



EPIDERMOLYSIS BULLOSA CENTER CHILD QUESTIONNAIRE

GENERAL INFORMATION:

CHILD'S NAME: _____ Nickname: _____

Age: _____ Birth Date: ____/____/____ Sex: Male Female

Weight: _____ Height: _____

Ethnicity: White Hispanic Asian Black Middle Eastern Other: _____

Primary language: English Spanish Other: _____

Mother/Guardian's Name: _____ Date of Birth: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Home #: _____ Work #: _____ Cell #: _____

Home E-mail: _____ Work E-mail: _____

Do you work outside the home? Yes No

Occupation: _____ Place of employment: _____

Primary language: English Spanish Other: _____

Mother's highest level of education? Elementary School High School College
 Graduate Degree Professional Schooling

Father/Guardian's Name: _____ Date of Birth: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Home #: _____ Work #: _____ Cell #: _____

Home E-mail: _____ Work E-mail: _____

Do you work outside the home? Yes No

Occupation: _____ Place of employment: _____

Primary language: English Spanish Other: _____

Father's highest level of education? Elementary School High School College
 Graduate Degree Professional Schooling

Name of Person Completing this Form: _____

Relationship to patient: mother father relative caregiver self other: _____

Signature: _____ Today's Date: ____/____/____

FAMILY/SOCIAL:

Please tell us about your home/family:

Child lives with: Biological Parents Single Parent Mother Single Parent Father
 Foster Parent Adoptive Parents Parent and Step-Parent
 Two Separate Households Other: _____

Please list the names and birth dates of **all family members, including the person(s)** being seen in EB Center, living in your household (such as: mother, father, siblings, grandparents).

Please also indicate if you have adult children no longer living in your household.

Name/Relationship to Child	Sex	Date of Birth	Special Health Needs or Medical Problems

Do you have any cultural or religious beliefs that we need to be aware of in order to provide the best care for your family? _____

Does either biological parent have any common relatives? Yes No
 If yes, please explain (such as: parents are cousins): _____

Do any other family members have Epidermolysis Bullosa? Yes No
 If yes, please list: _____

Family Member/Name	Type of EB	Relationship to Patient

SOCIAL SERVICES:

Do you receive services from any of the following?

WIC SSI BCMH Food Stamps Waiver
 Other State Programs: _____

PROVIDERS:

Please list below all medical persons involved in your child's care. By "v"ing the boxes below, you are giving the EB Center permission to send the caregiver a copy of the report from your child's visit. A copy will be sent to you also.

DOCTORS	
Name: _____	<input type="checkbox"/> Primary Physician
Specialty: _____	<input type="checkbox"/> Referring Physician
Address: _____ City: _____	<input type="checkbox"/> Subspecialties:
State: _____ Zip Code: _____ Phone: _____	<input type="checkbox"/> Derm <input type="checkbox"/> Plastic Surgery
Primary Focus of Treatment: _____	<input type="checkbox"/> Surgery <input type="checkbox"/> _____
<input type="checkbox"/> Check here to have information sent to this provider.	

DOCTORS	
Name: _____	<input type="checkbox"/> Primary Physician
Specialty: _____	<input type="checkbox"/> Referring Physician
Address: _____ City: _____	<input type="checkbox"/> Subspecialties:
State: _____ Zip Code: _____ Phone: _____	<input type="checkbox"/> Derm <input type="checkbox"/> Plastic Surgery
Primary Focus of Treatment: _____	<input type="checkbox"/> Surgery <input type="checkbox"/> _____
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State: _____ Zip Code: _____ Phone: _____	<input type="checkbox"/> Derm <input type="checkbox"/> Plastic Surgery
Primary Focus of Treatment: _____	<input type="checkbox"/> Surgery <input type="checkbox"/> _____
<input type="checkbox"/> Check here to have information sent to this provider.	

OCCUPATIONAL THERAPY

Name: _____	<input type="checkbox"/> Primary Physician
Specialty: _____	<input type="checkbox"/> Referring Physician
Address: _____ City: _____	<input type="checkbox"/> Subspecialties:
State: _____ Zip Code: _____ Phone: _____	<input type="checkbox"/> Derm <input type="checkbox"/> Plastic Surgery
Primary Focus of Treatment: _____	<input type="checkbox"/> Surgery <input type="checkbox"/> _____
<input type="checkbox"/> Check here to have information sent to this provider.	

PHYSICAL THERAPY

Name: _____	<input type="checkbox"/> Primary Physician
Specialty: _____	<input type="checkbox"/> Referring Physician
Address: _____ City: _____	<input type="checkbox"/> Subspecialties:
State: _____ Zip Code: _____ Phone: _____	<input type="checkbox"/> Derm <input type="checkbox"/> Plastic Surgery
Primary Focus of Treatment: _____	<input type="checkbox"/> Surgery <input type="checkbox"/> _____
<input type="checkbox"/> Check here to have information sent to this provider.	

