Subject Contact Information

Name: _____
Last *First* *Middle name or initial* *Suffix*

Street Address/P.O. Box: _____

City: _____ **State:** _____ **Zip Code:** _____

Telephone No.: (___ ___ ___) ___ ___ ___ – ___ ___ ___ ___ **Alternate Telephone No.:** (___ ___ ___) ___ ___ ___ – ___ ___ ___ ___

E-mail address: _____

Additional Contact Information

Provide two additional contacts including the guardian of the subject as one. If subject is less than 18, at least one of the contacts should be residing at a different address than the subject.

Name	Relationship	Guardian	Address	Telephone No.	E-mail Address
1 Primary *(guardian if applicable)*: *Last:* _____ *First:* _____ *Middle:* _____	☐ Mother ☐ Father ☐ Sibling ☐ Aunt ☐ Uncle ☐ Grandparent ☐ Other *(specify)*: _____	☐ No ☐ Yes	☐ Same as above _____ *Street/PO Box* _____ *City State Zip Code*	☐ Same as above (__ __ __) __ __ __ - __ __ __ __ Alternate phone no.: (__ __ __) __ __ __ - __ __ __ __ **OR** ☐ NA	_____ @ _____ **OR** ☐ Not done
2 *Last:* _____ *First:* _____ *Middle:* _____	☐ Mother ☐ Father ☐ Sibling ☐ Aunt ☐ Uncle ☐ Grandparent ☐ Other *(specify)*: _____		☐ Same as above _____ *Street/PO Box* _____ *City State Zip Code*	☐ Same as above (__ __ __) __ __ __ - __ __ __ __ Alternate phone no.: (__ __ __) __ __ __ - __ __ __ __ **OR** ☐ NA	_____ @ _____ **OR** ☐ Not done
3 *Last:* _____ *First:* _____ *Middle:* _____	☐ Mother ☐ Father ☐ Sibling ☐ Aunt ☐ Uncle ☐ Grandparent ☐ Other *(specify)*: _____		☐ Same as above _____ *Street/PO Box* _____ *City State Zip Code*	☐ Same as above (__ __ __) __ __ __ - __ __ __ __ Alternate phone no.: (__ __ __) __ __ __ - __ __ __ __ **OR** ☐ NA	_____ @ _____ **OR** ☐ Not done

Family History

1 Does the biologic mother, father, or any sibling have history of the following diseases?

☐ Yes → **If Yes: Check all that apply:**

- ☐ Systemic lupus erythematosus
- ☐ Juvenile idiopathic arthritis/juvenile rheumatoid arthritis
- ☐ Fibromyalgia
- ☐ Rheumatoid arthritis
- ☐ Psoriasis
- ☐ Multiple sclerosis
- ☐ Ankylosing spondylitis
- ☐ Autoimmune thyroiditis (including Graves' and Hashimoto's)
- ☐ Spondyloarthropathy
- ☐ Celiac disease
- ☐ Crohn's disease or ulcerative colitis
- ☐ Diabetes Type 1
- ☐ Acute anterior uveitis
- ☐ Other autoimmune disease

☐ No
☐ Unknown

2 Does subject have any biologic sisters (full or half)?

☐ Yes
☐ No
☐ Unknown

3 Does subject have any biologic brothers (full or half)?

☐ Yes
☐ No
☐ Unknown

Demographics and Disease Characteristics

1 **Date of birth:** __ __ __ / __ __ / __ __ __ __
month day year

2 **Ethnicity** *(check all that apply)*:
- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino

3 **Race** *(check all that apply)*:
- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Unknown or do not wish to provide

4 **Gender** *(check only one)*:
- ☐ Male
- ☐ Female

5 **Household income (in US $ - annual gross)** *(check only one)*:
- ☐ < 25,000
- ☐ 25–49,999
- ☐ 50–74,999
- ☐ 75–99,999
- ☐ 100–150,000
- ☐ above 150,000
- ☐ Unknown

6 **Country of primary residence at onset of disease symptoms:**
- ☐ United States: Zip Code: __ __ __ __ __
- ☐ Canada: Postal Code: __ __ __ __ __
- ☐ Other country (specify): _____
- ☐ Unknown or do not wish to provide

7 **Antinuclear antibody test (ANA):**
- ☐ Positive
- ☐ Negative
- ☐ Not done

8 **What is the subject's rheumatologic disease diagnosis?** *(If multiple, please select those that meet disease classification criteria.)*
- ☐ Mixed connective tissue disease
- ☐ Systemic lupus erythematosus
- ☐ Primary Sjögren's disease
- ☐ Systemic sclerosis
- ☐ Juvenile dermatomyositis
- ☐ Localized scleroderma
- ☐ Juvenile idiopathic arthritis/juvenile ankylosing spondylitis
- ☐ Chronic vasculitis (excluding Kawasaki and Henoch-Schönlein purpura)
- ☐ Sarcoid
- ☐ Auto-inflammatory disease (including fever syndromes, chronic recurrent multifocal osteomyelitis)
- ☐ Idiopathic uveitis (not associated with other rheumatologic disease)
- ☐ Juvenile primary fibromyalgia

9 **Month and year of onset of disease symptoms** *(record UNK for unknown day or month, make best estimate of year)*:
__ __ __ / __ __ / __ __ __ __
month *day* *year*

10 **Date first seen by pediatric rheumatologist** *(record UNK for unknown day or month, make best estimate of year):*
__ __ __ / __ __ / __ __ __ __
month *day* *year*

Demographics and Disease Characteristics (continued)

