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because the cost of doing nothing is too great

School Guide on Epidermolysis Bullosa (EB)

FOR PARENTS, EDUCATORS, AND SCHOOL NURSES

Support and Planning Toolkit

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Introduction

This booklet, created by debra of America, is designed to assist parents, educators, and school nurses in supporting children with Epidermolysis Bullosa (EB) as they navigate the school environment. Epidermolysis Bullosa (EB) is a rare, often misunderstood condition that causes the skin to be extremely fragile, resulting in chronic, painful blistering and wounds.

For children with EB, everyday activities - such as walking, playing, or participating in classroom tasks - can present significant challenges. These obstacles can make the school experience more difficult, but with the right support, students with EB can thrive academically, socially & emotionally.

By understanding the needs of children with EB, schools can implement strategies to manage skin care, prevent injury, and accommodate any physical limitations.

Parents, educators, and school nurses are key partners in this process. Together, they coordinate care, communicate effectively, and implement accommodations to support the child's health and success in school. The development of an IHP (Individualized Healthcare Plan), 504 Plan, and/or an IEP (Individualized Education Plan) is essential for creating a framework that supports the child's unique needs.

Integrating the student with EB can become a natural part of the school experience for all involved. This guide provides the tools and knowledge needed to foster an environment where children with EB feel understood, respected, and empowered to reach their full potential.

When schools and families work together, children with EB can thrive, growing academically, socially, and emotionally.

About EB

Epidermolysis Bullosa (EB) is a rare genetic condition that causes extremely fragile skin and, in some cases, life-threatening medical issues. There are four main types: Simplex, Junctional, Dystrophic, and Kindler. The severity of EB can range widely even within the same type of EB. In addition to limited mobility due to chronic blisters and wounds on the skin, eating may be difficult for a child with EB due to blistering of the oral mucosa and esophagus. The eyes, urethra, kidneys, airway, digestive system and other organs may also be impacted. Each person's experience with EB is unique, and their treatment needs vary accordingly.

While medical complications of EB can be complex, day-to-day treatment is usually supportive. The focus is on treating and protecting the skin, pain management, preventing infections, meeting dietary needs, and providing emotional support.

All people with EB need special wound care. Most families develop a daily routine of inspecting the skin before school and taking necessary action. In the mildest forms of EB, this will involve identifying new blisters, draining them and keeping the affected area clean. In the more severe forms, care is very time consuming, often taking hours each morning and/or evening. This daily routine is essential to the health and safety of a child with EB. Unlike normal blisters, which typically heal quickly and resolve on their own, EB blisters are much deeper, more severe and will continue to grow if not attended to. Healing can be very slow and the skin may never fully recover.

It is not difficult to imagine the stress and pain a student (and parent) may have suffered before arriving at school in the morning. Even students with very mild EB may come to school with a couple of newly drained blisters and several healing ones which, although not visible in school clothes, could be causing considerable pain and limitation of mobility. Thus, it is important to consider the impact this may have on the student's well-being throughout the day.

EB causes severe, chronic blistering and constant pain, requiring meticulous wound care.

Types of EB

Dystrophic EB (DEB)

Dominant (DDEB) Subtype
Blistering can be significant and may lead to mobility issues; often affecting high-friction areas like the hands, feet, elbows, and knees.

Recessive (RDEB) Subtype
Blistering is widespread and cumulative, leading to severe physical challenges and secondary complications, often impacting organ function. Non-healing wounds and scarring, along with changes to the hands and feet, significantly affect mobility and overall health.

EB Simplex

Blistering may be localized to the hands and/or feet, or may be generalized and affect the entire body. While blistering can be continuous, skin may heal without significant scarring. These children may often have hidden challenges. There may be few to no lesions visible but the child may face considerable pain and problems with mobility due to the potential for or the actual development of blisters.

Junctional EB (JEB)

Blistering may be widespread and slow to heal, often healing with scars or changes in pigmentation. While some children with JEB experience only skin involvement, others may face airway issues, hair loss, and complications involving the eyes, mouth, teeth, or other organs. Junctional EB (JEB) is considered less common than simplex or dystrophic EB.

Kindler

This is the rarest form of EB, and may present more internally by comparison.

