

DeBRA Currents

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

INSIDE:

Staff	2
Clinical Testing	4
Supplies to Share	4
Ask Madeline	5
Patient Care Conference	6/7
In the News	8
Susan Craighead	4
Summer Camp	5

Research

HOW CAN I LEARN MORE ABOUT EB RESEARCH?

Currents will feature regular updates and topical articles about research. In addition, complete information on DebRA Grants and EB Research can be found at <http://www.debra-international.org/research.htm>

HOW DOES DEBRA INTERNATIONAL'S RESEARCH PROGRAM WORK?

An essential part of DebRA's mission is to fund research into the causes of and possible treatments for all three types epidermolysis bullosa (EB). The research priorities DebRA has set are aimed at gaining new information in the areas of wound healing, genetics, gene therapy, cancer, pain management and psychosocial issues.

This is accomplished through the DebRA International Medical and Scientific Advisory

Panel, a group responsible for the centralized peer-review research grant assessment process on behalf of all of the member groups of DebRA International. Peer review is considered the gold-standard in research funding and charges a panel of independent experts with the evaluation of grant applications from researchers. These experts evaluate grant applications to rate and rank applications to determine what research has the most potential for advancing basic science or improving diagnosis or clinical management of EB. The DebRA panel, which includes DebRA of America Scientific Advisory

Currents will feature regular updates and topical articles about research

continued on page 3



Please keep an eye out for our most recent mailing profiling Bruce Gunn (RDEB). Bruce has been involved with DebRA for several years and his story is one of inspiration and a testament and perseverance of those in the EB community.

EB Wound Healing Drug Study Begins

RegeneRx Biopharmaceuticals, Inc. is proceeding to initiate a Phase II clinical trial designed to test the safety and wound healing properties of several dosages of Thymosin Beta 4 (TB4) in eligible patients with dystrophic and junctional EB. Study medication (TB4 or Placebo) will be supplied as a gel that is applied once daily to a single lesion (a sore selected by the physician investigator for treatment evaluation). Study medication will be applied until the lesion completely heals or for up to fifty-six days, whichever comes first.

TB4 is a naturally occurring substance present

in virtually all human cells and 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, known to promote cell migration and adhesion, important components of the wound healing process.

Announcements will be forthcoming regarding the physician investigators who will participate in the study, and other relevant information.

In Phase II clinical trials, the study drug or treatment is given to a patient in order to further evaluate its safety and to learn about its effects. A double-blind study is one in which neither

continued on page 3



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STAFF

Announcements



Alecia Baker

DebRA of America is pleased to announce the appointment of a new staff member.

Alecia Baker is now the full-time Office Manager at DebRA after having served in a temporary capacity for over three months. Prior to joining DebRA, Alecia held the position of Office Manager/Bookkeeper at the Sanmar Holding Company, a dental referral agency.

Alecia brings more than ten years in office management and accounting to the position.

Need more up-to-date and accurate information?
Visit our website at www.debra.org

Research continued from page 1

In 2005, DebRA International gave EB research grants totaling \$2.26 million and had committed to fund \$6.1 million in EB research over the lifespan of its current grants.

Board Members Dr. Jo-David Fine, Dr. Jouni Uitto and Dr. Dennis Roop, meet two times each year to review grant applications.

WHAT IS DEBRA OF AMERICA'S ROLE IN RESEARCH?

DebRA of America is one of the member groups of DebRA International that pools its resources to fund EB research worldwide. While DebRA of America contributes to the full roster of DebRA International grants, it has particular responsibility to promote and encourage grant applications from U.S. scientists.

HOW MUCH IS BEING SPENT ON EB RESEARCH?

In 2005, DebRA International gave EB research grants totaling \$2.26 million and had committed to fund \$6.1 million in EB research over the lifespan of its current grants. EB research also

got a big boost from an additional \$5.9 million for research via the European Union. In the United States, the National Institutes of Health spent \$172 million on skin disease research in 2005 with wounds and skin ulcers as high priority research areas.

WHAT TYPE OF RESEARCH IS DEBRA FUNDING?