11 Does the subject have any of the following pre-existing conditions:

☐ Yes: **Check all that apply:**

- ☐ Autism spectrum disorder
- ☐ Auto-immune hepatitis
- ☐ Auto-immune thyroid disease
- ☐ Celiac disease
- ☐ Cerebral palsy
- ☐ Chronic asthma
- ☐ Congenital heart disease
- ☐ Cystic fibrosis
- ☐ Demyelinating disease
- ☐ Diabetes – Type 1
- ☐ Diabetes – Type 2
- ☐ Malignancy
- ☐ Primary immunodeficiency syndrome(s)
- ☐ Seizure disorder
- ☐ Trisomy-21
- ☐ Other autoimmune disease *(specify)*: _____
- ☐ Other major congenital or acquired disease/condition (*specify)*: _____

☐ No

☐ Unknown

12 ACR Functional Class worst ever *(from Baseline Physician's Worksheet) (check only one)***:**

☐ Class I *(completely able to perform usual daily activities)*

☐ Class II *(able to perform usual self-care and vocational activities, but limited in avocational activities)*

☐ Class III *(able to perform usual self-care activities, but limited in vocational and avocational activities)*

☐ Class IV *(limited ability to perform usual self-care, vocational, and avocational activities)*

☐ Not done

☐ Unknown

Visit date: __ __ / __ __ __ / __ __ __ __
day month year

Subject Data

1 **Height:** __ __ __ . __ cm **OR** ☐ Not done

2 **Weight:** __ __ __ . __ kg **OR** ☐ Not done

3 **Blood pressure**: __ __ __ / __ __ __ **OR** ☐ Not done

4 **Does the subject smoke?** ☐ Yes ☐ No ☐ Unknown

5. **Does anyone else in the subject's household smoke?** ☐ Yes ☐ No ☐ Unknown

Insurance Status

Does subject have health insurance?
☐ Yes
☐ No
☐ Unknown

Health Related Quality of Life Score (from Parent/Subject Worksheets)

Score *(check only one)*: ☐ Excellent ☐ Very good ☐ Good ☐ Poor ☐ Very poor **OR** ☐ Not done

Parent/Subject Assessments (from Parent/Subject Worksheets)

Overall well-being score: _____ **OR** ☐ Not done

Pain score (Parent completes if subject <4; Subject completes if >9): _____ **OR** ☐ Not done **OR** ☐ Not applicable at this age

Faces Pain Scale score (subject 4-9 years old)**:** _____ **OR** ☐ Not applicable at this age **OR** ☐ Not done

CHAQ (from Parent/Subject Worksheet)

CHAQ disability index score: _____ **OR** ☐ Not done

Physician Global Assessment (from Baseline Physician Worksheet)

Score: _____ **OR** ☐ Not done

ACR Functional Class Current (from Baseline Physician Worksheet)

Check only one:
☐ Class I *(completely able to perform usual daily activities)*
☐ Class II *(able to perform usual self-care and vocational activities, but limited in avocational activities)*
☐ Class III *(able to perform usual self-care activities, but limited in vocational and avocational activities)*
☐ Class IV *(limited ability to perform usual self-care, vocational, and avocational activities)*
☐ Not done
☐ Unknown

Parent/Subject Questionnaires

Date completed: __ __ __ / __ __ / __ __ __ __
month day year

Person completing form: ☐ Mother ☐ Father ☐ Subject ☐ Other *(specify)*: _____

Parent

1 **How do you rate your child's health?** ☐ Excellent ☐ Very good ☐ Good ☐ Poor ☐ Very poor

2 **Considering all the ways that your child's rheumatic condition affects your child, rate how your child is doing:**

0	1	2	3	4	5	6	7	8	9	10
Very Well										Very Poor

Please circle one number

3 **We are also interested in learning whether or not your child has been affected by pain because of his/her rheumatic condition.**

How much pain do you think your child had because of his/her rheumatic condition in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Pain									Very Severe	Pain

Please circle one number

OR Subject

1 **How do you rate your health?** ☐ Excellent ☐ Very good ☐ Good ☐ Poor ☐ Very poor

2 **Considering all the ways that your rheumatic condition affects you, rate how you are doing:**

0	1	2	3	4	5	6	7	8	9	10
Very Well										Very Poor

Please circle one number

3 **We are also interested in learning whether or not you have been affected by pain because of your rheumatic condition.**

How much pain have you had because of your rheumatic condition in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Pain									Very Severe	Pain

Please circle one number

Faces Pain Scale – Revised (FPS-R)

In the following instructions, say "hurt" or "pain," whichever seems right for a particular child.

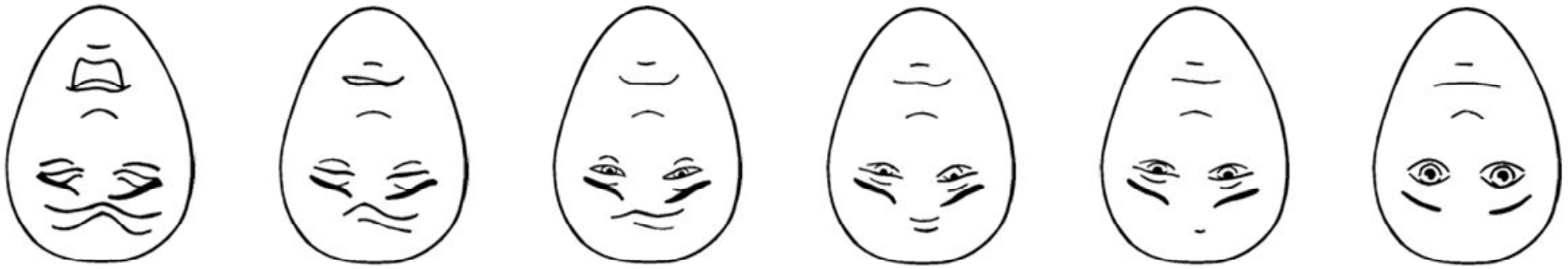
"These faces show how much something can hurt. This face *[point to left-most face]* **shows no pain**. **The faces show more and more pain** *[point to each from left to right]* **up to this one** *[point to right-most face]* **- it shows very much pain**. **Point to the face that shows how much you hurt** [right now]**."**

*Score the chosen face **0**, **2**, **4**, **6**, **8**, or **10**, counting left to right, so '0' = 'no pain' and '10' = 'very much pain.' Do not use words like 'happy' and 'sad'. This scale is intended to measure how children feel inside, not how their face looks.*

Sources. Hicks CL, von Baeyer CL, Spafford P, van Korlaar I, Goodenough B. The Faces Pain Scale – Revised: Toward a common metric in pediatric pain measurement. *Pain* 2001;93:173-183. Bieri D, Reeve R, Champion GD, Addicoat L, Ziegler J. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: Development, initial validation and preliminary investigation for ratio scale properties. *Pain* 1990;41:139-150.

