1. What was the date of diagnosis of X-Linked Lymphoproliferative Syndrome?

2. Was the XLP diagnosis confirmed by genetic testing?
   1. yes
   2. no
   3. unknown

3. Specify if the recipient displayed evidence of the following disorders at diagnosis of XLP:
   1. yes
   2. no
   3. unknown
   
   - Aplastic anemia
   - Hemophagocytic disorder (fulminant infectious mononucleosis)
   - Hypogammaglobulinemia
   - Lymphoproliferative disorder

4. Was X-linked inheritance demonstrated in the recipient’s maternal family members?
   1. yes
   2. no
   3. unknown

5. History of Infection at Diagnosis

   9. Were pre-HSCT Epstein-Barr virus (EBV) serology titers determined?
     1. yes
     2. no
     3. unknown

   10. Date tested: 
       Month Day Year

       Specify titers tested:
       11. 1 positive 2 negative 3 not tested Viral capsid IgG titer
       12. 1 positive 2 negative 3 not tested Viral capsid IgM titer
       13. 1 positive 2 negative 3 not tested Early antigen titer
       14. 1 positive 2 negative 3 not tested EBNA titer
15. Was hemophagocytic disorder (fulminant infectious mononucleosis) present at any time?
1. yes 2. no

16. Specify site(s) of hemophagocytosis:
- 1. yes 2. no Bone marrow
- 1. yes 2. no Cerebrospinal fluid (CSF)
- 1. yes 2. no Liver
- 1. yes 2. no Lymph nodes
- 1. yes 2. no Spleen
- 1. yes 2. no Other site

22. Specify other site: ______________________

17. Specify other site: ______________________

18. Specify other site: ______________________

19. Specify other site: ______________________

20. Specify other site: ______________________

21. Specify other site: ______________________

23. Specify other site: ______________________

24. Specify other site: ______________________

25. Specify other site: ______________________

26. Specify other site: ______________________

27. Specify radiation field: ______________________

28. Specify total dose: _______ cGy

29. Specify radiation field: ______________________

30. Specify total dose: _______ cGy

31. Specify total dose: _______ cGy

32. Specify other drug: ______________________

33. Specify other drug: ______________________

34. Specify: ______________________

35. Was the hemophagocytic syndrome triggered by an acute EBV infection?
1. yes 2. no 3. unknown

36. Was immunologic function tested at diagnosis?
1. yes 2. no 3. unknown

37. Specify findings at diagnosis:
- Natural killer cell function (specific cytosis of NK-sensitive target cell)
- Absent (≤ 10% normal)
- Decreased (11–50% normal)
- Normal
- Increased
- Not available

38. IgG prior to receiving IVIG
1. yes 2. no

39. IgM prior to receiving IVIG
1. yes 2. no

40. IgA prior to receiving IVIG
1. yes 2. no

41. IgE prior to receiving IVIG
1. yes 2. no

42. Is a copy of the immunologic report or other documentation attached?
1. yes 2. no

43. Did the recipient receive IVIG within two months prior to the above immunoglobulin measurement?
1. yes 2. no

44. Is a copy of the immunologic report or other documentation attached?
1. yes 2. no
44. Did the recipient develop lymphoma prior to the preparative regimen?
   1 [ ] yes  2 [ ] no

Specify treatment(s) given for lymphoma:
45. 1 [ ] yes  2 [ ] no Chemotherapy
46. 1 [ ] yes  2 [ ] no Radiation

47. What was the response of the lymphoma to treatment prior to the preparative regimen?
   1 [ ] complete response
   2 [ ] partial response
   3 [ ] progressive disease
   4 [ ] not applicable / no treatment given

48. Was the lymphoma associated with an EBV infection?
   1 [ ] yes
   2 [ ] no
   3 [ ] unknown

49. Is a copy of the pathology report or other documentation attached?
   1 [ ] yes
   2 [ ] no

50. Did the recipient develop hypogammaglobulinemia prior to the preparative regimen?
   1 [ ] yes  2 [ ] no

Specify treatment(s) given for hypogammaglobulinemia:
51. 1 [ ] yes  2 [ ] no IVIG
52. 1 [ ] yes  2 [ ] no Other treatment

53. Specify: ____________________________

54. Did the recipient develop aplastic anemia prior to the preparative regimen?
   1 [ ] yes  2 [ ] no

Specify treatment(s) given for aplastic anemia:
55. 1 [ ] yes  2 [ ] no Growth factor
56. 1 [ ] yes  2 [ ] no Immunosuppression
57. 1 [ ] yes  2 [ ] no Other treatment

58. Specify: ____________________________

59. Did the recipient have magnetic resonance imaging (MRI) of the brain immediately prior to the preparative regimen?
   1 [ ] yes
   2 [ ] no
   3 [ ] unknown

60. Is a copy of the MRI report attached?
   1 [ ] yes
   2 [ ] no

61. Signed: ____________________________

Person completing form

Please print name: ____________________________

Phone: (__________) ____________________________

Fax: (__________) ____________________________

E-mail address: ____________________________