DebRA funded research includes projects in both the laboratory and at the bedside. They explore areas of all three types of EB. Within these types the project areas vary, but the grants encompass the genetics of EB, gene therapy, squamous cell carcinoma, wound healing, pain management and psychological issues in EB.

DebRA also supports the Dermatology Foundation Research Awards Program. These awards aim to develop the careers of the next generation of researchers and academic leaders in medical and surgical dermatology. In 2006, DebRA is supporting the following research grant – "Mesenchymal Stem Cells in Skin Wound Healing: Application to Epidermolysis Bullosa", Fatima Rouan, PhD of Thomas Jefferson University in Philadelphia. This award was made at press time and additional information will follow in an upcoming issue of Currents.

EB Wound continued from page 1

the participants nor the study staff know which participants are receiving the experimental treatment and which ones are receiving a placebo. Double-blind studies are performed so neither the patients' nor the doctors' expectations about the experimental drug can influence the outcome. All clinical trials have criteria and guidelines about who can get into the program. Guidelines are based on such factors as age, type of disease, medical history, and current medical condition. Before a person joins a clinical trial, he/she must qualify for the study and only a predetermined num-

Double-blind studies are performed so neither the patients' nor the doctors' expectations about the experimental drug can influence the outcome.

ber of patients can participate. The success of a phase two clinical trial is highly dependent on participants completing the full course of the trial so that the results can be accurately evaluated.

This randomized, double-blind, placebo-controlled trial will be conducted at a number of medical centers throughout the U.S. RegeneRx Biopharmaceuticals, Inc. is currently in the process of qualifying the study sites and plans to begin the study as soon as this is completed. Announcements will be forthcoming regarding the physician investigators who will participate in the study, and other relevant information.



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Clinical Trials Basics

A clinical trial is a research study to answer specific questions about new therapies or new ways of using known treatments. Clinical trials (also called medical research and research studies) are used to determine whether new drugs or treatments are both safe and effective.

All clinical trials have guidelines about who can participate. Using [HYPERLINK "http://www.clinicaltrials.gov/ct/info/glossary"](http://www.clinicaltrials.gov/ct/info/glossary) "inclusion" inclusion/exclusion criteria is an important principle of medical research that helps to produce reliable results. The factors that allow someone to participate in a clinical trial are called "inclusion criteria" and those that disallow someone from participating are called "exclusion criteria". These criteria are based on such factors as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. Before joining a clinical trial, a participant must qualify for the study. It is important to note that inclusion and exclusion criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help ensure that researchers will be able to answer the questions they plan to study.

The ethical and legal codes that govern medical practice also apply to clinical trials. In addition, most clinical research is federally regulated with built in safeguards to protect the participants. The trial follows a carefully controlled protocol, a study plan which details what researchers will do in the study.

Every clinical trial in the U.S. must be approved and monitored by an Institutional Review Board (IRB) to make sure the risks are as low as possible and are worth any potential benefits. An IRB is an independent committee of physicians, statisticians, community advocates, and others that ensures that a clinical trial is ethical and the rights of study participants are protected. All institutions that conduct or support biomedical research involving

people must, by federal regulation, have an IRB that initially approves and periodically reviews the research.

A placebo is an inactive pill, liquid, or powder that has no treatment value. In clinical trials, experimental treatments are often compared with placebos to assess the experimental treatment's effectiveness.

A double-blind study is one in which neither the participants nor the study staff know which participants are receiving the experimental treatment and which ones are receiving a placebo. Double-blind studies are performed so neither the patients' nor the doctors' expectations about the experimental drug can influence the outcome.

Clinical trials are conducted in phases. The trials at each phase have a different purpose and help scientists answer different questions:

PHASE I TRIALS: Initial studies to determine the metabolism and pharmacologic actions of drugs in humans, the side effects associated with increasing doses, and to gain early evidence of effectiveness; may include healthy participants and/or patients.

PHASE II TRIALS: Controlled clinical studies conducted to evaluate the effectiveness of the drug for a particular indication or indications in patients with the disease or condition under study and to determine the common short-term side effects and risks.

