TB4's ability to regulate the cell-building protein, actin, a vital component of cell structure. Additionally, it has been reported that TB4 directly influences the production of laminin-5, a protein, important to the wound healing process because it is known to promote cell migration and adhesion.

### LISTED HERE ARE SOME OF THE CRITERIA PATIENTS MUST MEET IN ORDER TO BE ELIGIBLE TO PARTICIPATE IN THIS STUDY:

- Age 2 or older
- Junctional or Dystrophic EB
- Lesion to be treated must be:
  - located on a limb or the trunk
  - 14-28 day duration
  - 5cm<sup>2</sup> to 50cm<sup>2</sup>
  - Clear of infection

- No investigational drug within 30 days
- No immunotherapy or cytotoxic chemotherapy within 60 days
- No systemic or topical steroidal therapy within 30 days (except inhaled steroids)
- No systemic antibiotics within 7 days
- No current or former malignancy, including SCC
- No Diabetes Mellitus
- Not pregnant or breastfeeding

### ADDITIONAL CONSIDERATIONS:

- Females of childbearing potential
- Other health issues
- Availability for study visits

For more information about the study and how to participate, you may contact one of the physicians listed above or Madeline Weiner, RN, RegeneRx Biopharmaceuticals Inc., at 919-929-1855 or madeline.weiner@mindspring.com.

# Summer Camps for Youths with EB



Campers enjoy a moment together.

For youth with serious skin conditions, summer camp provides the opportunity embark on new adventures and friendships in a safe and supportive atmosphere.

Camp Discovery offers a summer camping experience unlike any they've had before. Every year, the American Academy of Dermatology sponsors a week of fishing, boating, swimming, water skiing, arts and crafts. Under the expert care of dermatologists and nurses, children are offered the opportunity to spend a week among others with similar skin conditions. Many of the counselors have serious skin conditions as well and can provide support and advice to campers. The organizers work to ensure that fun, friendship, and independence are on the top of everyone's agenda.

Camp Horizon takes place in mid-August at Camp Victory in Millville, PA. The 35-acre campsite features 10 sleeping cabins, a large mess hall, outdoor activity pavilions, fishing and paddleboat pond, a

low-ropes course, a pool and a fully equipped infirmary. The first camp had 18 campers and has since grown to accommodate over 80 campers.

Campers from Camp Wonder shared their favorite things about the camp. The most common comments included: "No one stared at me.", "No one made fun of me.", "I could wear a bathing suit" and "I got hugs." According to Donald Tenconi of Camp Wonder, "It is a sanctuary where children can enjoy a world without stares and without hurtful comments...it is a protected environment where, for one week, the children are viewed like every other child and treated as a kid." He continues, "At camp we see only children and the warmth, excitement, curiosity and laughter within them."

There is no fee for the camps. Full scholarships, including transportation, are provided.

Application forms can be downloaded at the websites listed:

## **CAMP WONDER**

[www.csdf.org](http://www.csdf.org)

Telephone: 925-947-3825

Fax: 925-947-2158

Livermore, CA

Tentative Camp Date: Last week in June

Please check website for additional information

## **CAMP HORIZON**

[www.aad.org](http://www.aad.org)

August 12 – 19th, 2007

Millville, PA

## **CAMP DISCOVERY**

[www.campdiscovery.org](http://www.campdiscovery.org)

Telephone: 847-240-1737

Email: [jmueller@aad.org](mailto:jmueller@aad.org)

July 7–13 Teen Camp, Crosslake, MN  
(ages 15–16)

July 14–20, Junior Camp, Crosslake, MN  
(ages 10–14)

August 5–10, Camp Dermadillo, Burton, TX  
(ages 9–16)

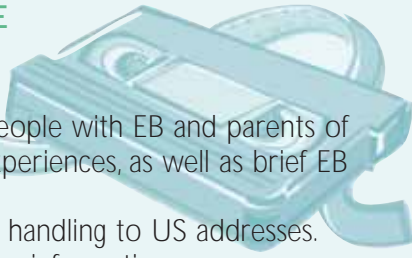
August 12–19, Camp Horizon, Millville, PA  
(ages 8–13)

## VIDEO NOW AVAILABLE

*More than Skin Deep*  
VHS Tape Format Only, 1999

This 10-minute video features people with EB and parents of children with EB sharing their experiences, as well as brief EB information.