First Steps

For parents of students who are entering kindergarten or new to a school, the best time to reach out is in the spring, ideally several months before the school year begins—around March to May. This allows ample time for communication, planning, and coordination with school staff.

Here's why timing matters:

Advance Notice for Planning: Reaching out in the spring ensures the school has enough time to review your child's needs, consult with medical professionals if necessary, and make appropriate accommodations (like creating an Individualized Health Care Plan or considering a 504 Plan or IEP). The process of determining eligibility for an IEP or 504 Plan can take several weeks, and it often involves assessments, meetings, and coordination between parents, nurses, and specialists.

Early Meetings: It gives parents the opportunity to meet with key staff members, such as the principal, teacher, and school nurse, before the school year starts. These meetings help to ensure everyone is informed about EB and prepared to provide proper care and support.

Securing Resources: Some schools may need time to organize and allocate resources, such as health aides, specific supplies, or training for staff.

Smooth Transition: Your child can begin the school year feeling supported and confident, with opportunities to build familiarity with the school environment, routines, and staff.

Is your child younger than grade school? There's a special section just for you!

Check out our 'Preschool & Early Intervention' section (pg. 13) for additional tips on early support and starting preschool.

What to Discuss in Early Meetings

By establishing clear communication early on, you help ensure that everyone involved in the student's educational experience feels prepared and equipped to provide the best possible care and learning environment. Points to consider:

1. **Medical Needs:** Ensure that the school has a detailed plan in place for any medical needs or emergencies. This may include wound care, any medication your child takes, and protocols for dealing with blisters that may arise or other complications related to EB.

2. **Dietary Restrictions:** May sure the school is aware of any dietary restrictions or needs special accommodations (e.g., avoiding specific food items that may cause blistering; allowing extra time to eat; choking precautions).

3. **Individualized Care and Education Plans:** Discuss creating an Individualized Healthcare Plan (IHP) and potentially an Individualized Education Plan (IEP) or 504 Plan for your child. These may include specialized support, such as physical therapy, and accommodations to help your child succeed academically. Make sure staff is aware of how EB may impact your child's energy levels, physical limitations, or ability to participate in certain activities. The school will likely set up an evaluation to assess your child's specific needs.

4. **Comfort and Familiarity:** Familiarize your child with the school environment before the first day. Schedule a visit to meet the teacher, nurse, and any other relevant staff. If possible, arrange for your child to explore the classroom, play in the schoolyard, or even practice routines like walking to the cafeteria or using the bathroom.

5. **Social and Emotional Support:** EB can affect a child's social and emotional well-being in unique ways, and it's important that the school is prepared to address these. Talk about how teachers can support your child socially, help with friendships, and educate other students, when appropriate, about EB.

6. **Open Lines of Communication:** Establish regular check-ins with the school throughout the year. It's important for parents and school staff to stay in close contact to address any concerns or issues that arise as your child settles into the school routine.

Individualized Support Plans, Explained

Once you meet with the school nurse and administrators, the process will begin to develop an IHP tailored to your child's specific needs. IHP stands for Individualized Healthcare Plan. It is a document created to address the medical needs of a student in a school setting, outlining how healthcare services will be provided during school hours, including specific care instructions, medication administration, and emergency procedures. It may also include: transportation needs, academic accommodations, activity restrictions, mobility assistance, weather considerations, hygiene needs, feeding/swallowing plan, fragile skin precautions, delegated procedures such as lancing blisters, safety issues, medication management, when to notify the parents, when to call 911, what to do during evacuations, and excused time for medical appointments. A child with EB should have an IHP in place. **See a sample IHP for a student with EB at the end of this booklet.**

These health plans are written by the school nurse in collaboration with information provided by the parents, and the child's health care providers. The IHP is reviewed and signed by the parents, the school and often the child's doctor. The IHP is updated as needed, at least annually.

An IHP can be integrated with an IEP (Individualized Education Plan) or 504 Plan if the child meets qualifications to receive one. Depending on your child's individual needs, they may or may not be eligible for an IEP or 504 Plan. IEPs and 504 Plans are more comprehensive in addressing educational needs, while an IHP is focused on managing medical care & health-related accommodations.