PHASE III TRIALS: The experimental study drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the experimental drug or treatment to be used safely.

PHASE IV TRIALS: Post-marketing studies to delineate additional information including the drug's risks, benefits, and optimal use.

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. These products will be distributed on a first-come-first-serve basis, and supplies vary over time.

Contact DebRA at 866-Debra76 or send an email to nurse@debra.org. Remember, if you have supplies you no longer need and want to help others, please let DebRA know. We're always happy to receive donations of non-expired, unopened, non-prescription products to help those in need.

AVAILABLE SUPPLIES

- **Vigilon**
- **Kendall Kerlix Super Sponges**
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- **Kendall conform 4 inch rolled gauze**
- **Ensure Plus**
- **Enteral nutrition bags**
- **large syringes for G-Tube feedings**
- **Mepilex (Nonstick) 18 x 20**
- **Econo Paste**
- **Adaptic**
- **Sorbalgon Calcium Dressing**
- **Gauze Bandages**
- **Kendall A.M.D. Gauze**

• Ask Madeline •

EXPERT ADVICE FROM OUR NURSE EDUCATOR, MADELINE WEINER, R.N.

Dear Madeline:

I am 37 years old and have RDEB (recessive dystrophic EB). Since childhood I have had mild webbing and curling of my fingers. In the past few years, it seems like it has gotten worse. I am no longer able to open my hand completely and it is getting difficult for me to hold things with one hand, like my hand won't open enough to grab and hold something. I met a few other people with EB at a DebRA conference a couple of years ago who had hand surgery and it didn't last. Their hands were in bad shape. I don't want to have this done if it isn't going to help. What do you recommend?

**Signed,
Not-So-Handy Man**

Dear Handy Man:

Because the *function* of your hands is impaired, it would be a good idea to consult with either a Plastic Surgeon or a Hand Surgeon. The surgeon will examine your hands and determine if you would benefit from surgery. The surgical procedure involves separating the fused digits (the webbed fingers) and releasing the contractures (curled fingers and hand) while under anesthesia. To facilitate healing, skin grafts or various bioengineered skin products may be applied to your hand wounds following surgery. Aggressive hand therapy and daily hand wrapping is essential if you are to maintain improved hand function after your hand heals. In order to prevent the fingers from fusing and curling again, it may be necessary to bandage each finger individually in order to maintain the web spaces. Hand splints are often used to help keep the fingers separated and the hands in an extended position, post surgically. This entire regime requires a lot of work and a real commitment and will also probably require assistance from another person. Think it through before having the surgery. I would not recommend having the surgery without an aggressive post-operative plan and a true commitment to stick with it.

Dear Friends,

After over a decade of working with EB on more than a full time basis, I have decided to take a bit of a break. I am thankful to DebRA of America for providing me with the means and opportunity to do the work I love so much. It has been an honor to represent our organization and *you*, our patients, families and members.

My intention is to remain a helpful force to the EB population and to continue to support DebRA of America. I am hoping my personal and family commitments will be more manageable with a part-time schedule.

I will be consulting on a couple of exciting EB projects. National Rehab, Inc., DebRA's long time sponsor and friend, wishes to enhance the services and support it offers its EB clients, as well as others in the EB community. They have asked me to work with them to build an educational (EB) website and to help educate insurance companies about the special needs of people with EB. RegeneRx Biopharmaceuticals, Inc. has contracted with me to provide consulting services as they take their new EB wound healing drug, Thymosin Beta 4, through clinical trials. (see story p.?) I'll be balancing my 3-4 days a week work schedule between these two projects, and spending time with my family.

I wish to extend my gratitude and warm wishes to each of you. Please welcome the new DebRA Nurse Educator to our family. I ask you to offer her the support and assistance you've always given me. This will afford her the same opportunity I've had for a successful, rewarding work and life experience.

With kind regards and much love,
Madeline Weiner

DebRA's 2006 Patient Care Conference

June 1-4, 2006



You are cordially invited to attend DebRA's 2006 Patient Care Conference (PCC) and "Get in Tune With EB" in "Music City, USA"—Nashville, Tennessee, June 1-4, 2006.