\$5/copy plus \$2.50 shipping and handling to US addresses.  
Contact [staff@debra.org](mailto:staff@debra.org) for more information.



## COMING SOON...

*The Boy Whose Skin Fell Off DVD*

To add your name to the waiting list please go to [www.debra.org](http://www.debra.org) and click on the Order Video link under Jonny Kennedy's photo.

This award-winning documentary featured on TLC follows Jonny Kennedy, a man who had Recessive Dystrophic EB and died in 2003 at age 36 after losing his battle against skin cancer. In his last months, Jonny decided to work with filmmaker Patrick Collerton to document his life and death, and the result was a film that is an uplifting and provocatively humorous story of a singular man. Not shying away from the grim reality of EB, the film was also a celebration of a life lived to the fullest.

# MORE INFO

See page 10 to find out more about the **Eric Lopez Fund** and the **Family Crisis Fund**.



## *Brad Rasmussen Supports DeBRA and the EB Community.*

Toronto Born, U.S. grown big league vocalist Brad Rasmussen flaunts his talent on his debut album, **UNCOMMON**. And that is the essence of Brad, and his music. A broad range of influences with the likes of Tori Amos, George Michael and Sting touching down near the top. Rent from the ragged edges of a smooth soul. His expression is genuine.

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**But you will feel it.**

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[www.bradmusic.com](http://www.bradmusic.com)

# Funds Assist Families in Need

## DebRA has two ways for people with EB in need to apply for assistance.

The **FAMILY CRISIS FUND** provides emergency assistance to alleviate some of the financial burden of un-reimbursed costs of medical supplies, other comforting aids, or procedures. This fund accepts applications throughout the year and is limited to one grant per

year per person with EB.

The **ERIC LOPEZ FUND** offers an opportunity for people with EB to achieve a higher level of independence and/or improve the activities of daily living. DebRA is now accepting applications for 2007, which are due on March 1, 2007. The fund has a maximum grant of \$750.

Individuals 13 years of age or older or the parent/guardian of a minor 13 years of age or older who has EB may apply. The fund was established to help an individual with EB acquire, in part or in whole:

- Adaptive devices or equipment (for example for driving, exercising, recreation, etc.)
- Independent living aids

- Equipment to be used for recreational or professional purposes such as electronic or computer equipment, materials, supplies, games or toys that will:

Aid in mobility and promote independence

Facilitate communication with others and/or

Assist in the pursuit of special interests or hobbies that will advance personal or

Professional growth and development

Applications for both Funds are available at [www.debra.org](http://www.debra.org) or through the DebRA office by calling 212-868-1573 or via email at [staff@debra.org](mailto:staff@debra.org).

# Supplies to SHARE

DebRA's Wound Care Clearinghouse accepts donations of wound care products which are passed on, free of charge, to people in need.

Please contact DebRA at 866-DEBRA76 or send an email to [nurse@debra.org](mailto:nurse@debra.org).

Availability of supplies varies; contact DebRA to discuss your specific needs.

## AVAILABLE SUPPLIES

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- **Kendall Conform 4 inch rolled gauze**
- **Enteral nutrition bags**
- **Adaptic**
- **8x8 Allevyn Non-adhesive dressing**

# PROFILES IN EB

## Jan Plyler and Bruce Gunn

*Editor's Note: The following article is the result of conversations with Jan Plyler (74 years old, Junctional Non-Herliz) and Bruce Gunn (40 years old, Recessive Dystrophic) about their experiences as adults living with EB.*

### Did your EB change over time?

**BRUCE:** Yes, from my childhood years it was bad, it wasn't until late in high school, going through puberty at 18 or 19 my upper body started to heal more & wasn't breaking down, especially around my neck and shoulder area.

