



FRAGILE SKIN STRONG SUPPORT: MANAGING EPIDERMOLYSIS BULLOSA (EB) IN SCHOOLS


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Financial Disclosure



I have no relevant financial relationships with commercial interests.

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Objectives

- Review the importance of attending school
- Understanding Epidermolysis Bullosa (EB) and the care involved
- Identify common student health needs related to EB and potential accommodations
- Go over basic blister lancing procedure and dressing application
- Consider the patient and family experience of living with EB
- Brief overview of current Treatment Options
- Review Resources

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Why is attending school important? What does the research tell us?

- Chronic illness** can greatly impact a child's attendance and ability to participate in school activities. Due to this isolation from school, chronic illness can generate feelings of **loneliness and social avoidance**, as well as **problems with concentration and focus** (Almazroui, 2023).
- Being absent from school too often, excused or not, can put a child's **academic achievement—and future health—at risk**. A new policy statement from the American Academy of Pediatrics recommends health care providers promote good **school attendance as preventive medicine** (AAP, 2019).
- Care Coordination** interventions generated statistically significant improvement in parent perception of child's overall health and slight **drop in missed school days** (Barnard-Brak, Stevens & Carpenter, 2017). National Survey of Children with Special Health Care Needs

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EB-Part I: Understanding the basics of epidermolysis bullosa

My Butterfly Children 



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Epidermolysis bullosa is “the worst disease you’ve never heard of” ...until now

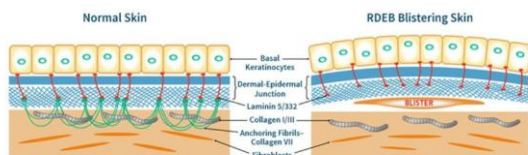
- A group of rare inherited disorders characterized by blistering of the skin and mucous membranes resulting in painful blisters and wounds after minor mechanical trauma
- estimated 1/20,000 births in the US
- Prognosis varies widely
 - Lethal to normal life expectancy
 - mild to medically complex
- EB affects all genders, racial, and ethnic groups
- No cure yet, but emerging treatments offer hope



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Epidermolysis Bullosa (EB)



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- Proteins connect the Epidermis to the Dermis
- In EB, these proteins are weak or missing, resulting in extreme skin and mucosa fragility, blistering, and scarring
- This doesn't only affect the skin - it affects many body systems

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What School Nurses Need to Know:

- Epidermolysis Bullosa (EB) is a rare, often misunderstood condition that causes acute and chronic painful blisters and wounds **both internally and externally**.
- EB is not contagious
- Symptoms range from **stealth to medically complex**
- Wounds are chronic, heal slowly, and may lead to infection, chronic pain, and limited mobility
- Students may need accommodations for G-tubes, soft diet, mobility aids, shade, and careful handling during activities
- Beyond the proteins in their skin, they are like any other students. Smart, Capable, Funny, Brave, and simply hoping to be included




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There are four major types of EB each caused by different genetic mutations.

EB Simplex(EBS)
 Junctional EB (JEB)
 Dystrophic EB (DEB)
 Kindler Syndrome



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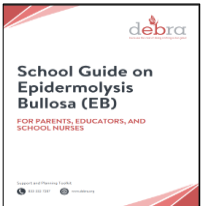
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The multisystem nature of EB requires a management team

Potential Complications	Management Considerations
Nutritional Deficiency	dietitian consults, nutritional supplements, labs, vitamins, tube feeds
Delayed Milestones	early intervention therapies, socialization, manage expectations, let them be kids
Anemia	blood transfusions, iron infusions, iron supplements, lab monitoring
Contractures/Mobility & Dexterity limitations	PT, OT, custom orthotics, mobility and dexterity aides, shoes, gloves, padding
Oral complications (microstomia, dental disease)	informed gentle dental care per practice guidelines, extra extra soft toothbrushes
Dysphagia/Esoophageal Strictures	esophageal dilatations, tube feeds, medications, soft foods, choking precautions
Risk of Cardiomyopathy	routine echocardiograms
Risk of Squamous Cell Carcinoma	skin monitoring
Psychosocial impacts of chronic illness	camps, mental health therapy, child life therapists, social work consults
School/Work Accommodations	IEP or 504, debra School Guide, letters for occupational health
Constipation	diet, medication, keeping stools soft, barrier creams, blot with alcohol free wipes,
Corneal Abrasions, Blisters, Scaring	preventative lubrication, prevent infection, contact bandages, protect from light
Pain, Itch	Pain medications, psychological support, itch management, palliative care