(fold along dotted line)

10 8 6 4 2 0



Childhood Health Assessment Questionnaire (CHAQ)

Instructions

In this section we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response that best describes your child's usual activities (averaged over an entire day) **OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS THAT ARE DUE TO ILLNESS**. If most children at your child's age are not expected to do a certain activity, please mark it as "Not Applicable." **For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but not because he/she is RESTRICTED BY ILLNESS, please mark it as "Not Applicable."**

CHAQ Functional Ability Scoring and Coding

(Adapted from the scanned instructions received from Dr. Nicola Ruperto)

The DAILY FUNCTION section is designed to assess the patient's functional ability over the past week. It is composed of eight categories, each of which has at least two component questions. Parents are also asked to indicate the use of any aids or devices or if the child needs help from another person for any of these activities. The eight categories are: dressing & grooming, arising, eating, walking, hygiene, reach, grip, and activities.

Possible responses for the component questions are:

Without ANY difficulty	= 0
With SOME difficulty	= 1
With MUCH difficulty	= 2
UNABLE to do	= 3

The highest score for any component question determines the score for that category. If a component question is left blank or the response is too ambiguous to assign a score, then the score for the category is determined by the remaining completed question(s). If all component questions are blank/not applicable, then the category is not scored and not used in the calculation of the final disability index.

If the parent's mark is between the response columns, then move it to the closest one. If it's directly between the two, move it to the higher one.

If either devices and/or help from another person is checked for a category, the score=2. This may determine the score unless the score on any other component question=3. For example, the response to "Dress yourself…" is with SOME difficulty (score=1). The parent has checked the use of a device for dressing, thereby increasing the score to 2. The response to "Shampoo your hair" is UNABLE to do (score=3). Therefore, the score for the DRESSING category is 3.

Devices associated with each category:

DRESSING & GROOMING	Devices used for dressing (button hook, zipper pull, long handles shoe horn, etc.)
ARISING	Built up or special chair
EATING	Built up pencil or special utensils
WALKING	Cane, walker, crutches, wheelchair
HYGIENE	Raised toilet set, bathtub seat, bathtub bar, long-handled appliances in bathroom
REACH	Long-handled appliances for reach
GRIP	Jar opener (for jars previously opened)

Devices written in the "Other" sections are considered only if they would be used for any of the stated categories.

Disability Index Calculation

The index is calculated by adding the scores for each of the categories and dividing by the number of categories answered. If questions in each category were answered, divide by 8. This gives a score in the 0 to 3.0 range.

Scoring worksheet:

1. Dressing and Grooming:	____	5. Hygiene:	____
2. Arising:	____	6. Reach:	____
3. Eating:	____	7. Grip:	____
4. Walking:	____	8. Activities:	____

Add scores from 1-8 above to get TOTAL: _____

Divide above TOTAL by number of answered categories to get Disability Index (0.00-3.00): ___.___ ___

Enter value in the above box for CHAQ score

Childhood Health Assessment Questionnaire (CHAQ)

Date completed: __ __ __ / __ __ / __ __ __ __
month day year

Person completing form: ☐ Mother ☐ Father ☐ Subject ☐ Other *(specify)*: _____

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
Dressing and Grooming: Is your child able to…					
Dress, including tying shoelaces and doing buttons?	☐	☐	☐	☐	☐
Shampoo his/her hair?	☐	☐	☐	☐	☐
Remove socks?	☐	☐	☐	☐	☐
Cut fingernails?	☐	☐	☐	☐	☐
Arising: Is your child able to…					
Stand up from a low chair or floor?	☐	☐	☐	☐	☐
Get in and out of bed or stand up in a crib?	☐	☐	☐	☐	☐
Eating: Is your child able to…					
Cut his/her own meat?	☐	☐	☐	☐	☐
Lift up a cup or glass to mouth?	☐	☐	☐	☐	☐
Open a new cereal box?	☐	☐	☐	☐	☐
Walking: Is your child able to…					
Walk outdoors on flat ground?	☐	☐	☐	☐	☐
Climb up five steps?	☐	☐	☐	☐	☐

Please check any AIDS or DEVICES that your child usually uses for any of the above activities:			
Cane	☐	**Devices used for dressing** *(button hook, zipper pull, long-handled shoe horn, etc.)*	☐
Walker	☐	**Built up pencil or special utensils**	☐
Crutches	☐	**Special or built up chair**	☐
Wheelchair	☐	**Other** *(specify)*:	☐

Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:			
Dressing and grooming	☐	**Eating**	☐
Arising	☐	**Walking**	☐

Reprinted from Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of health status in children with juvenile rheumatoid arthritis. Arthritis Rheum 1994; 37: 1761–9. With permission.

