

Supplement I

Demographics

1. Name of patient
2. Who is filling out the survey?
 - a. Patient?
 - b. Caregiver?
 - i. Name of caregiver.
 - ii. How many years have you been the caregiver for this patient?
 - iii. How many hours/day do you care for the patient?
 - iv. How many days/week do you care for the patient?
 - v. What do you help the patient with on a daily basis? (Check all that apply)
 - Feeding
 - Bathing
 - Dressing
 - Toileting
 - Grooming
 - Walking
 - Giving medicines
 - Transportation
 - c. Patient and Caregiver together?
3. Age of patient
4. Sex (M/F)?
5. Diagnosis
 - a. Dystrophic epidermolysis bullosa
 - b. Junctional epidermolysis bullosa
 - c. Epidermolysis bullosa simplex
 - d. Kindler's syndrome
 - e. Unknown
6. Subtype of EB (using skip-logic to question 5)
 - a. Dystrophic epidermolysis bullosa
 - i. Recessive dystrophic epidermolysis bullosa
 - ii. Dominant dystrophic epidermolysis bullosa
 - b. Junctional epidermolysis bullosa
 - iii. Herlitz junctional epidermolysis bullosa
 - iv. Non-Herlitz junctional epidermolysis bullosa
 - c. Epidermolysis bullosa simplex
 - v. Epidermolysis bullosa simplex Dowling-Meara
 - vi. Epidermolysis bullosa simplex Weber-Cockayne
 - d. Unknown
 - e. Other (Free text)

7. How would you describe the overall severity of your EB?
- Mild
 - Moderate
 - Severe

Bathing Products

8. On average, how many days per week do you usually bathe?
- 1 day/week
 - 2 days/week
 - 3 days/week
 - 4 days/week
 - 5 days/week
 - 6 days/week
 - 7 days/week

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
9. How does bathing affect your itch?					

10. Do you use pool salts in your bath? (Y/N)

11. (Skip logic, if yes to question 10)

	Rarely	Sometimes	Often	Always
How often do you use pool salts?				

12. (Skip logic, if yes to question 10):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
How do pool salts affect your itch?					

13. Do you use bleach in your bath? (Y/N)

14. (Skip logic, if yes to question 13):

	Rarely	Sometimes	Often	Always
How often do you use bleach in your bath?				

15. (Skip logic, if yes to question 13):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
How does bleach affect your itch?					

Moisturizers

16. Do you use **moisturizers** (including Aquaphor) on your skin? (Y/N)

17. (Skip logic, if yes to question 16): When do you use moisturizers? (Check all that apply):

- a. After bathing
- b. During other times of the day

18. (Skip logic, if yes to question 16): What type of **moisturizers** do you use? (Check all that apply)

- c. Creams (Examples like: Eucerin, Nivea, Cetaphil, CeraVe)
- d. Lotions (Examples like: Curel, Aveeno)
- e. Greasy ointments (Examples like: Aquaphor, Vaseline, petroleum jelly, paraffin)
- f. Oils (Examples like: sunflower oil, grape seed oil, olive oil, emu oil)
- g. Other: (free response)

19. (Skip logic, based on response to question 18):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
How do (answer response in question 18) affect your itch?					

20. (Skip logic, based on response to question 18):

	Rarely	Sometimes	Often	Always
How often do you use (based on response to question 18)?				

Topical Products

21. Have you tried **over-the-counter topical products** to help with the itch? (Y/N)

22. (Skip logic, if yes to question 21): Which of the following **over-the-counter topical products** have you tried for your itch? (Check all that apply)

- a. Diphenhydramine (Benadryl)
- b. Benzocaine (Lanacane cream)
- c. Hydrocortisone 0.5% or 1%
- d. Pramoxine (PraxeGel)
- e. Topical capsaicin (Capsagel)
- f. Calamine lotion
- g. Menthol/camphor (Sarna)
- h. Menthol/pramoxine (Gold Bond)
- i. Vaporub (Vicks)
- j. Other: Free text

23. (Skip logic, based on response to question 22):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did (answer response in question 22) have on your itch?					