HOME HEALTH AGENCY

Name: _____	<input type="checkbox"/> Primary Physician
Specialty: _____	<input type="checkbox"/> Referring Physician
Address: _____ City: _____	<input type="checkbox"/> Subspecialties:
State: _____ Zip Code: _____ Phone: _____	<input type="checkbox"/> Derm <input type="checkbox"/> Plastic Surgery
Primary Focus of Treatment: _____	<input type="checkbox"/> Surgery <input type="checkbox"/> _____
<input type="checkbox"/> Check here to have information sent to this provider.	

ATTACH COPY OF ALL INSURANCE CARDS – BOTH FRONT AND BACK SIDES.

Medical Insurance Information

Primary
Medical Ins. Co.: _____ Subscriber Name: _____
Policy Subscriber #: _____ Phone #: _____
Address: _____ City: _____ CO-PAY: _____
State: _____ Zip Code: _____ Phone: _____ Contact: _____

Secondary
Medical Ins. Co.: _____ Subscriber Name: _____
Policy Subscriber #: _____ Phone #: _____
Address: _____ City: _____ CO-PAY: _____
State: _____ Zip Code: _____ Phone: _____ Contact: _____

Dental Insurance Information

Primary
Dental Ins. Co.: _____ Subscriber Name: _____
Policy Subscriber #: _____ Phone #: _____
Address: _____ City: _____ CO-PAY: _____
State: _____ Zip Code: _____ Phone: _____ Contact: _____

Secondary
Dental Ins. Co.: _____ Subscriber Name: _____
Policy Subscriber #: _____ Phone #: _____
Address: _____ City: _____ CO-PAY: _____
State: _____ Zip Code: _____ Phone: _____ Contact: _____

BIRTH HISTORY:

My child is adopted: No Foster child: history known
 Yes: history known Foster child: history unknown
 Yes: history unknown

My child was born: Full term
 Born early? How many weeks early? _____
or (how many weeks gestation was the pregnancy) _____

During pregnancy, did the mother have?
 Hypertension
 Gestational diabetes
 Preeclampsia
 Other complications: _____

Delivery was: Vaginal Caesarian Section

Medications taken during pregnancy other than multi-vitamins (include any illegal drugs; such as, marijuana): _____

During pregnancy mother: smoked cigarettes did not smoke cigarettes
 did not drink alcohol drank 1-2 times per week

Maternal age at time of delivery: _____ years

Previous pregnancies (not including this child): Yes No
If yes, how many? _____

Any miscarriages? Yes No
If yes, how many? _____

DEVELOPMENTAL HISTORY:

My child stayed in the special nursery after birth: Yes No

My child was discharged from the hospital at _____ days or _____ weeks or _____ months of age.

My child sat at _____ months.

My child walked at _____ months.

Does (did) your child have any delays in their development? Yes No

If yes, which areas are/were delayed? Please indicate if delay is: current / past

<input type="checkbox"/> Ability to understand/learn	<input type="checkbox"/>	/	<input type="checkbox"/>
<input type="checkbox"/> Motor	<input type="checkbox"/>	/	<input type="checkbox"/>
<input type="checkbox"/> Speech	<input type="checkbox"/>	/	<input type="checkbox"/>
<input type="checkbox"/> Social	<input type="checkbox"/>	/	<input type="checkbox"/>

Do you have any current deficits? Yes No

If yes, please list: _____

Does your child receive any home nursing care? Yes No
If yes, how many hours per day and how many days per week? _____

Do you or have you ever received any respite care? Yes No
If yes, please explain: _____

SCHOOL PROGRAM:

Is your child in a school program? Yes No
If yes, what grade: Preschool
 Elementary _____ grade
 Jr. High / Middle School _____ grade
 High School _____ grade

Name of school: _____

Contact person: _____ Phone #: _____

May the EB Center communicate with your child's school? Yes* No
*By checking yes, you are giving permission for release of information to the school.

Does your child require any special assistance in school? Yes No
Example: use of a wheelchair, etc.

Is there a nurse or aide at school with your child? Yes No
If yes, please describe: _____

What types of activities does the nurse or aide assist with? _____

Is your child's level of education age-appropriate (grade level)? Yes No
If no, describe: _____

Does your child have an IEP? Yes No

THERAPY PROGRAM:

Does your child attend any programs related to health or developmental needs?
Home/School
 Occupational Therapy Attends: _____ Days / Week / Reason: _____
 Physical Therapy Attends: _____ Days / Week / Reason: _____

Speech Therapy Attends: _____ Days / Week / Reason: _____
 Early Intervention Attends: _____ Days / Week / Reason: _____

ADAPTIVE DEVICES:

Does your child use any adaptive/supportive devices (i.e., toothbrush, adaptor, toileting)?