IEP

- Provides support and special education services to help access curriculum
- Includes measurable goals, tracks progress
- Includes accommodations
- Should attach Individualized Health Plan
- Created by a team including parents, teachers, administration, and specialists
- More oversight (federal) and protections for students
- Annual review with triannual evaluation

504 PLAN

- Eligibility based on functional impact of impairment (physical and/or mental)
- Includes accommodations; some related services may be included (e.g. nursing)
- Created by a team 'familiar with the child'
- Does not have to be a written document, but you can request a written copy
- Review period varies by state, usually annually. Reevaluations as needed

Allies

Supporting a student with EB is a team effort. This list may help guide you in understanding how various school staff members can support a student with Epidermolysis Bullosa (EB) in both medical and everyday school situations.

Primary Medical Support

- **School Nurse:** Provides care, manages medical needs, and educates, trains, coordinates and supervises the school staff who provide care to your child. The nurse will be your key partner, primary contact and champion for your child. The nurse may not be familiar with EB yet, but they should be willing and eager to learn from you, and the resources available.
- **UAP (Unlicensed Assistive Personnel):** A UAP may be delegated to tasks around safety, wound care, blister lancing, toileting needs and nutrition support, etc. The UAP may be assigned as a 1:1 only to your child, or available in the classroom to help with all of the students.
- **Private Duty Nurse:** When specialized care is needed throughout the school day that is beyond the scope of the UAP, and requires more time than the school nurse has available, a private duty nurse is often hired by the family with a doctor's referral, or hired by the school. This person would be contracted with the school to provide 1:1 care for your child during the school day.

Educational & Therapeutic Support

- **Occupational Therapist:** Helps develop fine motor skills and adapt to daily tasks such as using school supplies, in ways that minimize stress on the skin
- **Physical Therapist:** Works on mobility, strengthening, and accessing the school environment
- **Speech Therapist:** Assists with swallowing, speaking, and other oral functions
- **Psychologist:** Supports the student's emotional well-being
- **Social Worker:** Assists with social, emotional, and logistical challenges
- **Physical Education Teacher:** Tailors physical education, ensuring activities are safe & suitable
- **Principal:** Ensures resources and support are in place to meet the child's needs
- **Teacher:** Adapts classroom activities and lessons to accommodate the child's needs

Parents: You are your child's fiercest advocate, ensuring their needs are communicated and met.

Student: The most important member of the team, sharing their own needs, preferences, and feelings to help guide their care and education.

Checklist

1. Register your child for school with the district.

2. Contact the school and request a meeting with the school nurse and administration to plan for their arrival.

3. Offer education and resources on EB and the unique needs of your child and build rapport.

4. Facilitate communication from your child's doctor to the school for medication, feeding and wound care orders.

5. Work with the school nurse to develop an Individualized Healthcare Plan and review carefully.

6. Discuss the appropriateness for an IEP evaluation or 504 Plan.

7. Provide the school nurse with supplies, medication, equipment, and dressings to be kept at the school.

8. Continue to communicate effectively with your child's school and let them know of any concerns you or your child may have.

Advocate: If your child's public school team isn't working with you to ensure a safe learning environment, you may elevate concerns to district administration, such as the superintendent, special education dept., or student services office.

Step-By-Step

Accommodations

Considerations and Strategies for Supporting Students with EB.

Health and Safety

While for the most part care will take place at home, it is essential to have an EB Care Kit available at school for bandaging wounds or providing necessary treatment throughout the day. Speak with the child's parents to understand their child's ability to care for their own wounds at school, and determine the level of support needed.

Support Needs

For older children, self-care may be encouraged. However, for younger children, as well as tweens/teens with severe cases of EB, medical care and other support needs will be delegated to the school nurse and/or aide(s). This includes wound care, such as reapplying dressings or managing new blisters.

Communications

The school nurse and administrators should be eager to learn from the student's parents and physicians, and ask questions to understand how to best care for the student during school hours. Parents should provide any necessary doctor's orders or written permissions to ensure their child receives the appropriate support. These documents should be kept on file in the school nurse's office and shared with other relevant staff members.

EB Care Kit

Ensure the kit is stocked with essential supplies and store the kit in an easily accessible, clean location in the nurse's office. Keep a copy of the wound care instructions in the kit at all times. Dressing types and protocols may vary from child to child. General guidance on how to lance a blister and manage an EB wound may be found in our sample IHP at the end of this booklet.