24. (Skip logic, based on response to question 22):

	Rarely	Sometimes	Often	Always
How often did you use (answer response in question 22) to control your itch?				

25. Are you still currently using (answer response in 22) to control your itch? (Y/N)

26. (Skip logic, if no to question 25): Why did you stop using (answer response in 22)? (Free response)

27. Have you tried **prescription topical products** to help with your itch? (Y/N)

28. (Skip logic, if yes to question 27): Which of the following **prescription topical products** have you tried for your itch? (Check all that apply)

- a. Doxepin 5% cream (Zonalon)
- b. Topical prescription corticosteroids (Examples like: 2% hydrocortisone, triamcinolone, betamethasone, clobetasol, fluocinonide, mometasone)
- c. Topical pimecrolimus (Elidel)
- d. Topical tacrolimus (Protopic)
- e. Silvadene cream 1%
- f. Medihoney
- g. Other: Free text

29. (Skip logic, based on response to question 28):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did (answer response in question 28) have on your itch?					

30. (Skip logic, based on response to question 28):

	Rarely	Sometimes	Often	Always
How often did you use (answer response in question 28) to control your itch?				

31. Are you still currently using (answer response in 28) to control your itch? (Y/N)

32. (Skip logic, if no to question 31): Why did you stop using (answer response in question 28)? (Free response)

Oral Medications

33. Have you tried **oral medications** to help with your itch? (Y/N)

34. (Skip logic, if yes to question 33): Which of the following **oral medications** have you taken for your **itch**? (check box)

- a. Aprepitant (Emend)
- b. Amitriptyline (Elavil)
- c. Cetirizine (Zyrtec)
- d. Chlorpheniramine (Chlortrimeton)
- e. Cholestyramine (Questran)
- f. Cyproheptadine (Periactin)
- g. Desloratadine (Clarinex)
- h. Diazepam (Valium)
- i. Diphenhydramine (Benadryl)
- j. Doxepin (Adapin, Sinequan)
- k. Fexofenadine (Allegra)
- l. Gabapentin (Neurontin)
- m. Loratidine (Claritin)
- n. Hydroxyzine (Atarax)
- o. Mirtazapine (Remeron)
- p. Ondansetron (Zofran)
- q. Oral corticosteroids (Examples like: prednisone, hydrocortisone)
- r. SSRIs (Examples like: Fluoxetine (Prozac), Paroxetine (Paxil), Sertaline (Zoloft), etc.)
- s. Other: (Free text)

35. (Skip logic, based on response to question 34):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did (answer response in question 34) have on your itch?					

36. (Skip logic, based on response to question 34):

	Rarely	Sometimes	Often	Always
How often did you take (answer response in question 34) to control your itch?				

37. Are you still currently taking (based on response to question 34) for your itch? (Y/N)

38. (Skip logic, if no to question 37): Why did you stop taking (answer response in question 34)? (Free response)

39. Have you used **oral medications** for **pain**? (Y/N)

40. (Skip logic, if yes to question 39): Which of the following **oral medications** have you tried to control your **pain**? (Check all that apply)

- a. NSAIDS (Examples like: ibuprofen, Advil)
- b. Acetaminophen (Tylenol)
- c. Opioids (Examples like: hydrocodone, morphine, fentanyl, oxycodone)
- d. Ketamine
- e. Gabapentin (Neurontin)
- f. Other (free text)

41. (Skip logic, based on response to question 40):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did (answer response in question 40) have on your itch?					