**JAN:** As a child it was pretty mild; it just affected my fingernails and teeth. My skin became more fragile as I got older. I noticed a change after I got pregnant – it became more severe.

### What was the knowledge of EB when you were younger among doctors, and what did your family tell you?

**BRUCE:** There wasn't really much knowledge from doctors, other than the basics on how to care for the wounds and staying on top of it.

**JAN:** Very little information was available when I was younger. My father took me to Duke University and the doctor told me that once my baby teeth were gone, my adult teeth would be fine. That wasn't the case; I've since had them capped. Also, I wasn't diagnosed until I was 31!

### What information was not available then but is now?

**BRUCE:** Well, I knew I had the severe form of RDEB but didn't know until 8 years ago what form of EB I had. What doctors didn't tell me then, that I now know is the skin cancer aspect and how much of a risk I had with my sub-type. Plus infections were always a risk, but didn't become a problem until I had a wound not heal for 18 months that turned into SCC, and then the infections set in.

**JAN:** At 12, I started to operate on my feet myself with a razor to relieve the pressure. Now I've found that foam rubber soles help.

### How has daily treatment of your condition changed?

**BRUCE:** I think it's the medical supplies we have today, like Mepilex, plus I use Xeroform. I also would have to say the prescriptions drugs, from antibiotics to creams, ointment, and powders to heal wounds and silver dressings. Also, iron infusions, and being able to get Procrit shots for anemia, not having blood transfusions so much anymore and the dilatations we have done to help us eat much easier when it is needed.

**JAN:** The bandaging has improved. I do a lot more bandaging now than I had done when I was younger. I just started wrapping in the past few years.

### Do you have any observations from experience that may be helpful for others with EB?

**BRUCE:** Be sure to aware of all your wounds, if they look or feel different, and are not healing within the usual amount of time, get to a doctor right away. Do the dressing changes – I hear that some Ebers don't keep up with there dressing changes, and realize because it's very painful to have them changed, but very important & vital to do so.

**JAN:** Be aware of eye issues; I had cornea blistering and went to the Boston Institute for Sight to have them taken care of over two years ago.

### What are your hopes for the future?

**BRUCE:** Well, I hope to see a cure for RDEB/HS in my life time, but more so for the children & young adults who need the cure now as so many are suffering.

**JAN:** To keep on living! I would like to see more medication to help heal sores and toughen up the skin. I also am hopeful that gene therapy will be available.

### Has DebRA made a difference in your life?

**BRUCE:** I am thankful for the central air conditioners they bought for me back when I moved into my Habitat Home



Bruce Gunn and Jan Plyler

back in May of 2000, the medical supplies over the years & support, and attending the Patient Care Conference. I been able to attend the last three conferences, and met so many incredible people, and sharing my story to able to help others. Very important, because my first 30 + years, I didn't have the knowledge or support until I got sick and stumble into EB by the way of the internet, and has helped me a great deal.

Parents today have it much easier than my parents when I was born – a lot wasn't known back then, but so much is known today with the advances in the medical field. There is much more support for parents & Ebers inline with the support groups, getting advice and solutions to issues for their child or adults. Parents & Ebers have experience and take that information to their doctors and narrow the issues. Sharing your experience and helping others is a great asset. I have helped many parents and Ebers from what I have gone through, but what works for me may not work for them. Make sure to be there with your doctor making a decision, asking questions and to be sure that the solution is what is best for your child and/or for yourself.

**JAN:** I love getting the DebRA newsletter and hearing what's going on in the EB community. The Nurse Educators are a wonderful asset. Before DebRA, there wasn't any information available.



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