EB Care Kit Essentials
SAMPLE

Rubber gloves – To ensure hygiene and prevent infection when handling wounds.

Sterile needles or lancets – For safely lancing blisters under medical guidance.

Ointment – To promote healing and prevent infection in open wounds.

Non-adherent dressings – To promote healing and protect wounds. May require multiple layers; products and protocols vary widely from patient to patient.

Gauze rolls – To secure the applied non-adherent dressings, and add cushioning. ****Do NOT apply rolled gauze directly to open wounds****

Retainer Net Dressing - To help keep the dressings and rolled gauze in place.

Preparing the Classroom

Inspect classroom furniture for sharp edges so that a change can be made or extra care exercised. Check for obstacles which may cause tripping and falling.

The student's desk should have enough leg room so they don't bump against bars, and be large enough for work on a laptop or tablet computer.

Avoid placing the child next to a heater, heat vent or next to a sunbaked window since heat can exacerbate blistering. Air-conditioned classrooms are important, but in cases where this is not possible, a portable AC unit may be used to keep blistering to a minimum in warm months.

A foam mat, padding, sheepskin, or other soft material may be used as a cushion for chairs.

Navigating the School

Blistering of the feet is enough to make walking painful and some children will need to limit the amount of walking they do at school or utilize a wheelchair.

Avoid crowds and crush situations by allowing the child with EB to be first or last in line. If the child has very severe EB it may be appropriate for them to arrive and leave a few minutes before or after the rest of the class.

If an elevator is available, allow the student to use it as needed.

Classwork and Assignments

Carrying a heavy school bag may be difficult for many children with EB. Consider soft padding on the shoulders, a roller bag, a second set of books at home, and/or having a student partner or aide available to carry supplies when necessary.

The use of computers or tablets for schoolwork may be helpful.

Joint contractures, pain and damage to the hands may lead to slower task completion. Consider providing the student with class notes & extended time for tests. Consider homework modifications, such as partial completion or adjusted assignments, if wound care is significant at home.

Consider unlimited lateness or absences without penalty.

Writing and Art Work

The hands of children with EB can be subject to constant stress and injury but a balance is needed between protection and participation.

Some aids, such as a foam-tube covering for pencils, may be of assistance. Easy grip scissors may also be made available, minimizing damage and helping to avoid friction on fingers and thumbs. Consult with the school's OT/PT for what may be right for the student's unique needs .

Whether clay, paint or other craft materials can be used may depend on the day to day condition of the hands. Consult parents prior to use when appropriate.

Physical Activities

Consider whether gym activities will have to be modified, or in some cases eliminated. Games involving physical contact, and exercises that include kneeling, running or jumping may be problematic. However, as a rule, the parents & student are the best source to determine the types of activities that they can participate in & when they are feeling well enough to participate.

Allow the student to set their own pace during an activity. Alternative, low-impact options can help ensure inclusion while minimizing the risk of injury.

Recess

Whether a child participates in recess may depend on their comfort level, available space, weather, and any potential risks. Participation may be possible in many cases. If participation isn't possible, create indoor activities where other children can rotate as companions.

One-on-One Support

In more severe cases, students with EB may be assigned one-on-one support to assist with daily care needs, as the amount of attention required may be significant. This should be discussed with the parents to determine the most appropriate support for the student.

Lifting the Child

Remember that friction may cause blisters and skin damage; direct pressure usually will not. A student with EB must never be lifted from underneath the arms, as this will likely result in painful blistering and this area is very difficult to bandage and heal. If lifting is required from a sitting position, ask the child to lean forward slightly and place one hand under the bottom and the other behind the back or shoulders, and lift in one movement.

Educating Other Students

Consider whether it would be appropriate to set aside time on the first day of school to explain EB to the class in a way that fosters understanding and support. It may be beneficial to include the parent. The student may or may not want to be included in the discussion. Educating classmates about why a student may wear bandages or have certain activity limitations can promote kindness, reduce fear, and encourage support.

It may also be helpful to provide educational materials to parents during a meeting or via email to foster understanding within the broader school community.