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**PART II
 BEST PRACTICE FOR EB CARE IN SCHOOLS**



School Guide on Epidermolysis Bullosa (EB)
 FOR PARENTS, EDUCATORS, AND SCHOOL NURSES


Table of Contents

- 1. Introduction
- 2. About Epidermolysis Bullosa
- 3. Types of EB
- 4. How to Recognize EB
- 5. How to Diagnose EB
- 6. How to Treat EB
- 7. How to Support Your Child
- 8. How to Support Your Student
- 9. How to Support Your Teacher
- 10. How to Support Your School Nurse
- 11. How to Support Your Community
- 12. How to Support Your Self
- 13. Appendix
- 14. Glossary
- 15. Acknowledgments
- 16. About DeBRA
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Steps to Success

1. Meet with the family and reach out to the medical team to plan for their arrival and build rapport
2. Assess the unique needs of your student to develop IHP
3. Facilitate communication with the CHCO EB team to obtain wound care, medication, and feeding orders
4. Educate and build a care team at school, delegate as needed
5. Decide between 504 plan vs IEP evaluation (most need IEP and many benefit from 1:1 paras)
6. Ask family if someone should educate classmates on EB and how to be a good friend
7. Ensure wound care supplies, medication, and equipment are brought in to be kept at school
8. Sign up for Epic Care Link to remain an active member of the student's care team
9. Use your resources, Ask Questions



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Services




- 1:1 nursing care
- Adaptive PE
- OT, PT, Speech
- Vision Services
- Mental Health Therapy (ERMHS)


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Skin Care Goals for School

- **Protect Fragile skin** → minimize the development of wounds/blisters from minor trauma
- **Minimize Blisters** → lance and drain blisters before they enlarge
- **Nonstick Dressings** → as needed for healing, protection, & comfort
- **Prevent Infection** → clean new wounds, clean soiled bandages,
- **Skin they can Live in** → bandages that protect and heal without restricting movement and function
- **Despite 3 newly approved therapies, there remains a high unmet need for therapies that improve disease severity and quality of life**



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Traditional Adhesive

- Sticks to top layer of skin
- Removal rips away skin cells

Silicone Products

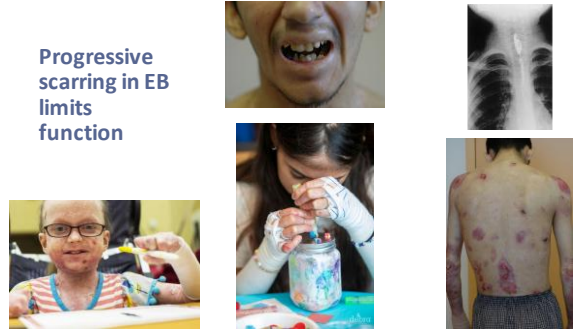
- Flows between skin pores

NEVER Ever use tape or adhesives on their skin!!!



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Progressive scarring in EB limits function



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They should avoid clothing and shoes that increase friction and pressure. Please allow for dress code exceptions.

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Desired Outcomes for School



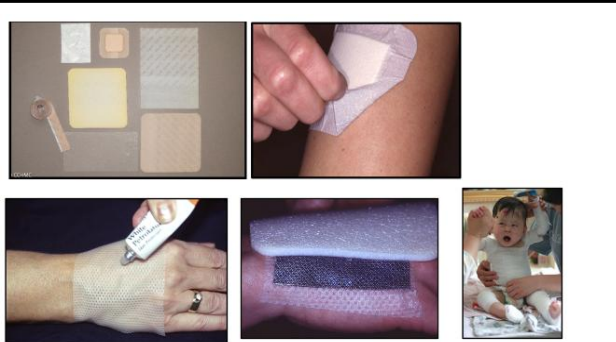
- Effective communication and care coordination between all members of the students care team
- Creation of knowledgeable school health teams who consider the unique needs of the student
- Implementation of a appropriate accommodations
- Welcoming Classroom Culture established
- Improved school attendance
- Access to Free Appropriate Public Education in the least restrictive environment
- Optimal Child Health and well being

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Draining blisters prevents blister enlargement



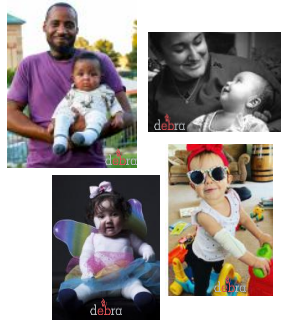
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Newborn/Toddler Considerations

