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JUVENILE ARTHRITIS MULTIDIMENSIONAL ASSESSMENT REPORT (JAMAR)

2 **English translation** **Parent's version**

3 **Patient's name and surname (or initials):**_____ **Date:**_____

4 Parent filling in the questionnaire: Mother ☐ Father ☐

5 The aim of this questionnaire is to gather information on the current state of your child's illness.
6 Your answers will help us improve our clinical evaluation.
7 Please read the questions below carefully and choose the answers that best apply to your child.
8 If you have doubts or need any clarification, please ask for our help.
9 There are no right or wrong answers.
10 We simply ask that you answer exactly as you feel.

11 **1. Evaluation of functional ability**
12 Please choose the answer that best describes your child's ability to carry out the activities listed below *during the **past four weeks"***.
13 Please indicate only the difficulties or limitations **caused by the illness**.
14 If your child has difficulty carrying out any of these activities because he/she is too young and **not because of the illness**, indicate "**Not applicable**".

15		With NO difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do	Not applicable
16	1. Run on flat ground for at least 10 metres	☐	☐	☐	☐	☐
17	2. Walk up 5 steps	☐	☐	☐	☐	☐
18	3. Jump forward	☐	☐	☐	☐	☐
19	4. Squat	☐	☐	☐	☐	☐
20	5. Bend down to pick up an object off the floor	☐	☐	☐	☐	☐
21	6. Carry out activities that require the use of his/her fingers	☐	☐	☐	☐	☐
22	7. Open and close his/her fists	☐	☐	☐	☐	☐
23	8. Squeeze an object with his/her hands	☐	☐	☐	☐	☐
24	9. Open a door by lowering the handle	☐	☐	☐	☐	☐
25	10. Open and close a tap or open a previously opened jar	☐	☐	☐	☐	☐
26	11. Stretch out his/her arms	☐	☐	☐	☐	☐
27	12. Put his/her hands behind his/her neck	☐	☐	☐	☐	☐
28	13. Turn his/her head and look over his/her shoulders	☐	☐	☐	☐	☐
29	14. Bend his/her head back and look at the ceiling	☐	☐	☐	☐	☐
30	15. Bite into a sandwich or an apple	☐	☐	☐	☐	☐

31 **2. How much pain has your child had because of the illness over the past week?**
32 **(choose the most accurate score)**

33 **NO PAIN** **EXTREME PAIN**

○ ○

Feil!

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

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Objekter kan ikke lages ved å redigere feltkoder.

3. Please indicate if <u>today</u> your child is feeling <u>pain</u> or has <u>swelling</u> in any of the joints listed below

LEFT SIDE	Presence of pain or swelling	RIGHT SIDE	Presence of pain or swelling
Fingers	☐	Fingers	☐
Wrist	☐	Wrist	☐
Elbow	☐	Elbow	☐
Shoulder	☐	Shoulder	☐
Hip	☐	Hip	☐
Knee	☐	Knee	☐
Ankle	☐	Ankle	☐
Toes	☐	Toes	☐
Neck	☐		
Lower back	☐		
My child has no joints with pain or swelling	☐		

4. Has your child had <u>joint stiffness</u> upon waking up <u>over the past week</u>? Yes ☐ No ☐

If you answered "yes", how long does it last?

Less than 15 minutes	15 to 30 minutes	30 minutes to 1 hour	1 to 2 hours	More than 2 hours
☐	☐	☐	☐	☐

5. Please indicate if your child has had either or both of the symptoms listed below <u>over the past week</u>

Fever > 38°C (if due to arthritis)	Yes ☐	No ☐
Skin rash (if due to arthritis)	Yes ☐	No ☐

6. Considering all the symptoms, such as pain, joint swelling, morning stiffness, fever (if due to arthritis), and skin rash (if due to arthritis), please evaluate the <u>level of activity</u> of your child's illness <u>at the moment</u> (choose the most accurate score)

NO ACTIVITY ○ **MAXIMUM ACTIVITY**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

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7. How would you evaluate the <u>current state</u> of your child's illness?

Complete absence of symptoms (**remission**)	Continuing presence of symptoms (**persistent activity**)	Recurrence of symptoms after a period of complete well-being (**relapse**)
☐	☐	☐

PATIENT ID_____ **DATE OF VISIT (D/M/Y)**_____

(ie Italy Paolo Rossi date of birth 25 March 1970 = IT PR 250370)

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8. Compared to his/her last visit, how would you evaluate the course of your child's illness?

