

FOLLOW-UP INSERT XXVIII
Juvenile Idiopathic Arthritis (JIA)
(Previously JRA or JCA)

FOR REGISTRY USE ONLY:
 I.D. - -
 Date received:

TEAM: IUBMID:
(Institutional Unique Blood or Marrow Transplant Identification Number)

Registry (circle one): **IBMTR** ABMTR EBMT

Date of transplant for which this form is being completed:
 Month Day Year

Date of report:
 Month Day Year

Follow-up Information*

* Report data for date of last contact or immediately prior to death

1. Date of evaluation for this report:
 Month Day Year

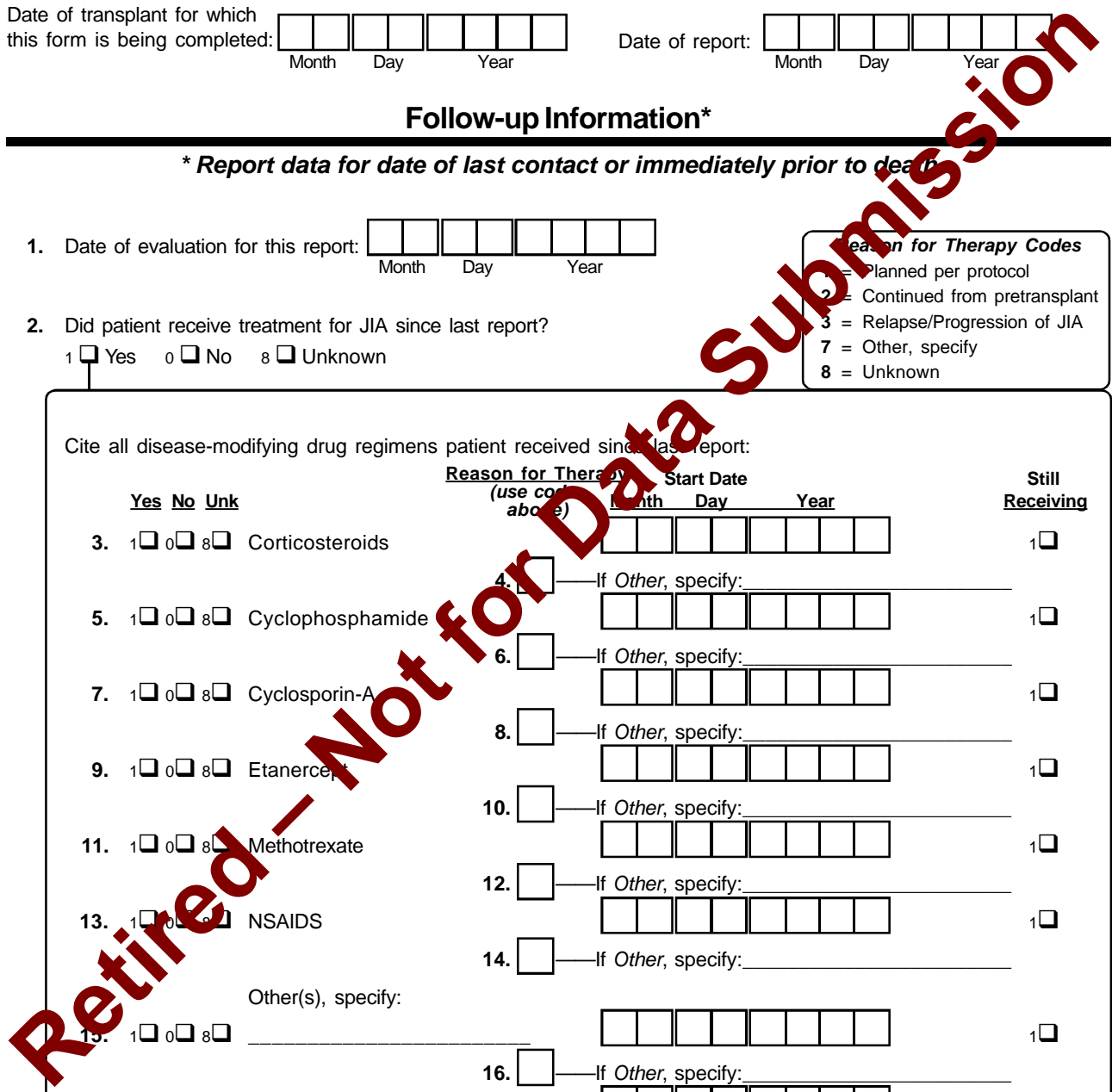
2. Did patient receive treatment for JIA since last report?