Middle School and High School: Special Considerations

Entering middle or high school presents new challenges for students with EB. Moving between classrooms, accessing lockers, and carrying heavier backpacks can worsen blistering or mobility issues. Balancing homework and extracurricular activities with daily wound care can be equally challenging. As students with EB move into middle and high school, they enter a stage where they are expected to become more independent and take on greater responsibility. While some may need additional support, it's important that any help provided is done in a way that promotes autonomy.

Moving Between Classes and Growing Independence

Arrange classrooms to be adjacent or in close proximity when possible. Dismissal from class five minutes early so the student can navigate in empty halls and avoid crowds may be helpful.

Modify the school day by scheduling PE and other electives during first or last period so the student may come late or leave early if needed without missing the core curriculum.

The physical layout of a larger school may be an obstacle. When school choices are available, parents can involve their child in the decision of which school he/she will attend.

When feasible, students can use a webcam to attend classes virtually.

As students with severe EB get older, they may unfortunately experience longer periods of illness or hospitalization. In these cases, tutors or home instructors may be beneficial during absences or on a regular basis as courses become more challenging to account for missed class time.

Living with EB is challenging physically and emotionally. A school counselor should be assigned to the student, along with a safe space to talk.

Preschool and Early Intervention: Extra Support

For children with EB who attend public preschool or receive early intervention services, the planning process for entering kindergarten may somewhat differ from other families. This section covers educational pathways and additional accommodations to consider.

Early Intervention (Before Age 3):

If your child is under three, they may qualify for Early Intervention (EI) services. These services are often provided in-home or in a daycare setting and offer therapies such as occupational, physical, speech, and/or feeding therapy. Your child's pediatrician can help determine if EI services may be beneficial, and provide contact information. You can also request an evaluation for EI services independently. Most EI services end at three years old, but your child's EI support staff will guide you through options and next steps.

Public vs. Private Preschool (Age 3+)

Some areas of the United States offer full-time (free) public preschool, while others offer part-time programs, or none at all. If you live in an area with public preschool and enroll your child, they would be eligible for an IHP and potentially an IEP starting at this time (3 years +). As the child approaches kindergarten, your child's assigned support staff can help facilitate the transition. In private (tuition-based) preschool, formal educational plans may unfortunately not be available.

Medical planning, school accommodations, and effective collaboration with staff at any school remain key in planning for your child's education. Some considerations for pre-school students may include:

- **Gentle Transitions & Routines:** Use visual schedules, songs, or soft cues to help with transitions, reducing stress and unnecessary movement that could cause friction.
- **Safe Exploration:** Ensure play areas are free of rough or textured surfaces that could cause skin damage. Use soft play equipment, carpeted areas, and non-abrasive toys.
- **Hands-Free Assistance:** Encourage the use of small backpacks with soft straps or lightweight carts for carrying belongings instead of expecting little ones to carry items themselves.
- **Mess-Free Art & Sensory Play:** Swap textured crafts to soft materials to minimize irritation.
- **Extra Time & Assistance for Self-Care:** Allow for gentle handwashing routines, assistance with clothing fasteners, and soft wipes instead of harsh paper towels or toilet paper.
- **Nap Time Comfort:** Provide extra padding on cots or foam nap mats, and allow soft breathable fabrics for bedding.

Tools & Resources

Care Management

debra of America is a reliable source for all things Epidermolysis Bullosa, providing educational resources, how-to guides, free services and practical support for families and schools. Our resources are designed to help you navigate daily care challenges with confidence and provide the support needed for proper EB care. Contact: programs@debra.org

Expert Advice

EB Nurse Educator Program

debra of America offers expert guidance and support through phone & email for both parents and school nurses who have questions about EB care. Our experienced nurse is available to discuss your child or student's unique needs, and provide valuable advice on managing the condition. Contact: nurse@debra.org

Free Care Packages

Wound Care Distribution Program

Families and school nurses can request free wound care supplies to keep at school for students with EB. This ensures that necessary medical supplies are always accessible and readily available to support the student's needs. At times, medical insurance may not cover enough for extra supplies for the school. In these cases, we're here to help. Contact: woundcare@debra.org

Visit **debra.org** to access resources.

Acknowledgements

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About debra of America

Established in 1980, debra of America's mission is to improve the lives of those impacted by Epidermolysis Bullosa (EB) — “The Worst Disease You’ve Never Heard Of.”

debra of America integrates direct-to-patient programs and services, education, advocacy, close partnership with treatment developers, and research funding to foster meaningful change for those living with EB. We envision a future where the burdens of EB are eased and eradicated, empowering those affected to lead lives free from the challenges of EB.