Childhood Health Assessment Questionnaire (CHAQ)

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
Hygiene: Is your child able to…					
Wash and dry entire body?	☐	☐	☐	☐	☐
Take a tub bath (get in and out of tub)?	☐	☐	☐	☐	☐
Get on and off the toilet or potty chair?	☐	☐	☐	☐	☐
Brush teeth?	☐	☐	☐	☐	☐
Comb/brush hair?	☐	☐	☐	☐	☐
Reach: Is your child able to…					
Reach and get down a heavy object such as a large game or books from just above his/her head?	☐	☐	☐	☐	☐
Bend down to pick up clothing or a piece of paper from the floor?	☐	☐	☐	☐	☐
Pull on a sweater over his/her head?	☐	☐	☐	☐	☐
Turn neck to look back over shoulder?	☐	☐	☐	☐	☐
Grip: Is your child able to…					
Write or scribble with pen or pencil?	☐	☐	☐	☐	☐
Open car doors?	☐	☐	☐	☐	☐
Open jars that have been previously opened?	☐	☐	☐	☐	☐
Turn faucets on and off?	☐	☐	☐	☐	☐
Push open a door when he/she has to turn a door knob?	☐	☐	☐	☐	☐
Activities: Is your child able to…					
Run errands and shop?	☐	☐	☐	☐	☐
Get in and out of a car or toy car or school bus?	☐	☐	☐	☐	☐
Ride bike or tricycle?	☐	☐	☐	☐	☐
Do household chores (e.g., wash dishes, take out trash, vacuuming, yard work, make bed, clean room)?	☐	☐	☐	☐	☐
Run and play?	☐	☐	☐	☐	☐

Please check any AIDS or DEVICES that your child usually uses for any of the above activities:

Raised toilet seat	☐	Bathtub bar	☐
Bathtub seat	☐	Long-handled appliances for reach	☐
Jar opener *(for jars previously opened)*	☐	Long-handled appliances in bathroom	☐

Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:

Hygiene	☐	Gripping and opening things	☐
Reach	☐	Errand and chores	☐

Baseline Physician Worksheet

Date completed: __ __ __ / __ __ / __ __ __ __
month day year

Rheumatologic Disease Diagnosis

What is the subject's rheumatologic disease diagnosis? *(If multiple, please select those that meet disease classification criteria.)*

- ☐ Mixed connective tissue disease
- ☐ Systemic lupus erythematosus
- ☐ Primary Sjögren's disease
- ☐ Systemic sclerosis
- ☐ Juvenile dermatomyositis
- ☐ Localized Scleroderma
- ☐ Juvenile idiopathic arthritis/Juvenile ankylosing spondylitis
- ☐ Chronic vasculitis (excluding Kawasaki and Henoch-Schönlein purpura)
- ☐ Sarcoid
- ☐ Auto-inflammatory disease (including fever syndromes, chronic recurrent multifocal osteomyelitis)
- ☐ Idiopathic uveitis (not associated with other rheumatologic disease)
- ☐ Juvenile primary fibromyalgia

Physician Global Assessment of Disease Activity

Instructions: Indicate the assessed level of this subject's disease activity. *(To be filled out the **same day** as subject's visit. Do not wait for laboratory results.)*

At this time, the overall disease activity is:

Not Active										Very Active
0	1	2	3	4	5	6	7	8	9	10

Please circle one number

ACR Functional Class

1 ACR functional class worst ever *(check only one)*:

- ☐ Class I *(completely able to perform usual daily activities)*
- ☐ Class II *(able to perform usual self-care and vocational activities, but limited in avocational activities)*
- ☐ Class III *(able to perform usual self-care activities, but limited in vocational and avocational activities)*
- ☐ Class IV *(limited ability to perform usual self-care, vocational, and avocational activities)*
- ☐ Not done
- ☐ Unknown

2 ACR functional class current *(check only one)*:

- ☐ Class I *(completely able to perform usual daily activities)*
- ☐ Class II *(able to perform usual self-care and vocational activities, but limited in avocational activities)*
- ☐ Class III *(able to perform usual self-care activities, but limited in vocational and avocational activities)*
- ☐ Class IV *(limited ability to perform usual self-care, vocational, and avocational activities)*
- ☐ Not done
- ☐ Unknown

Medication History

Please indicate all sources of information used to answer medication items below (select all that apply):
☐ Family or subject recall ☐ Limited chart review ☐ Provider recall ☐ Complete chart review ☐ Other

Has subject been in any blinded drug trial(s) where treatment assigned has not yet been revealed to physician or subject not yet transitioned to open-label phase?
☐ Yes → **Check all that apply:**
☐ Current study → **Specify drug(s):** _____
_____
☐ Past study → **Specify drug(s):** _____
_____
☐ No
☐ Unknown

1 Non-biologic immune modulators and disease-modifying antirheumatic drugs *(DMARDS)***:**
☐ No ☐ Yes → **If Yes: Check one answer per medication**

Azathioprine *(Imuran)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Cyclophosphamide oral *(Cytoxan)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Cyclophosphamide pulse *(Cytoxan)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Cyclosporine A *(Neoral, Sandimmune, Gengraf)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Hydroxychloroquine *(Plaquenil)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Leflunomide *(Arava)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Methotrexate—oral	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Methotrexate—subcutaneous	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Mycophenylate mofetil *(CellCept, Myfortic)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Sulfasalazine *(Azulfidine)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Tacrolimus *(Prograf)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Lenalidomide *(Revlimid)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Thalidomide *(Thalomid)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
Colchicine *(Colcrys)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown

Current use: Physician has prescribed and another scheduled dose is intended or stopped on day of visit. Do not include drugs newly prescribed at this visit.