If yes, please list: _____

Does your child use hand splints? Yes No

If so, who prescribed/made the splints? When do they wear and how long?

ACTIVITY LEVEL:

What is your child's physical activity level? _____

What is their favorite activity? _____

Do they participate in any organized activities? Yes No

If yes, please describe: _____

Do they participate in gym/music/art at school? Yes No

If yes, please describe: _____

Does your child use a computer or other technological devices? _____

How is your child doing socially? _____

Other comments: _____

EB OVERVIEW:

My child had **missing skin** at birth? Yes No

Location: _____

Any treatment: (i.e. grafting, etc.)? _____

My child's **blistering first appeared:**

- At birth
- Within 2 weeks of birth
- Within one month of birth
- At _____ years of age

My child's blistering is located on the:

- | | | | |
|---|-------------------------------|--------------------------------|--|
| <input type="checkbox"/> Head and/or Neck | <input type="checkbox"/> Legs | <input type="checkbox"/> Arms | <input type="checkbox"/> Hands |
| <input type="checkbox"/> Face | <input type="checkbox"/> Feet | <input type="checkbox"/> Trunk | <input type="checkbox"/> Perineum/Buttocks |

At what age was this diagnosis made? _____

How was this diagnosis made?

- Electron microscopy
- Genetic testing
- Immunofluorescent BM mapping
- Immunofluorescent mapping - specific
- Skin biopsy
- Other: _____

What facility was used to make this diagnosis? _____

PLEASE OBTAIN ANY BIOPSY / TEST RESULTS AND HAVE THEM SENT TO THE EB CENTER

NUTRITION:

Does your child have any food allergies? Yes No
 If yes, please list allergies and reactions: _____

Has your child had trouble growing/gaining weight? Yes No

How would you describe your child's eating habits and weight gain overall? _____

Do you have any current concerns about your child's growth or eating habits? Yes No
 If yes, please explain: _____

Do they require soft foods, pureed foods, etc.? Yes No
 If yes, please describe what types of food you eat: _____

If your child is on formula, please list the name, amount taken and frequency of feedings. _____

Does your child have problems chewing or swallowing now or in the past? Yes No
If yes, please explain: _____

Does your child finish the amount of food provided? Yes No

How long does it take your child to finish a meal? _____

Has your child seen a dietician or nutritionist before? Yes No
If yes, please list their name and where they were seen. Include any suggestions made.

Does your child have any problems with constipation? Yes No

Do they strain with bowel movements? Yes No

How often do they have a bowel movement? _____

Does your child take any dietary supplements or calorie enhancers? Yes No
If yes, please list product, amount, frequency and if taken orally or by G-tube. _____

Does your child take a vitamin, mineral or herbal supplement? Yes* No
*If yes, please list in the medication section of this form.

Does your child have a G-tube? Yes No
If so, please provide the following information:

Night Feed or Bolus Feed	Pump or Gravity	Product Name	Rate Per Hour	Amount of Time Feed Given Over	Total Amount Received

Please fill out attached 3 day Food Intake Record

MEDICAL HISTORY:

Has your child ever been hospitalized or treated at Cincinnati Children’s Hospital Medical Center, Ohio? Yes No

Has your child ever been hospitalized or treated at any hospital? Yes No

Please list below **ALL** hospital visits at any facility where your child has been treated?

Date of Visit	Length of Stay	Name of Hospital	Location: City and State / or Country	Inpatient/ Outpatient/ Emergency Room	Reason for Visit

HOSPITAL VISITS/TEST/PROCEDURES:

Has your child had any of these procedures to evaluate or treat his/her Epidermolysis Bullosa?