SAMPLE -LETTER TO SCHOOL

Basic Guidelines: Letter to Nurse and Administration

This letter requests a meeting with the school nurse and administration to discuss your child's medical needs and necessary accommodations. Briefly introduce your child's condition and mention the goal of the meeting: to review health care requirements and school adjustments. Be sure to offer flexible meeting times and follow up if needed.

Subject: Request for Meeting to Discuss [Child's Name]'s Health Care Needs

Dear [Principal's Name] and [Nurse's Name],

I hope this message finds you well. My child, [Child's Name], will be entering [Grade] at [Name of School] this year and has a condition called Epidermolysis Bullosa (EB), which makes their skin extremely fragile and prone to blisters with even minor friction. In addition to skin care, this condition may also require some accommodations in the classroom to ensure [Child's Name] has a safe and successful experience at school.

I would like to request a meeting to discuss [Child's Name]'s health care needs, the creation of an Individualized Healthcare Plan (IHP), and any necessary school accommodations or adjustments to their learning environment. We want to ensure that everyone involved—administration, teachers, and the school nurse—has the appropriate information to provide the best support for [Child's Name].

Specifically, I would like to review the medical care required at school (such as wound care and mobility needs) as well as any necessary accommodations in the classroom to ensure they can fully participate in activities and access appropriate education.

Please let me know your availability to schedule a meeting. I am happy to work around your schedules to find a time that is convenient.

Thank you for your attention to this important matter. I look forward to working together to support [Child's Name] throughout the school year.

Best regards,
[Your Full Name]
[Your Phone Number]
[Your Email Address]

Tips for Personalizing Your Child’s School Materials

Parents may find it helpful to bring personalized materials—such as a one-page overview about their child or a visual guide for staff—when meeting with the school to discuss accommodations. While not required, these extra resources can help educators and classmates better understand your child’s unique needs, strengths, and personality.

✅ **Use Photos** – Picture(s) of your child smiling, playing, or participating in their favorite activity can help staff connect with them as a person beyond their medical needs.

✅ **Tell Their Story –** A short, warm introduction (like “Meet Sam!”) can help others learn about your child and their unique personality.

✅ **Highlight Strengths** – What does your child love? What are they great at? Sharing their interests and talents makes inclusion easier.

✅ **Keep Key Info Simple** – Make sure critical instructions are clear, easy to find, and in everyday language. Bullet points, icons, or color-coding can help school staff quickly reference important info.

✅ **Encourage Questions** – Reassure staff that questions (at any time) are welcome and appreciated.

✅ **Update as Needed** – As your child’s needs evolve, refresh materials to ensure they remain accurate and helpful.

✅ **Make It Your Own!** – There’s no single “right way.” Whether it’s a simple one-pager or a mini-booklet, choose what best fits your child’s needs and personality.

You got this!

SAMPLE - LETTER TO CLASS PARENTS

BASIC GUIDELINES: Letter to Parents
Write a letter if your child is new to kindergarten, first grade, or the school. Focus on your child's abilities and when they may need assistance, not their medical history. Keep it comfortable for your child—only share what they're okay with. Get teacher approval before distributing and include your contact info for questions.

Subject: Introducing Jane in Ms. Teacher's Class and Epidermolysis Bullosa

Dear Kindergarten Parents,

We are excited about the upcoming school year! Our daughter, Jane Smith, will be in Ms. Teacher's class with your child. Jane has a rare genetic disorder called Epidermolysis Bullosa (EB), which causes her skin to be extremely fragile and prone to blistering and tearing with even minor friction. While EB affects her skin and some internal organs, Jane is not contagious and poses no risk to others. However, she does need special medical care to heal wounds, prevent infections, and avoid new injuries.

We'll be explaining a bit about EB on the first day of class, and we're happy to answer any questions the students may have. While EB limits some of Jane's physical abilities, she enjoys the same activities as other children her age. She may be a little shy at first, but she loves making new friends!