Medication History (continued)

2	**Biologics:** ☐ No ☐ Yes → **If Yes: Check one answer per medication**			
	Abatacept *(Orencia)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Adalimumab *(Humira)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Anakinra *(Kineret)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Belimumab *(Benlysta)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Canakinumab *(Ilaris)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Certolizumab *(Cimzia)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Epratuzumab *(LymphoCide)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Etanercept *(Enbrel)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Golimumab *(Simponi)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Infliximab *(Remicade)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	IVIG	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Rilonacept *(Arcalyst)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Rituximab *(Rituxan)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Tocilizumab *(Actemra)*	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Other biologic *(specify)***:**	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Other biologic *(specify)***:**	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
3	**Glucocorticoids (other than inhaled and intranasal):** ☐ No ☐ Yes → **If Yes: Check one answer per medication**			
	Intraarticular corticosteroids	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	IV pulse steroids	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Systemic corticosteroids long term daily	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	If current or prior use, what is cumulative exposure?	☐ < 1 month	☐ ≥ 1 month	☐ Unknown	
	Intraocular injections	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
	Steroid eye drops	☐ Current use	☐ Prior use	☐ Never	☐ Unknown
4	**Other drugs of interest**			
	Daily nonsteroidal anti-inflammatory drugs *(NSAIDs)*	☐ Current use	☐ Not Taking	☐ Unknown
	Selective serotonin reuptake inhibitors *(SSRIs)*	☐ Current use	☐ Not Taking	☐ Unknown
	Tri-cyclic antidepressants	☐ Current use	☐ Not Taking	☐ Unknown
	Serotonin norepinephrine reuptake inhibitors *(SNRIs)*	☐ Current use	☐ Not Taking	☐ Unknown
	Gamma-amniobutyric acid *(GABA)* **analogues**	☐ Current use	☐ Not Taking	☐ Unknown
	Opioids	☐ Current use	☐ Not Taking	☐ Unknown
	Cimetidine	☐ Current use	☐ Not Taking	☐ Unknown
	Herbals or non-vitamin supplements	☐ Current use	☐ Not Taking	☐ Unknown

Current use: Physician has prescribed and another scheduled dose is intended or stopped on day of visit. Do not include drugs newly prescribed at this visit.

Juvenile Idiopathic Arthritis/ Juvenile Ankylosing Spondylitis Disease Specific Form Baseline

1 **Physician assigned category** *(check only one)*:

- ❑ Systemic JIA
- ❑ Polyarticular RF (–)
- ❑ Polyarticular RF (+)
- ❑ Oligoarticular persistent
- ❑ Oligoarticular extended
- ❑ Psoriatic
- ❑ ERA
- ❑ Undifferentiated
- ❑ Juvenile Ankylosing Spondylitis (JAS)
- ❑ Other

2 **Total number of joints ever affected with arthritis:** ❑ < 5 joints ❑ ≥ 5 joints

3 **Total number of currently active joints:** _____

4 **Has subject ever had any of the following disease manifestations** (Current = at the current visit or within the last month; Past = not within the last month but has in the past)**:**

Quotidian fever for > 2 weeks AND daily for > 3 days	❑ Current ❑ Past ❑ No ❑ Unknown
Evanescent rash	❑ Current ❑ Past ❑ No ❑ Unknown
Generalized lymphadenopathy	❑ Current ❑ Past ❑ No ❑ Unknown
Hepatomegaly	❑ Current ❑ Past ❑ No ❑ Unknown
Splenomegaly	❑ Current ❑ Past ❑ No ❑ Unknown
Serositis	❑ Current ❑ Past ❑ No ❑ Unknown
Nail pitting	❑ Current ❑ Past ❑ No ❑ Unknown
Dactylitis	❑ Current ❑ Past ❑ No ❑ Unknown
Leg length discrepancy	❑ Current ❑ Past ❑ No ❑ Unknown
Psoriasis	❑ Current ❑ Past ❑ No ❑ Unknown
Enthesitis	❑ Current ❑ Past ❑ No ❑ Unknown
Sacroiliac joint tenderness and/or inflammatory lumbosacral pain	❑ Current ❑ Past ❑ No ❑ Unknown
Limited lumbosacral mobility (modified Schober test)	❑ Current ❑ Past ❑ No ❑ Unknown
Inflammatory bowel disease	❑ Current ❑ Past ❑ No ❑ Unknown
Uveitis	❑ Current ❑ Past ❑ No ❑ Unknown *(if Current, complete Baseline Uveitis form)*
Pulmonary hypertension	❑ Current ❑ Past ❑ No ❑ Unknown
Rheumatoid nodules	❑ Current ❑ Past ❑ No ❑ Unknown
Interstitial lung disease	❑ Current ❑ Past ❑ No ❑ Unknown

5 **Has the subject ever had any of the following positive diagnostic tests:**

Positive Anti-CCP	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive IgM RF initial	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive IgM RF confirmatory	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive HLAB27	❑ Yes ❑ No ❑ Not done ❑ Unknown

6a **Has the subject ever had imaging evidence of joint damage** (joint narrowing, erosion, ankylosis)**:**

- ❑ Yes
- ❑ No
- ❑ Imaging not done
- ❑ Unknown

6b **Has the subject ever had radiographic, CT or MRI evidence of damage, or CT or MRI evidence of active inflammation involving the sacroiliac joint(s)?**

- ❑ Yes
- ❑ No
- ❑ Imaging not done
- ❑ Unknown

7 **Parent/subject assessment of disease activity** (from worksheet)**:** _____ **OR** ❑ Not done

RHEUMATOLOGIC JOINT ASSESSMENT (page 1 of 2)

Date of visit (dd/mmm/yyyy): __ __ /__ __ __ / __ __ __ __	**Visit: _____**

RIGHT SIDE				UPPER	LEFT SIDE			
Swelling	POM	Tend	LOM	Joint	Swelling	POM	Tend	LOM
				Temp. Mand.				
			N/A	**Sterno.clav**				N/A
			N/A	**Acro. Clav.**				N/A
				Shoulder				
				Elbow				
				Wrist				
				MCP I				
				MCP II				
				MCP III				
				MCP IV				
				MCP V				
				PIP I				
				PIP II				
				PIP III				
				PIP IV				
				PIP V				
				DIP II				
				DIP III				
				DIP IV				
				DIP V				

RHEUMATOLOGIC JOINT ASSESSMENT (page 2 of 2)