Every two years DebRA's PCC provides the opportunity to gather and attend educational sessions about various medical issues in EB and to ask questions of the expert presenters. It is also a great way to meet and reunite with friends in the EB community.

Following are some helpful conference details:

REGISTRATION

The Conference is Free!

The enclosed registration form must be filled out and returned to DebRA by Friday, May 15, 2006.

HOTEL & GROUND TRANSPORTATION

The 2006 PCC will be held at the Millennium Maxwell House in Nashville.

DebRA was able to get a special room rate of \$95/night. Please mention you are a part of the DebRA conference to assure you get this special rate. We urge you to make your reservations early for accessible rooms, rooms with roll-in showers, and for any other special needs.

When making your reservation, please indicate number of beds needed in your room.

This special room rate will only be available until Saturday, April 15, 2006 or until rooms are sold out.

Please note that a fee of \$100 will be charged to your credit card for each room cancellation after April 15, 2006.

The hotel provides FREE shuttle service to and from the airport. If you need wheelchair accessible transportation, please indicate on the registration form and DebRA will provide a wheelchair accessible shuttle van service at scheduled times.

REFRIGERATORS

For your convenience, we have made special arrangements to have one large refrigerator available for DebRA guests. If you would like to put medications, formula, etc. in this refrigerator, you will need to put these items in a zip lock bag and label each item and the outer bag with your name and room number. A limited number of refrigerators are available for rental at \$10/night and on a first come first served basis.

CHILD CARE

A Kid's Corner will be provided with supervised activities for children five years of age and older during the conference educational sessions on Friday and Saturday.

Children under five may come to the Kid's Corner only when accompanied by Parent/Guardian/Designated Caretaker.

MEALS

DebRA will provide attendees with a Thursday evening Reception with finger food and soft drinks and Lunch Friday and Saturday. Soft meals available upon request.

We look forward to seeing you at the PCC and please write us at pcc@debra.org with any questions or call us at 866-DEBRA76.

TOPICS TO INCLUDE

- Understanding EB
- Wound Care
- Molecular Analysis: Is there a Clinical Correlation?
- Genetic Counseling in EB
- GI Manifestations
- Nutrition and EB
- Dental Manifestations
- Hand Care and Wrapping
- Hope through Research
- Anemia and Other Non-Cutaneous Manifestations of EB
- Cancer and EB
- Insurance & Reimbursement of Products & Dressings
- Entering the School System
- Independent Living for Young Adults
- Pain Management in EB: Medication & Other Strategies
- Psychosocial Adjustment of Individuals & Families with EB

PCC Registration Form **CONFERENCE IS FREE!**

Please fill out this form and return by **MAY 15, 2006** to:

Patient Care Conference, DebRA of America, 5 West 36th Street, Suite 404, New York, New York 10001
Phone 212.868.1573 • Fax 212.868.9296 • pcc@debra.org

DebRA of America Patient Care Conference

DATE: June 1–4, 2006

HOTEL: Millennium Maxwell House

2025 MetroCenter Blvd., Nashville, Tennessee

Tel. 866-866-8086 • www.millenniumhotels.com

NAME _____

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PLEASE CHECK ONE OF THE FOLLOWING:

I cannot attend the PCC, but I would like to Support DebRA in the amount of: _____

I will be attending the conference and staying in the hotel.

Please circle one: Check Enclosed /Amex /VISA/MasterCard

Amount to be charged: \$ _____

Credit Card # _____

Expiration Date _____ Billing Zip Code _____

I will be attending the meeting but not staying in the hotel.

Please register # _____ guests to attend the Reception on Thursday, June 1, 2006 from 7PM to 8:30 PM.

SPECIAL ROOM RATE: \$95 OFFER EXPIRES APRIL 15TH

To get this special rate you must book by calling the hotel and indicating you are booking as part of the DebRA group's block of rooms.

Online reservations will not get this rate.

REGISTER NOW—SPACE IS LIMITED

A non-refundable fee of \$100 will be charged to your credit card for any room cancellation after April 15th, 2006.