Jane wears bandages at all times to protect her skin. Simple things like being accidentally pushed or lifting heavy books can cause injury, so being mindful and offering a hand when needed can make a big difference. Jane will ask for help when necessary.

If you have any questions about EB or about having Jane in class, please feel free to contact me via email or phone. You can also visit debra.org for more information about the condition.

Thank you, and I look forward to getting to know all of you!

Best,
Judy Smith

SAMPLE - INDIVIDUALIZED HEALTHCARE PLAN

Our sample IHP outlines the key categories typically incuded in an elementary school Individualized Healthcare Plan (IHP) Form, with considerations to help customize each section to your child's unique needs with EB. *****Reminder, there is a wide range of symptoms and severity within EB. This document is for educational purposes and not an exhaustive list. Only some of these suggestions may apply to your child.*****

BASIC INFO	*This information may include student's name, date of birth, grade, school, district, school nurse's name, parent/guardian contact information and physician details, emergency contacts, and preferred hospital.*
CURRENT HEALTH DIAGNOSIS	*Briefly describe the student's primary health condition (e.g., Epidermolysis Bullosa) and any other relevant diagnoses that may impact their school care.* SAMPLE: Epidermolysis Bullosa, a genetic disorder that causes chronic blisters from heat, friction, rubbing or everyday minor trauma. Blistering and widespread wounds may occur in these areas: skin (generalized or localized to ________________________), eyes, mouth, throat, GI tract, genitourinary system, etc.
PERTINENT HEALTH HISTORY	*Provide important health details related to the student's condition, including treatments, previous complications, or any ongoing health concerns that need to be considered during school care.* SAMPLE: [Student's Name] has Epidermolysis Bullosa (EB), a genetic disorder that causes skin blisters from heat, friction, rubbing or minor trauma. Blisters may appear at various healing stages and can become infected. Treatment includes special baths and dressing changes at home. Other concerns: delayed physical development, physical therapy.
ALLERGIES	*List known food, environmental, or other allergies, symptoms, and reaction management.*
CURRENT MEDICATION	*List all medications the child is currently taking, including over-the-counter medications (ie., Ibuprofen) and supplements, preferred bandages, topical treatments or ointments. Distinguish between home and school.*

RESTRICTIONS	*Provide any physical activity or dietary restrictions related to the child's condition, including limitations on certain movements, activities, or foods that may cause discomfort or harm due to EB.* • **Dietary**: Avoid hard, crunchy, spicy, or sharp foods (e.g., pretzels, granola, nuts, hot sauce, citrus). • **Physical**: ○ NO TAPE OR BANDAIDS. ○ Avoid picking up underarms; use scooping motion to lift if unable to walk or to evacuate during emergencies. ○ Do not allow child to pull on skin or scratch; redirect with a cool pack, emollient, vibration tool, or may encourage patting (vs. scratching) ○ Avoid hand sanitizer, do risk of stinging.
HEALTH ISSUE: SKIN BREAKDOWN	*Highlight specific symptoms or triggers, and proper management.* Goal: Prevent skin breakdown and manage new blisters as they arise. Friction, rubbing, or heat on the skin may cause blistering. Action: Lower the chance of getting a new blister and manage skin breakdown effectively as it arises. Manage blistering: Check for visible blisters (dime-sized or larger) at 12:00 PM daily, and/or when student reports new blister. • If new blisters form, manage ASAP to avoid large wounds. • Encourage student to report new blisters or abrasions. • Parents will provide supplies for wound care (dressings, etc.). **Step-by-Step Procedure (by delegated staff only):** • Wash hands, assemble supplies, put on gloves. • Explain procedure to student. • Gently push the fluid to one corner of the blister. • Prick 1 or 2 holes on the side of the blister (not the top). The hole should be big enough to drain the fluid. • Gently drain the fluid using gauze or a q-tip to push the fluid toward the slit in the blister. Another piece of gauze can be used to soak up the liquid from the blister. Liquid may be clear, cloudy, or blood. • Keep roof of blister intact (*do not remove*). • May use lancet on more than one blister, if there are no signs of infection indicated by white or cloudy drainage. • Apply designated ointment > then apply a **non-adherent** clean bandage(s) > then apply rolled gauze and retainer net dressing to secure bandage as needed. **NO ADHESIVE TAPE OR REGULAR BANDAIDS.**