Date of visit (dd/mmm/yyyy): __ __ /__ __ __ / __ __ __ __

RIGHT SIDE				LOWER	LEFT SIDE			
Swelling	POM	Tend	LOM	Joint	Swelling	POM	Tend	LOM
N/A				**Hip**	N/A			
				Knee				
				Ankle				
N/A				**Subtalar**	N/A			
				Tarsi				
				MTP I				
				MTP II				
				MTP III				
				MTP IV				
				MTP V				
				Toes (PIP) I				
				Toes (PIP) II				
				Toes (PIP) III				
				Toes (PIP) IV				
				Toes (PIP) V				
NA			N/A	**Sacroiliac**	N/A			N/A
				Cervical spine	N/A			
				Thoracic spine	N/A			
				Lumbar spine	N/A			

_____ (to be signed by assessor)

Parent/Subject Disease Activity Assessment (JIA only)

Date completed: __ __ __ / __ __ / __ __ __ __
(month / day / year)

Person completing form: ☐ Mother ☐ Father ☐ Subject ☐ Other *(specify)*: _____

Parent

How do you rate your child's disease activity in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Disease										Very Active

Please circle one number

OR Subject

How do you rate your disease activity in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Disease										Very Active

Please circle one number

Juvenile Dermatomyositis Disease Specific Form — Baseline

1 **JDM category** (check one): ❑ Definite ❑ Probable ❑ Amyopathic

2 **Childhood Myositis Assessment Scale** (CMAS) **score** (0–52)**:** ___ ___ **OR** ❑ Not done

3 **Manual muscle test (MMT-8) score** (0–80)**:** ___ ___ **OR** ❑ Not done

4 **Does the subject have any of the following disease manifestations at today's study visit** (please answer all questions)**:**

Symmetric proximal muscle weakness	❑ None ❑ Mild ❑ Moderate ❑ Severe ❑ Not done
Gottren's sign, papules or heliotrope	❑ Yes ❑ No ❑ Not done ❑ Unknown
Malar or facial erythema	❑ Yes ❑ No ❑ Not done ❑ Unknown
V or shawl sign	❑ Yes ❑ No ❑ Not done ❑ Unknown
Lipodystrophy	❑ Yes ❑ No ❑ Not done ❑ Unknown
Skin ulcers	❑ Yes ❑ No ❑ Not done ❑ Unknown
Periungual telangiectasia (nailfold capillary changes)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Contractures	❑ Yes ❑ No ❑ Not done ❑ Unknown

5 **Has the subject ever had documented evidence of the following** (Current = at today's study visit or within the last month; Past = not within the last month but has in the past)**:**

Calcinosis	❑ Current ❑ Past ❑ Never ❑ Unknown
Small joint arthritis	❑ Current ❑ Past ❑ Never ❑ Unknown
Large joint arthritis	❑ Current ❑ Past ❑ Never ❑ Unknown
Dysphagia or dysphonia	❑ Current ❑ Past ❑ Never ❑ Unknown
Muscle enzyme elevation	❑ Current ❑ Past ❑ Never ❑ Unknown
Cardiac involvement (check all that apply)	❑ Current ➔ **If Current: Check all that apply:** ❑Arrhythmia ❑Decreased cardiac output ❑Myocarditis ❑ Other ❑ Past ➔ **If Past: Check all that apply:** ❑ Arrhythmia ❑ Decreased cardiac output ❑ Myocarditis ❑ Other ❑ Never ❑ Unknown
Interstitial lung disease	❑ Current ❑ Past ❑ Never ❑ Unknown
GI ulceration due to JDM	❑ Current ❑ Past ❑ Never ❑ Unknown

6 **Has the subject ever had any of the following diagnostic assessments:**

Pulmonary function testing (PFTs)	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Normal ❑ Decreased FVC ❑ Decreased DLCO ❑ Reversible airway disease ❑ Other ❑ No ❑ Not done ❑ Unknown
MRI consistent with inflammatory muscle disease ever	❑ Yes ❑ No ❑ Not done ❑ Unknown
EMG consistent with inflammatory myopathy ever	❑ Yes ❑ No ❑ Not done ❑ Unknown
Muscle biopsy consistent with inflammatory muscle disease ever	❑ Yes ❑ No ❑ Not done ❑ Unknown

CHILDHOOD MYOSITIS ASSESSMENT SCALE (CMAS) SCORING SHEET

1. HEAD LIFT:
   0 = Unable 3 = 30-59
   1 = 1-9 sec 4 = 60-119 sec
   2 = 10-29 5 = > 2 min
   Score ____

2. LEG RAISE/TOUCH OBJECT:
   0 = Unable to lift leg off table.
   1 = Able to clear table, but cannot touch object (examiner's hand).
   2 = Able to lift leg high enough to touch object (examiner's hand).
   Score ____

3. STRAIGHT LEG LIFT/DURATION:
   0 = Unable 3 = 30-59 sec
   1 = 1-9 sec 4 = 60-119 sec
   2 = 10-29 sec 5 = > 2 min
   Score ____

4. SUPINE TO PRONE:
   0 = Unable. Has difficulty even turning onto side; able to pull right arm under torso only slightly or not at all.
   1 = Turns onto side fairly easily, but cannot fully free right arm and is unable to fully assume a prone position.
   2 = Easily turns onto side; has some difficulty freeing arm, but fully frees arm and fully assumes a prone position.
   3 = Easily turns over, fully frees right arm with no difficulty.
   Score ____

5. SITS-UPS:
   Hands on thighs, with counterbalance ____
   Hands across chest, with counterbalance ____
   Hands behind head, with counterbalance ____
   Hands on thighs, without counterbalance ____
   Hands across chest, without counterbalance ____
   Hands behind head, without counterbalance ____
   Score (0-6) ____

6. SUPINE TO SIT:
   0 = Unable by self.
   1 = Much difficulty. Very slow, struggles greatly, barely makes it. Almost unable.
   2 = Some difficulty. Able, but is somewhat slow, struggles some.
   3 = No difficulty.
   Score ____