Test / Procedure:	Date(s):	Name of Hospital / Facility Location: City, State or Country	Results (if known):
Ba Swallow			
Ba Swallow			
Esophageal Dilatation			
Esophageal Dilatation			
Hand Surgery			
MRI/CT Scan			
Skin Biopsy			
X-Ray			
Other:			
Other:			
Other:			

MEDICAL PROBLEMS:

My child has experienced problems with:

<i>Problems with:</i>	<i>Never</i>	<i>Past</i>	<i>Current</i>	<i>Unknown</i>
Abdominal Pain				
ADHD				
Apnea				
Bleeding				
Bronchitis				
Chest Pain				
Easy Bruising				
Fatigue				
Frequent Fevers				
Headaches				
Hearing Problems				
Heart Murmur				
Heart Problems				
Hypertension/ High Blood Pressure				
Isolation Needed				

<i>Problems with:</i>	<i>Never</i>	<i>Past</i>	<i>Current</i>	<i>Unknown</i>
Joint/Muscle Pain				
Kidney Disease				
Low Iron				
Pain				
Paleness				
Poor Growth				
Skin Rashes				
Poor Growth				
Poor Weight Gain				
Rapid Breathing				
Recurrent Pneumonia				
Respiratory Problems				
Seizures				
Skin Rashes				
Visual Problems				
List Others				

PAIN:

Does your child experience any discomfort with his/her Epidermolysis Bullosa? Yes No
If yes, describe: _____

Does your child ever take pain medication: Yes* No
*If yes, please list in the medication section of this form.

Is itching a problem for your child? Yes No

If yes, please comment here and list any medications taken for itching in the medication section of the form: _____

BEHAVIORAL CONCERNS:

Does your child or adolescent experience any of the following:

- Difficulty coping with pain (crying, flinching, guarding, worrying, reduced activity level) Yes No
- Periods of tearfulness, depression, or sadness, more than another child of the same age Yes No
- Lots of worries and fears than seem more extreme than children his/her age Yes No
- Frequent tantrums or anger outbursts Yes No
- Too much energy or hyperactivity Yes No
- Significant problems with arguing or refusing to comply with parent/teacher requests Yes No
- Behavior problems around medical routines, such as dressing changes or wound care Yes No
- Problems with excessive use of substances such as tobacco, alcohol, or drugs Yes No

SKIN CARE ROUTINE/DRESSING PRODUCTS:

SKIN CARE ROUTINE/DRESSING CHANGE/SUPPLIES	HAVE USED IN PAST	ARE USING NOW
TOPICAL ANTIBIOTICS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
BY MOUTH/GT ANTIBIOTICS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
EMOLLIENTS/MOISTURIZERS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
ANTIHISTAMINES FOR ITCHING: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
DRESSINGS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
SOAPS/CLEANSERS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
WRAPS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
NEEDLES/LANCETS: List: _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
OTHER: List: _____ _____	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>

PLEASE DESCRIBE IN DETAIL, STEP BY STEP, YOUR CHILD'S DAILY SKIN CARE AND BATHING ROUTINE (SUCH AS: BATH, SHOWER, SPONGE BATH). Include how often, if dressings are removed before the bath or during.

Is your child cooperative for their bath? Yes No

If no, please describe: _____

Do they require pain medication for the bath or dressing change? Yes No

If yes, please explain: _____

Is there a skin care product that you have tried that did NOT work well for you? Yes No

If yes, please describe: _____

COMMUNICATION/LEARNING DIFFICULTY(S):

(Please check all that apply.) My child or I.....

	<i>My Child</i>	<i>I</i>		<i>My Child</i>	<i>I</i>
Have difficulty speaking			Use a special communication device		
Have difficulty hearing			Use TTY/TTD		
Use hearing aids			Learn best with video		
Have difficulty seeing			Learn best with verbal instructions		
Wear glasses/contacts			Learn best with demonstration		
Primary language is not English			Learn best with written instructions		
Need an interpreter			Other:		

INTERPRETER:

If your primary language is not English would you like/need an interpreter available during your appointment with the Epidermolysis Bullosa Center Team? Yes No

If yes, what language would be needed for translation? _____

(Members of the team must be able to ask you / your child questions, as well as understand you. If in doubt, please ask for interpreter.)

CURRENT CONCERNS:

How can the Epidermolysis Bullosa Center team best help you?

Please list or describe all concerns that you would like us to address at this visit?

Include any questions that you have:

Include any information about your child's past medical history that would be helpful.

Please tell us about your child:

What is their personality like?

How are they doing currently?

Is there anything else about your child that you would like to share?

In EB Center, your child will typically be seen by the following departments (services):

- Dermatology •Gastroenterology •Nursing •Nutrition •Occupational Therapy
- Pain Management •Physical Therapy •Psychology •Social Services •Surgery

Some specialists cannot see your child while in the EB Center due to equipment they require to examine your child. Indicate below if you need an appointment with any of these additional services and we will work to schedule them on the day of, before, or after your EB Center visit.

- Dental Hand Surgeon Orthopaedics (foot problems)
- Otolaryngology (ENT) Ophthalmology Other: _____

*Additionally, after reviewing the Intake Packet information, the EB Team may request you have other appointments or testing scheduled. You will be contacted if this is necessary to discuss any other evaluation recommendations.

Please attach a recent photograph of your child.