HEALTH ISSUE: SKIN BREAKDOWN (Continued)	If blister is broken or breaks at school on it's own: • Apply ointment directly to new clean bandage (to prevent rubbing on skin) > place bandage on area > cover with retainer sleeve. If a wound is weeping: • Wet gauze with water and carefully pat weeping area. Do not leave gauze on skin or it may stick to skin and cause further blistering > apply ointment directly to bandage of weeping area. Cover with non-stick bandage and rolled gauze/retainer dressing (as needed to secure bandage). • If unable to cover due to location of wound and unable to stop weeping, notify parent. For new cuts or scrapes: • Clean with saline, not soap or water. • Cover with non-adherent clean dressing and note in journal to communicate to parents **To reduce new blisters**, encourage repositioning often as sitting in one position all day puts pressure on one area of the body. Allow student to sit on a bean bag, pillow, cushion, or ball if needed to help prevent breakdown on buttock area.
HEALTH ISSUE: Injury Prevention & Management	Goal: Prevent injury, reduce risk of infection, protect wounds and minimize pain. Action: • No rough play or pushing. • Place first or last in line to avoid being bumped. • Avoid hot weather; ensure air-conditioning when possible. • Scoop student up from underneath; do not pull or grasp. • Provide a chair cushion and avoid sitting on hard surfaces. • Allow a water bottle at desk for hydration and time for protein snacks to support skin health. • NO BANDAIDS OR TAPE. Non-stick dressings only. • Only use special dressings provided by parents. • No hand sanitizer. Falls/Injuries: • Monitor student and discourage pulling on dead skin. Report any bleeding or infection to parents and school nurse. • Careful observation of skin should occur with any injury and diligent skin care as outlined above to reduce the chance of infection.

HEALTH ISSUE: Mobility	Goal: Ensure safe mobility and environment. Action: • Student may need assistance with balance and class transitions. Use wheelchair if necessary. • **Avoid** picking up under arms. • Provide shade and minimize sun exposure during drills or field trips.
HEALTH ISSUE: Swallowing Difficulty, Mouth or Throat Blistering	Goal: Safe eating and drinking. Action: • Provide soft foods and allow adequate time to eat. • Monitor for pain or difficulty with swallowing, notify parents with any changes. • Allow extra time to eat.
HEALTH ISSUE: PAIN	Goal: Manage pain. Action: • Observe for signs of pain (crying, mood changes). • Notify parents to determine if medication is needed. • Encourage non pharmacological skills to manage pain in addition to any medications that may be needed.
DISASTER EVACUATION PLAN	Follow the school site plan. Student may need a wheelchair or to be carried if they are unable to evacuate in a timely way. If lifting is required from a sitting position, ask the child to lean forward slightly and place one hand under the bottom and the other behind the back or shoulders and lift in one movement (do not pick up from under arms). The student should be able to wait in the shade and out of the direct sun light.
CALL PARENT OR GUARDIAN IF:	• Child's pain level increases. • Child has a physical injury resulting from accident.

Note: Work with the school team to ensure accommodations are included that are right for your child.

Supporting Students with Epidermolysis Bullosa (EB)

What is EB?

Epidermolysis Bullosa (EB) is a rare genetic condition that causes extremely fragile skin, leading to painful, chronic blisters and wounds from minor friction (ie., rubbing) or injury. It can also affect internal organs. There is no cure.

What Educators Need to Know

✅ **EB is NOT contagious** – It's a genetic condition present from birth.

✅ **EB does not affect intelligence** – Students with EB are just as capable as their peers.

✅ **EB is painful** – Wounds heal slowly and can lead to serious infections.

✅ **EB can limit mobility and function** – due to blistering, scarring, and joint contractures, a wheelchair or other mobility aid may be required

✅ Some students with EB may have **dietary restrictions or require a G-tube for nutrition** due to difficulty eating or mouth blisters. Soft foods may tolerated only.

How to Support a Student with EB

✓ It's okay to touch – Just be gentle to avoid causing blisters.

✓ Be mindful of their skin – Avoid rough contact, pulling, or grabbing.

✓ Encourage inclusion – They want to play and learn like any other child.

✓ Be flexible – They may need extra time for activities or accommodations.

For more information, visit debra.org/schoolguide

Ignite Potential