7. ARM RAISE/STRAIGHTEN:
   0 = Cannot raise wrists up to the level of the A-C joint.
   1 = Can raise wrists at least up to the level of the A-C joint, but not above top of head.
   2 = Can raise wrists above top of head, but cannot raise arms straight above head so that elbows are in full extension.
   3 = Can raise arms straight above head so that elbows are in full extension.
   Score ____

8. ARM RAISE/DURATION: Can maintain wrists above top of head for:
   0 = Unable 3 = 30-59 sec
   1 = 1-9 sec 4 = > 60 sec
   2 = 10-29 sec
   Score ____

9. FLOOR SIT: Going from a standing position to a sitting position on the floor:
   0 = Unable. Afraid to even try, even if allowed to use a chair for support. Child fears that he/she will collapse, fall into a sit, or harm self.
   1 = Much difficulty. Able, but needs to hold onto a chair for support during descent. Unable, or unwilling to try if not allowed to use a chair for support.
   2 = Some difficulty. Can go from stand to sit without using a chair for support, but has at least some difficulty during descent. May need Gower's. Descends somewhat slowly and/or apprehensively; may not have full control or balance as maneuvers into a sit.
   3 = No difficulty. Requires no compensatory maneuvering.
   Score ____

10. ALL FOURS MANEUVER:
    0 = Unable to go from a prone to an all-fours position.
    1 = Barely able to assume and maintain an all-fours position. Unable to raise head to look straight ahead.
    2 = Can maintain all-fours position with back straight and head raised (so as to look straight ahead). But, cannot creep (crawl) forward.
    3 = Can maintain all-fours, look straight ahead and creep (crawl) forward.
    4 = Maintains balance while lifting and extending one leg.
    Score ____

11. FLOOR RISE: Going from a kneeling position on the floor to a standing position:
    0 = Unable, even if allowed to use a chair for support.
    1 = Much difficulty. Able, but needs to use a chair for support. (Unable if not allowed to use a chair.)
    2 = Moderate difficulty. Able to get up without using a chair for support, but needs to place one or both hands on thighs/knees or floor. (Unable without using hands.)
    3 = Mild difficulty. Does not need to place hands on knees, thighs or floor, but has at least some difficulty during ascent.
    4 = No difficulty.
    Score ____

12. CHAIR RISE:
    0 = Unable to rise up from chair, even if allowed to place hands on sides of chair seat.
    1 = Much difficulty. Able, but needs to place hands on sides of seat. Unable if not allowed to place hands on sides of seat.
    2 = Moderate difficulty. Able, but needs to place hands on knees/thighs. Does not need to place hands on sides of seat.
    3 = Mild difficulty. Does not need to place hands on seat, knees or thighs but has at least some difficulty during ascent.
    4 = No difficulty.
    Score ____

13. STOOL STEP:
    0 = Unable.
    1 = Much difficulty. Able, but needs to place one hand on exam table (or examiner's hand).
    2 = Some difficulty. Able, does not need to use exam table for support, but needs to use hand on knee/thigh.
    3 = Able. Does not need to use exam table or hand on knee/thigh.
    Score ____

14. PICK-UP:
    0 = Unable to bend over and pick up pencil off floor.
    1 = Much difficulty. Able, but relies heavily on support gained by placing hands on knees/thighs.
    2 = Some difficulty. Has some difficulty (but not "much-difficulty"). Needs to at least minimally and briefly place hand(s) on knees/thighs for support. Is somewhat slow.
    3 = No difficulty. No compensatory maneuver necessary.
    Score ____

TOTAL CMAS SCORE: _____

The maximum possible total score for the 14 maneuvers is 52

Systemic Sclerosis Disease Specific Form — Baseline

1 **Is disease manifestation present at today's study visit?** Please answer all questions.

Skin changes	❑ Yes → **If Yes: Check all that apply:** ❑ Face ❑ Trunk ❑ Sclerodactyly ❑ Calcinosis ❑ Proximal to MCPs ❑ Proximal to elbow ❑ Telangiectasia ❑ Other ❑ No
Nail-bed capillary abnormalities	❑ Yes ❑ No
Digital ulceration/gangrene	❑ Yes ❑ No
Raynaud's	❑ Yes ❑ No
Musculoskeletal disease	❑ Yes → **If Yes: Check all that apply:** ❑ Contractures ❑ Myositis ❑ Tendinopathy ❑ Other ❑ Arthritis ❑ No

2 **Has the subject had any of the following disease manifestations within the last 6 months?**

Pulmonary involvement	❑ Yes → **If Yes: Check all that apply:** ❑ Dyspnea ❑ Decreased DLCO/hypoxemia ❑ Parenchymal pulmonary disease ❑ Restrictive lung disease ❑ Radiologic or pathologic evidence of fibrosis ❑ Pulmonary hypertension ❑ Other ❑ No
Cardiac disease	❑ Yes → **If Yes: Check all that apply:** ❑ Pericardial effusion ❑ Arrhythmia ❑ Myocardiopathy ❑ Angina ❑ Other ❑ No
Renal disease	❑ Yes → **If Yes: Check all that apply:** ❑ Abnormal urinary sediment ❑ Renovascular hypertension ❑ Elevated creatinine ❑ Imaging abnormality ❑ Fibrosis on biopsy ❑ Other ❑ No
GI disease	❑ Yes → **If Yes: Check all that apply:** ❑ Dysphagia ❑ Documented GERD ❑ GI dysmotility ❑ Esophagitis ❑ Stricture ❑ Malabsorption ❑ Other ❑ No

Systemic Sclerosis Disease Specific Form — Baseline (continued)	
3 **Results of diagnostic tests ever done:**	
Positive Anti-Sci70	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-centromere	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-PM/Sci	❑ Yes ❑ No ❑ Not done ❑ Unknown
Abnormal histology on biopsy of any site	❑ Yes ❑ No ❑ Not done ❑ Unknown