LIST FRIENDS/FAMILY MEMBERS ATTENDING

NAME _____ AGE _____ SEX _____ EB TYPE _____
Kid's Room Yes No Soft Diet Yes No
 Friday Saturday

NAME _____ AGE _____ SEX _____ EB TYPE _____
Kid's Room Yes No Soft Diet Yes No
 Friday Saturday

NAME _____ AGE _____ SEX _____ EB TYPE _____
Kid's Room Yes No Soft Diet Yes No
 Friday Saturday

NAME _____ AGE _____ SEX _____ EB TYPE _____
Kid's Room Yes No Soft Diet Yes No
 Friday Saturday

OTHER SPECIAL NEEDS:

Wheel Chair? Yes No

THERE WILL BE (1) DOUBLE PANEL ON FRIDAY, JUNE 2ND AND (2) ON SATURDAY, JUNE 3RD.

Please check your choice and indicate the (#) number attending:

FRIDAY, JUNE 2 • 4:30 - 5:00PM

Hand Wrap Demo # _____

Q&A Speaker Panel # _____

SATURDAY, JUNE 3 • 1:30 - 2:15PM

Entering School System # _____

Independent Living For Young Adults # _____

SATURDAY, JUNE 3 • 4:30 - 5:00PM

Mobility and PT Demo # _____

Q&A Speaker Panel # _____

Courses without adequate pre-registration are subject to cancellation.

The following are recent articles on EB. Many of these articles are available at www.debra.org under Newsroom.

A MOST FRAGILE BOY

People Magazine
February 20, 2006

TRUJILLO OVERCAME PAIN TO LEARN, LAUGH WITH OTHERS

Rocky Mountain News
February 5, 2006

FIGHTING A LITTLE KNOWN ENEMY

New York Times
February 4, 2006

SCARRED BY RED TAPE

The Columbus Dispatch
January 22, 2006

GRANDMOTHER RAISING MONEY TO FIGHT SKIN DISEASE

Florida Today
January 4, 2006

HOLIDAY JOY FOR TWO CHILDREN WHO TOUCHED MANY HEARTS

New York Times
December 27, 2005

KRISTIN EVANS WON'T LET PAINFUL SKIN DISEASE STOP HER ATTEMPTS AT A NORMAL LIFE

NorthJersey.com
December 14, 2005

A MOTHER TRYING TO PUT SOME JOY IN WHAT REMAINS OF HER 2 CHILDREN'S LIVES

New York Times
November 12, 2005


APPEASING THE GODS WON'T MAKE THE PAIN GO AWAY

Cape Gazette
September 29, 2005

TERRIFIED TO TOUCH MY LITTLE GIRL

Wales on Sunday
September 11, 2005



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PROFILES IN EB

Susan Craighead Commissioner, Court of Appeals



Susan Craighead

Growing up in Vermont with RDEB Inversa, Susan Craighead was taught that there were very few things beyond her reach. From an early age, her physician parents encouraged her to excel at everything she attempted from learning to ski to her interest in journalism. Her years at Princeton and as a Rhodes scholar at Oxford in England resulted in an undergrad degree in Journalism and a Masters in International Relations.

According to Craighead, living abroad with EB was difficult. The student quarters at Oxford proved challenging and her desire to work as a journalist specializing in international relations would have required freelancing without health insurance along with the heat and humidity of many of her locations brought an end to that portion of her career. She settled in Kentucky and worked for a paper in Louisville covering the court system for several

Sometimes it takes being “creative to get around physical obstacles. It helps to focus on the positive...this gets you through hard times.

years before her interest turned to law. She then obtained her law degree from Harvard Law.

“I began to see that the same inequalities that intrigued me about international development were also present in the United States. I wanted to work with people who needed assistance.” says Craighead when asked about her career change. She then spent over seven years as a public defender in Seattle. Marriage in 1994 and the adoption of a son in 1999 quickly followed. In 2002, Craighead moved to the Court of Appeals where as a Commissioner, she has the opportunity to review cases involving children and decide which cases would appear before the Appeals Court.