- **Developmental Support**
 - Early Intervention developmental therapies
 - Encourage holding with interaction and play
 - Dress in Soft breathable fabrics that move and won't overheat
 - Bandage selection, quantity, and placement needs evolve with growth and development
 - Crawling, Walking, Toilet Training may be delayed
- **Promote bonding and support systems**
 - Support and normalize all emotions, both joy and grief
 - Build parental confidence in ability to care for their baby
 - Identify a support system for family (it takes a village)
 - Blisters Happen, manage expectations
 - Allow toddlers to "help" with bandage changes and include distraction devices



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School Age Considerations

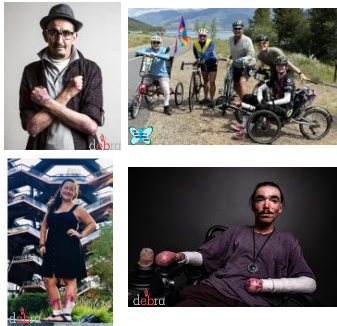
- **Attend School**
 - IEP/504
 - Encourage communication between home clinic and school
 - Debra School Guide
 - Advocate for appropriate accommodations
 - Keep wound care orders and supplies at school
- **Promote Confidence**
 - Adaptive sports/activities they enjoy
 - EB friendly Camps
 - Encourage self care, and self advocacy



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Adult Considerations

- **Developmental Support**
 - Discuss Sexual health and relationship concerns
 - Wheelchairs, handicapped parking
- **Support Autonomy**
 - Encourage working towards reasonable independence goals
 - Assist with transition to adult care services as needed
 - Discuss driving and occupational accommodations
 - OT evaluation for accessibility of environment
 - Consider homecare nursing support

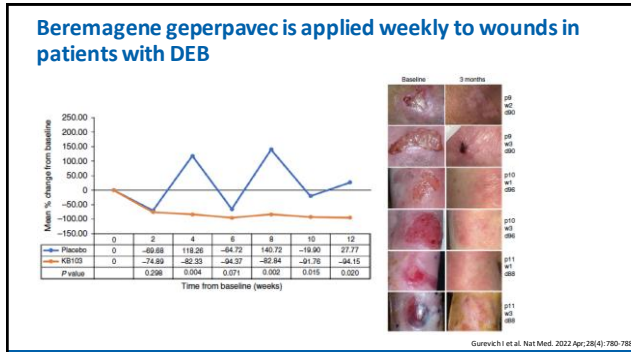


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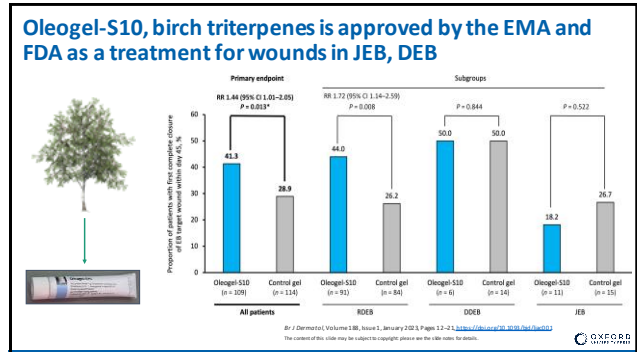
Approved Treatments



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Emerging tx options- prademagene zamikeracel trial STARTING SOON!

- First autologous cell-sheet gene therapy for RDEB wounds
- Patient's skin cells are corrected to produce **type VII collagen**, grown into sheets, and applied to chronic wounds
- Requires **5-7 day hospitalization** for immobilization & pain control
- Lifelong f/u needed for healing & safety monitoring

Biopsy
Skin biopsies are collected during your biopsy appointment and shipped to Advanced Therapeutics.

Transduction
A retroviral vector is used to integrate functional copies of the COL7A3 gene into your isolated epidermal cells, allowing them to express type VII collagen protein.

Expansion
Cells with the corrected gene are seeded and expanded into epidermal sheets.

Surgical application
Once the sheets have been grown, they are formed into a patch. A portion of the patch will be surgically applied into your selected wounds.





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Resources

- EB Nurse Care Coordination Nurses
 - Kari Price 720-777-4478
 - Carol Schober Flores 720-222-3582
- CHCO School Nurse Resource Page
- Debra School Resource Page <https://www.debra.org/other-resources/school-and-epidermolysis-bullosa>

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Questions?



- A strong school environment doesn't just teach academics; it shapes how kids see themselves, how they take risks, and how they grow into confident, capable humans.
- Thank you for advocating for your students with EB. You made a difference in the life of a child, and that can change the world.

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