Lucile Packard Children's Hospital AT STANFORD

STANFORD SCHOOL OF MEDICINE
Stanford University Medical Center

Epidermolysis Bullosa Clinic

PATIENT INFORMATION

Patient NAME: ______________________________ Nickname: ______________________

LPCH Medical Record Number: ____

Birth Date: ___/___/___ Gender: ☐ Male ☐ Female

Ethnicity:____

EB Type: ☐ Simplex ☐ Junctional ☐ Dystrophic ☐ Unknown
EB Subtype (if known):____

Diagnosis was made by: ☐ Clinical evaluation ☐ Skin Biopsy ☐ Electron Microscopy
☐ DNA analysis ☐ Immunofluorescence
At what medical center was the diagnosis made?______________________________________

CONTACT INFORMATION

Mother/Legal Guardian:_____________________________ Occupation: __________________

Father/Legal Guardian: _____________________________ Occupation: __________________

Address:____

City: ______________________________________ State: _____ Zip Code: __________

Phone Numbers: (H) _________________ (W) _________________ (C)_________________

Email(s): ____

Preferred language: _____________________ Do you require an interpreter for the visits? ____

HEALTH INSURANCE

Primary Insurance Company: _____________________ Phone Number: ________________

Subscriber Name: ______________________________ Policy Subscriber #: _____________

Secondary Insurance Company: ___________________ Phone Number: ________________

Subscriber Name: ______________________________ Policy Subscriber #: _____________

Does your child have CCS?_________

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PHYSICIAN CONTACT INFORMATION

Your Child's Doctors:

Primary Care Doctor: ____ Phone: ______________

Address: ____ Fax: ________________

City:________________________ State: _____ Zip Code: ________

☐ Check here to have information sent to this doctor.

Doctor: _______________________________________ Specialty: ________________________

Address: ____ Phone: ______________

City:________________________ State: _____ Zip Code: ________ Fax: ________________

☐ Check here to have information sent to this doctor.

Doctor: _______________________________________ Specialty: ________________________

Address: ____ Phone: ______________

City:________________________ State: _____ Zip Code: ________ Fax: ________________

☐ Check here to have information sent to this doctor.

PHARMACY INFORMATION

Medical Supply Company:____

Phone number: ____________________________ Fax number: ______________________

Pharmacy:____

Phone number: ____________________________ Fax number: ______________________

THERAPY CONTACTS

Home health care: ______________________ Ph #: ____________ Days/week attended:___

Occupational Therapy:___________________ Ph #: ____________ Days/week attended:___

Physical Therapy: ______________________ Ph #: ____________ Days/week attended:___

Speech Therapy: _______________________ Ph #: ____________ Days/week attended: ___

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CLINICAL INFORMATION

BIRTH HISTORY:

My child was: ☐ Full-term ☐ Born early. How early? _____

My child was adopted: ☐ No ☐ Yes- history unknown ☐ Yes - history known

My child developed blisters at age: ________________________

My child was diagnosed with EB at age: ___________________

SURGICAL HISTORY: My child has undergone the following procedures:

☐ Intubation When?____________ For how long?______

☐ GT-placement When?____________

☐ Nissen When?____________

☐ Esophageal dilatation When?____________ How many times?____

☐ Hand surgery When?____________ How many times?____

☐ Blood transfusions When?____________ How many times?____

PAST MEDICAL HISTORY:

Please list any other medical conditions your child has**:**

My child has had the following studies done: (please check all that apply and attach results)

	Test/Procedure	Date (s)	Medical Facility	Results (if known)
	Skin biopsy			
	Barium swallow			
	MRI/CT scan			
	Anemia studies			
	Chest x-ray			
	Echocardiogram, EKG			
	Bone density evaluation			
	DNA analysis			

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FAMILY HISTORY: Do any other family members have Epidermolysis Bullosa? If so, please list:

Name of family member with EB	Type of EB	Relationship to patient

FAMILY GOALS

What can we do to help your child? ____

____

Please check the issues that you would like help with and detail your concerns.

- ☐ Further diagnostic studies: ____
- ☐ Wound care advice: ____
- ☐ Nutrition advice/evaluation: ____
- ☐ Pain management: ____
- ☐ Hand surgery: ____
- ☐ Esophageal dilatation: ____
- ☐ Constipation: ____
- ☐ Anemia: ____
- ☐ Depression: ____
- ☐ Physical or occupational therapy: _______________________________________
- ☐ Dental care: ____
- ☐ Eye evaluation: ____
- ☐ Genetic counseling: ____
- ☐ Indicate other pediatric specialists you may want to visit: _______________________
- ☐ Other: ____

MEDICATIONS

Please include all prescriptions, herbal, and over-the-counter (non-prescription) medications.

Name of medication	Dose of medication	How many times per day?

ALLERGIES

Please list all medication allergies and describe the allergic reaction:

WOUND CARE

My child has the following skin involvement. (Check all that applies)

Body Site	Blisters	Erosions	Drainage	Scarring
Scalp				
Face				
Neck				
Back				
Chest				
Abdomen				
Bottom/genitals				
Arms				
Hands				
Legs				
Feet				

1. Are there specific areas of the skin you are concerned about now? Please describe.

2. How do you clean your child's skin?

3. What type of moisturizing creams or ointments are you applying to your child's skin?

4. Are you applying antibiotic creams to your child's skin?
   What is the name of the antibiotic cream?

   How often do you apply this and to what areas of the body?

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WOUND CARE DRESSING SUPPLIES

What types of bandages do you use? Please list.

Name of bandage	Size of bandage	How many pieces per month?

1. How often are you changing the bandages?

2. Are you happy with your current wound care dressings?

3. Have there been bandages that you have tried and found it to NOT work as well for your child's skin? Please describe.

Epidermolysis Bullosa Clinic
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