1 Yes 0 No 8 Unknown

Reason for Therapy Codes
 1 = Planned per protocol
 2 = Continued from pretransplant
 3 = Relapse/Progression of JIA
 7 = Other, specify
 8 = Unknown

Cite all disease-modifying drug regimens patient received since last report:

	Yes	No	Unk	Reason for Therapy (use codes above)	Start Date Month Day Year	Still Receiving
3. Corticosteroids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
4. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
5. Cyclophosphamide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
6. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
7. Cyclosporin-A	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
8. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
9. Etanercept	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
10. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
11. Methotrexate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
12. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
13. NSAIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
14. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
15. Other(s), specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
16. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
17. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
18. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
19. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
20. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>
21. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="text"/>	<input type="checkbox"/>
22. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Other, specify: _____	<input type="text"/>	<input type="checkbox"/>



TEAM:

IUBMID:

Disease Status at Current Evaluation

- 23. Number of painful/tender joints at current evaluation (Eular/ACR 28 joint count, Appendix A): Unknown
- 24. Number of swollen/effused joints at current evaluation (Eular/ACR 28 joint count, Appendix A): Unknown

Appendix A
(Fuchs and Pincus, Arthritis Rheum, 1994, 37:470)
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees

- 25. Pediatric EPM-Range of motion final score (0-3) Unknown
(Len C, et al, J Rheum, 1999, 26(4):909-913):

- 26. Was morning stiffness present?
1 Yes
0 No
8 Unknown
- 27. Specify duration: hours minutes

- 28. Specify patient's height at current evaluation: Specify unit: 1 cm 2 in

- 29. Specify patient's weight at current evaluation: Specify unit: 1 kg 2 lb

- 30. Was the erythrocyte sedimentation rate elevated?
1 Yes
0 No
8 Unknown

- 31. Was C-reactive protein elevated?
1 Yes
0 No
8 Unknown

Indicate results of the following immune function studies at current evaluation:

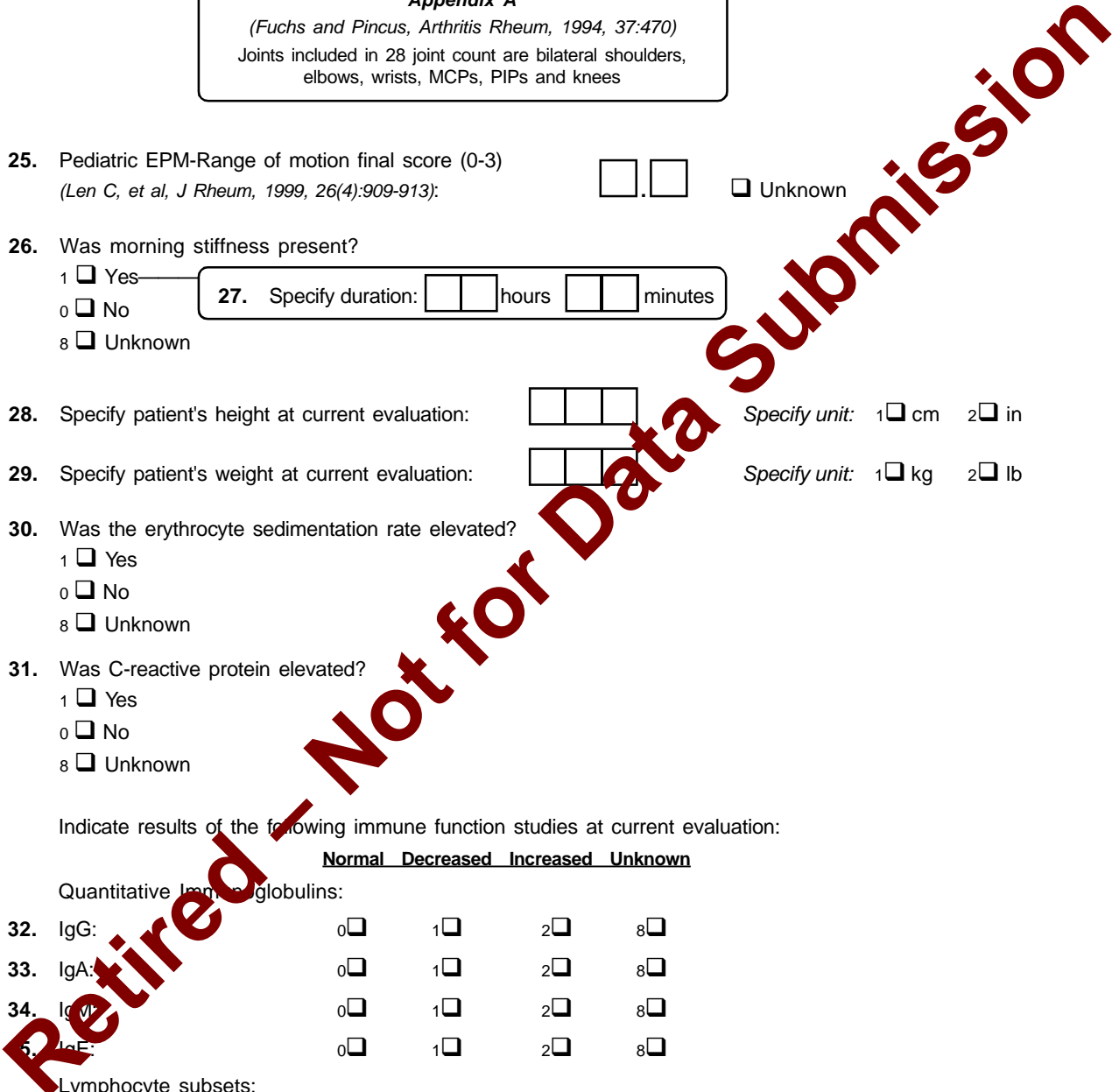
Normal Decreased Increased Unknown

Quantitative Immune Globulins:

- 32. IgG: 0 1 2 8
- 33. IgA: 0 1 2 8
- 34. IgM: 0 1 2 8
- 35. IgE: 0 1 2 8

Lymphocyte subsets:

- 36. CD3: 0 1 2 8
- 37. CD4: 0 1 2 8
- 38. CD8: 0 1 2 8
- 39. CD19: 0 1 2 8
- 40. CD16: 0 1 2 8



TEAM:

IUBMID:

Radiographic Evaluation at Current Evaluation

41. Were radiographic bone erosions present at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

42. Was advanced skeletal age of affected joints noted radiographically at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

43. Did patient have osteoporosis at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

44. Were osteoporotic fractures present?

- 1 Yes
- 0 No
- 8 Unknown

Patient Assessment at Current Evaluation

45. Did the patient complete a Childhood Health Assessment Questionnaire (CHAQ) at current evaluation (see Appendix B)?

- 1 Yes
- 0 No
- 8 Unknown

Specify range of possible scores for the CHAQ pain sub-scale:

46. Patient's score: .

47. Worst possible score: .

48. Best possible score: .

Specify range of possible scores for the CHAQ disability sub-scale:

49. Patient's score: .

50. Worst possible score: .

51. Best possible score: .

Specify range of possible scores for the CHAQ severity sub-scale:

52. Patient's score: .

53. Worst possible score: .

54. Best possible score: .

Appendix B
(Singh G, Athreya B, Fries J, Goldsmith DP. Measurement of health status in children with rheumatoid arthritis. "Arthritis Rheum" 1994, 37:1761-69)

55. Did the physician complete a Global Assessment of the patient's disease state at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

Specify range of possible scores for Physician Rated Global Assessment:

56. Patient's score: .

57. Worst possible score: .

58. Best possible score: .

Retired - Not for Data Submission

TEAM:

IUBMID:

59. Specify percent clinical improvement at time of best response compared with evaluation just prior to conditioning according to criteria of the American College of Rheumatology (ACR) (see Appendix C):

1 Disease is worse—Date of progression:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

2 No improvement

3 20% improvement (ACR20)—Date of maximal improvement:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

4 50% improvement (ACR50)—Date of maximal improvement:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

5 70% improvement (ACR70)—Date of maximal improvement:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

6 Remission—Date of remission:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

Appendix C
(Giannini, EH, et al., "Arthritis Rheum" 1997, Jul;40(7):1202-9)
Requires 20%* or more improvement in 3 of the following with no more than 1 of the remaining variables worsened by more than 30%*:

- Physician global assessment of disease activity
- Patient's global assessment of overall well-being
- Functional ability
- Number of joints with active arthritis
- Number of joints with limited range of motion
- Erythrocyte sedimentation rate (ESR)

Substitute 50% or 70%, for 50% and 70% improvement levels, respectively.

60. Specify percent clinical improvement at current evaluation compared with evaluation just prior to conditioning according to criteria of the American College of Rheumatology (ACR) (see Appendix C):

1 Disease is worse—Date of progression, if different from Q.59:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

2 No improvement

3 20% improvement (ACR20)

4 50% improvement (ACR50)

5 70% improvement (ACR70)

6 Remission

Retired - Not for Data Submission