Much improved ☐	Slightly improved ☐	Stable/unchanged ☐	Slightly worsened ☐	Much worsened ☐

9. Is your child taking any medication to treat arthritis? Yes ☐ No ☐

If you answered "no", please go directly to question 13

If "yes", please also answer questions 10, 11 and 12

10. Which medication is your child currently taking?

NSAIDs (e.g._____) ☐ Please specify_____					
Steroids (e.g._____) ☐ Please specify_____					
Methotrexate (e.g._____) ☐ *Oral* ☐ *Subcutaneous* ☐ *Intramuscular* ☐					
Salazopyrin (e.g. _____) ☐		Cyclosporine (e.g. _____) ☐			
Etanercept (Enbrel) ☐	Infliximab (Remicade) ☐		Adalimumab (Humira) ☐		
Golimumab (Simponi) ☐	Certolizumab (Cimzia) ☐		Abatacept (Orencia) ☐		
Anakinra (Kineret) ☐	Canakinumab (Ilaris) ☐		Rilonacept (Arcalyst) ☐		
Tocilizumab (Actemra) ☐	Other (please specify_____) ☐				
Other (please specify _____) ☐	Other (please specify_____) ☐				

11. Since your child's last visit, has he/she had any disturbances which may be caused by the medication he/she is taking? Yes ☐ No ☐

If you answered "yes", please specify which in the table below

Fever	☐	Pain or burning feeling in the stomach	☐
Headache	☐	Nausea	☐
Skin rash	☐	Vomiting	☐
Mouth sores	☐	Constipation	☐
Swollen/bleeding gums	☐	Diarrhoea	☐
Increased body hair	☐	Black or bloody stools	☐
Weight gain	☐	Blood in the urine	☐
Weight loss	☐	Swelling, bruising, pain, redness, etc., at the injection site	☐
Mood swings (excitement, depression, anxiety)	☐	Other (please describe)_____	☐
Sleep disturbances	☐	Other (please describe)_____	☐

12. Does your child take his/her medication regularly (as prescribed by the doctor) at home? Yes ☐ No ☐

If "no", why not?

He/she refuses to	☐	Too many administrations during the day	☐
Organisational difficulty (for example, problems taking medication at school)	☐	Fear of side effects	☐
The child takes too much medication	☐	Other (please specify) _____	☐

Which medication is most difficult to give on a regular basis? _____

13. Does your child attend school? Yes ☐ No ☐

If you answered "yes", what school-related problems does the illness cause?

None	☐	Difficulty in his/her relationships with teachers	☐
Numerous absences	☐	Decrease in performance	☐

95	Difficulty in remaining seated for a long time	☐	Other (please specify) _____	☐

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14. Evaluation of Quality of Life

Please choose the answer that best describes your child's overall health.

If a question is not applicable because your child is **too young**, choose "**Not applicable**".

Considering the **past four weeks**, we would like to know if your child:

	Never	Some-times	Often	Every day	Not applicable
1. Has had any difficulty taking care of him/herself, for example eating, getting dressed or washing	☐	☐	☐	☐	☐
2. Has had any difficulty taking a 15 minute walk or walking up a flight of stairs	☐	☐	☐	☐	☐
3. Has had any difficulty carrying out activities that require a lot of energy such as running, playing football, dancing etc.	☐	☐	☐	☐	☐
4. Has had any difficulty doing at-school activities or playing with friends	☐	☐	☐	☐	☐
5. Has had any pain	☐	☐	☐	☐	☐
6. Has appeared sad or depressed	☐	☐	☐	☐	☐
7. Has appeared nervous or anxious	☐	☐	☐	☐	☐
8. Has had any trouble getting along with other children	☐	☐	☐	☐	☐
9. Has had any difficulty concentrating or paying attention	☐	☐	☐	☐	☐
10. Has appeared to be dissatisfied with his/her physical appearance or abilities	☐	☐	☐	☐	☐

15. Considering all the ways the illness affects your child, please evaluate how he/she feels at the moment (choose the most accurate score)

VERY WELL ○ **VERY POORLY**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

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16. Considering all the ways the illness affects your child, would you be satisfied if his/her condition remained stable/unchanged for the next few months?

Yes ☐	No ☐

Thank you very much for having taken the time to fill in this questionnaire.

The information you have provided will be very useful for following the changes in the course of your child's illness in the best possible way.

The information in this questionnaire and in the questionnaire filled in by your child (if applicable) will be kept strictly confidential and will be used only for clinical or research activities.

All data will be handled anonymously.

Please indicate if you authorise or do not authorise the use for scientific purposes of the information in this questionnaire and in the questionnaire filled in by your child (if applicable).

I authorise ☐ **I do not authorise** ☐

Parent's name and surname or initials (please print)_____

Signature: _____