I began to see that the same inequalities that intrigued me about international development were also present in the United States. I wanted to work with people who needed assistance.

According to Craighead, one of the most challenging results of Inversa is the daily pain. As a public defender, she relied on the constant intensity of the job to distract from the pain. She remembers the days before Mepilex was available and having to contend with her sores soaking through her clothes. In a work atmosphere where most of Craighead’s co-workers wear suits, she often appears in knit dresses and fashionable jackets on account of her disease. She enjoys adding her own individual mark to the outfits with jewelry.

She notes that her colleagues are aware of her EB. On occasion, she will complete an I.V. hydration while at her desk. A lifetime of Inversa has given Craighead a unique perspective on childhood challenges. When asked to advise youth currently balancing everyday issues with the limitations of EB, she shared her own experiences and her suggestions.

“Find a small peer group of kids not crazy about things that others care so much about,” she said, “college is so much better, hang in there until college and you’ll be in a whole different world.”

Craighead continued, “Sometimes it takes being creative to get around physical obstacles. It helps to focus on the positive...this gets you through hard times.”

Craighead is currently pursuing a judicial appointment.

Summer Camps



Olympics at Camp Wonder

For youth with serious skin conditions, 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 insure that fun, friendship, and independence are on the top of everyone's agenda.

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.

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 answers included: "No one stared at me.", "No one made fun of me.", "I could wear a bathing suit" and "I got hugs."

Every year, the American Academy of Dermatology sponsors a week of fishing, boating, swimming, water skiing, arts and crafts.

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. All camps mentioned are currently accepting applications for summer 2006.

Application forms can be downloaded at the websites listed below:

CAMP DISCOVERY

www.campdiscovery.org
Telephone: 847-240-1737
Email: support@campdiscovery.org
Crosslake, Minnesota

CAMP WONDER

www.cdsf.org
Telephone: 925-947-3825
Fax: 925-947-2158
Livermore, California

CAMP HORIZON

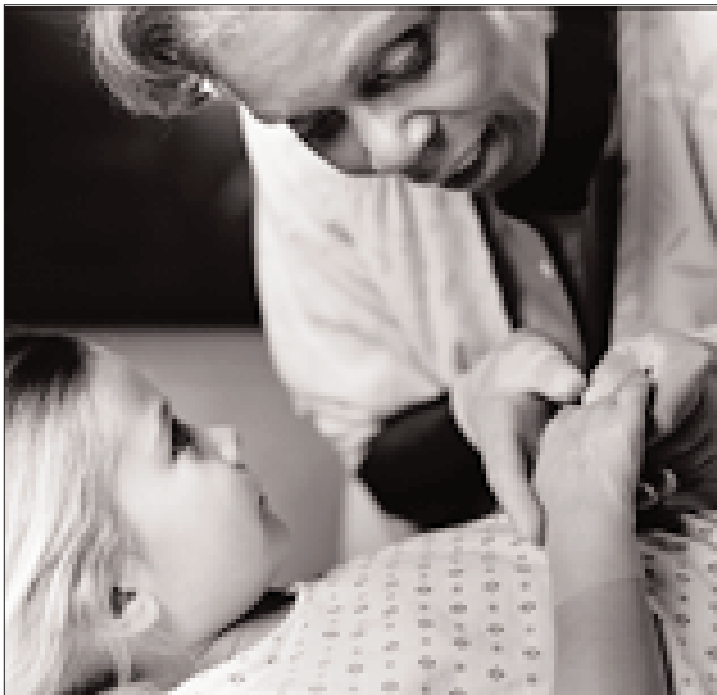
www.aad.org
August 12 – 19th, 2006-01-25
Millville, Pennsylvania

Second Annual Butterfly Benefit



Leslie Rader, event organizer and DebRA board member, and Lael Nesmith Synder pose with a handmade quilt donated for auction by the HappyHearts Quilt Guild at the 2nd Annual Butterfly Benefit Silent Auction and Luncheon held in Louisville, Kentucky in April. The event supports the New Family Advocate Program, of which Rader is the founder and Volunteer Coordinator.

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www.ebdressings.com

(800) 659 8037

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