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

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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

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Name of Person Completing this Form: _____

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

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

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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, <u>including the person(s)</u>** 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: _____

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FAMILY GOALS:

What are the reasons for your visit (check all that apply)?

Referred by another doctor: ☐ Yes ☐No Seeking a second opinion: ☐ Yes ☐No

Seeking medical Treatment: ☐ Yes ☐No ☐ Other: _____

How can the Epidermolysis Bullosa Center team best help?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

REFERRAL INFORMATION:

Name of Referring Physician: _____

Phone #: _____ Fax #: _____

Address: _____

E-mail: _____

Does your child have a diagnosis of a specific type of E.B.?

☐ Simplex ☐ Dominant Dystrophic ☐ Recessive Dystrophic

☐ Junctional ☐ Other: _____

Status of diagnosis:

☐ Confirmed ☐ Possible ☐ Probable

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PROVIDERS:

Please list below all medical persons involved in your child's care. By "√"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: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment:_____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

DOCTORS

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment:_____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

DOCTORS

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment:_____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

DOCTORS

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment:_____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

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DOCTORS

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment: _____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

OCCUPATIONAL THERAPY

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment: _____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

PHYSICAL THERAPY

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment: _____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

HOME HEALTH AGENCY

Name: _____

Specialty: _____

Address: _____ City: _____

State: _____ Zip Code: _____ Phone: _____

Primary Focus of Treatment: _____

❑ Check here to have information sent to this provider.

❑ Primary Physician	
❑ Referring Physician	
❑ Subspecialties:	
❑ Derm	❑ Plastic Surgery
❑ Surgery	❑ _____

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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: _____

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MEDICATIONS:

List all medications your child takes. ***Include all prescriptions, current pain medications, over the counter medications and all vitamins and herbal substances that your child takes by mouth, G-tube, injection or IV. Include all topical medications (ones used on the skin). Please fill in each column completely and accurately.***

Medication/Herbal Supplements	*Dose / Amount*	*Concentration*	*Frequency*	*Route*	*What is this medicine used for?*

ALLERGIES:

Does your child have any allergies? ☐ Yes ☐ No

List by Name and "√" reaction.

ALLERGIES: ☐ Unable to Obtain Drug/Contrast ☐ Yes ☐ No Food ☐ Yes ☐ No Product/Latex ☐ Yes ☐ No	Anaphylaxis	RESP Distress	Swelling	Hives	GI Symptoms	Rash	OTHER/COMMENTS

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BIRTH HISTORY:

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

	current		past
☐ Ability to understand/learn	☐	/	☐
☐ Motor	☐	/	☐
☐ Speech	☐	/	☐
☐ Social	☐	/	☐

Do you have any current deficits? ☐ Yes ☐ No
If yes, please list: _____

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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: _____

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☐ 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:

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☐ Head and/or Neck ☐ Legs ☐ Arms ☐ Hands
☐ Face ☐ Feet ☐ Trunk ☐ 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. _____

_____

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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

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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:			

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OTHER MEDICAL CONCERNS:

Does your child have other medical concerns? _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

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MEDICAL PROBLEMS:

My child has experienced problems with:

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

Problems with:	*Never*	*Past*	*Current*	*Unknown*
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				

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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

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OTHER CONCERNS:

Any other concerns that you would like to discuss with a psychologist?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Overall my child's general health has been: ☐ Excellent ☐ Good ☐ Fair ☐ Poor

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SKIN CARE ROUTINE/DRESSING PRODUCTS:

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

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PLEASE DESCRIBE IN DETAIL, STEP BY STEP, YOURCHILDS 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……..

	My Child	***I***		***My Child***	***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:		

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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**?**

_____

_____

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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.

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