42. Have you ever had to use **sleeping medications** because of your **itch**? (Y/N)

43. (Skip logic, if yes to question 42): Which **sleeping medications** have you used?
- Mirtazepine (Remeron)
 - Zolpidem (Ambien)
 - Eszopiclone (Lunesta)
 - Ramelteon (Rozerem)
 - Zaleplon (Sonata)
 - Doxepin (Silenor)
 - Benzodiazepines (Examples like: Halcion, Restoril, Xanax, Ativan, etc)
 - Trazodone (Desyrel)
 - Over the counter sleep aids (Examples like: Tylenol PM, Nyquil)

44. (Skip logic, based on response to question 43):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did (answer response in question 43) have on your itch?					

45. (Skip logic, based on response to question 43):

	Rarely	Sometimes	Often	Always
How often did you use (answer response to question 43)?				

46. Have you tried **nasal spray Butorphanol (Stadol)** for your itch? (Y/N)

47. (Skip logic, if yes to question 46):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did Butorphanol (Stadol) have on your itch?					

48. (Skip logic, if yes to question 46):

	Rarely	Sometimes	Often	Always
How often did you take Butorphanol (Stadol) to control your itch?				

49. Are you currently using Butorphanol (Stadol) to control your itch? (Y/N)

50. (Skip logic, if no to question 49): Why did you stop using Butorphanol? (Free response)

Dressings

51. Do you wear bandages? (Y/N)

52. (Skip logic, if yes to question 51): What types of **bandages** do you wear? (Check all that apply)

- a. Silicone dressings (Examples like: Mepitel)
- b. Silver dressings (Examples like: Restore Silver, Mepilex Ag, Acticoat, Silverlon)
- c. Xeroform
- d. Petrolatum dressings (Examples like: Vaseline gauze, Restore contact layer, Aquaphor gauze)
- e. Non-adherent gauze (Examples like Telfa, Release)
- f. Hydrogels (Examples like: Restore Hydrogel, DermaGauze, Vigilon)
- g. Foam dressings (Examples like: Mepilex, Mepilex Transfer, Mepilex Lite, Mepilex Border, Polymem, Restore foam, Allevyn)
- h. Hydrofiber wound (3% bismuth tribromophenate/petrolatum) dressing (Examples like: Aquacel, Restore Calcium Alginate)
- i. Gauze (Examples like: Kerlix)
- j. Retention gauze (Examples like: Tubifast, Surilast, Coban, Coflex)
- k. Adhesive bandages
- l. Other: (Free text)

53. (Skip logic, based on response to question 52):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect does/do (answer response in question 52) have on your itch?					

54. (Skip logic, based on response to question 52):

	Rarely	Sometimes	Often	Always
On average, how often do you wear (answer response in question 52)?				

Complementary/Alternative Methods

55. Have you tried **complementary or alternative methods** to control your itch (hypnosis, meditation, behavioral therapy, support groups, etc)? (Y/N)

56. (Skip logic, if yes to question 55): Which of the following have you tried? (Check all that apply)

- a. Hypnosis
- b. Meditation
- c. Biofeedback
- d. Cognitive behavioral therapy
- e. Mindfulness
- f. Aromatherapy
- g. Yoga
- h. Support groups
- i. Acupuncture
- j. Other: (free text)

57. (Skip logic, based on response to question 56):

	Relieves the itch a lot	Relieves the itch a little	No change	Increases the itch a little	Increases the itch a lot
What effect did (answer response in question 56) have on your itch?					

58. (Skip logic, based on response to question 56):

	Rarely	Sometimes	Often	Always
How often did you use (answer response to question 56) to control your itch?				

59. Are you still using (based on response to question 56) to control your itch? (Y/N)

60. (Skip logic, if no to question 59): Why did you stop using (based on response to question 56)? (Free response)

Other

61. Are there other conditions that we did not mention that make your itch worse? (Free response)

62. Are there other conditions that we did not mention that make your itch better? (Free response)

63. Have you stopped using any medications that we did not already mention because they made the itch worse? (Y/N)

64. (Skip logic, if yes to question 63): Which medications that we did not mention made the itch worse? (Free response)

65. Are there any other treatments that you use to alleviate the itch that we have not mentioned? (Free response)

66. Do you have any other comments? (Free response)