Localized Scleroderma Disease Specific Form — Baseline

1 **Localized scleroderma subtype** (check all that apply)**:**

- ❑ Circumscribed morphea → **Check all that apply:** ❑ Superficial ❑ Deep
- ❑ Linear scleroderma → **Check all that apply:** ❑ Linear involving trunk/limbs ❑ Linear involving face/scalp (En coup de saber, Parry-Romberg)
- ❑ Generalized morphea
- ❑ Pansclerotic morphea
- ❑ Eosinophilic fascilitis
- ❑ Other

2	**Location of lesions** (check all that apply)**:**	❑ Scalp ❑ Chest ❑ Arm ❑ Thigh ❑ Face ❑ Back ❑ Forearm ❑ Leg ❑ Neck ❑ Buttock ❑ Hand ❑ Foot ❑ Abdomen ❑ Other, specify _____
3	**Does the subject have any of the following disease manifestations on today's study visit or documented in the last six months?** Please answer all questions.	
	New lesion(s)	❑ Yes ❑ No ❑ Unknown
	Extension of previous lesion(s)	❑ Yes ❑ No ❑ Unknown
	Erythematous/violaceous lesion color	❑ Yes ❑ No ❑ Unknown
	Lesion warmth	❑ Yes ❑ No ❑ Unknown
	Skin Induration perimeter lesion	❑ Yes ❑ No ❑ Unknown
	Skin Thickening center of lesion	❑ Yes ❑ No ❑ Unknown
	Dermal atrophy	❑ Yes ❑ No ❑ Unknown
	Subcutaneous atrophy	❑ Yes ❑ No ❑ Unknown
	Hyperpigmentation	❑ Yes ❑ No ❑ Unknown
	Hypopigmentation	❑ Yes ❑ No ❑ Unknown
	Hair loss associated with lesion	❑ Yes ❑ No ❑ Unknown
	Muscle atrophy	❑ Yes ❑ No ❑ Unknown
	Extremity shortening	❑ Yes ❑ No ❑ Unknown
	Joint contracture	❑ Yes → **If Yes: Specify number of joints affected:** ❑ 1 ❑ 2 ❑ 3 ❑ 4 ❑ 5 ❑ >5 ❑ No ❑ Unknown
	Hemifacial atrophy	❑ Yes ❑ No ❑ Unknown
4	**Does the subject have any extracutaneous manifestations on today's study visit or documented in the last 6 months?**	❑ Yes → **If Yes: Check all that apply:** ❑ Arthritis ❑ GI involvement ❑ Neurological involvement ❑ Eye involvement ❑ Other ❑ No ❑ Unknown
5	**Has the subject had any abnormal laboratory findings or imaging abnormalities?** Please answer all questions below.	
	Abnormal CK	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Abnormal aldolase	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Presence of eosinophilia	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Elevated IgG	❑ Yes ❑ No ❑ Not done ❑ Unknown
	CNS imaging abnormality	❑ Yes ❑ No ❑ Not done ❑ Unknown
	GI study abnormality	❑ Yes ❑ No ❑ Not done ❑ Unknown

Juvenile Primary Fibromyalgia Syndrome Disease Specific Form — Baseline

1	**Has subject ever met either the ACR or Yunus and Masi criteria for JPFS?** ❑ Yes ❑ No	
2	**Has this subject had any of the following symptoms within the last month** (please answer all questions)**?**	
	Widespread pain?	❑ Yes ❑ No ❑ Unknown
	Disordered sleep?	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Non-restorative ❑ Increased sleep latency ❑ Hypersomnia ❑ Frequent wakings ❑ Other ❑ No ❑ No, on medication ❑ Unknown
	Frequent headaches?	❑ Yes ❑ No ❑ Unknown
	Irritable bowel syndrome (IBS) symptoms with prior physician diagnosis?	❑ Yes ❑ No ❑ Unknown
	Subjective soft tissue swelling of the extremities?	❑ Yes ❑ No ❑ Unknown
	Numbness and tingling of the extremities?	❑ Yes ❑ No ❑ Unknown
	Pain modulated by physical activity?	❑ Yes ❑ No ❑ Unknown
	Pain modulated by weather?	❑ Yes ❑ No ❑ Unknown
	Pain modulated by stress/anxiety?	❑ Yes ❑ No ❑ Unknown
	Fatigue?	❑ Yes ❑ No ❑ Unknown
3	**Does subject have hypermobility?**	❑ Yes ❑ No ❑ Unknown
4	**Has subject participated in organized physical activity since the onset of pain symptoms?**	❑ Yes ❑ Yes, but curtailed due to pain ❑ No ❑ Unknown
5	**Has subject ever been diagnosed with depression and/or anxiety disorder?**	❑ Yes ❑ No ❑ Unknown

6 **What treatments have been recommended/prescribed/provided by a pediatric rheumatologist to the subject** *(check all that apply)***?**

❑ Education regarding fibromyalgia and chronic pain	❑ Referral for psychotropic medications
❑ Sleep hygiene	❑ Pain clinic ➔ **Choose type of pain clinic:** ❑ Pediatric pain clinic ❑ Adult pain clinic
❑ Graduated aerobic exercise program	
❑ Physical therapy for stretching and strengthening	
❑ General counseling	❑ Integrative medicine clinic
❑ Cognitive behavioral therapy	❑ Rehabilitation clinic
❑ Biofeedback	❑ Other
❑ Medications	❑ None

Juvenile Primary Fibromyalgia Syndrome Disease Specific Form — Baseline (continued)	
7 **Did subject pursue these recommendations?**	❑ None of recommendations were pursued ➔ **If None:** **Indicate reason** (check all that apply)**:** ❑ Services not available ❑ Insurance would not cover services ❑ Subject/family not interested ❑ Only some recommendations were pursued ➔ **If Only some:** **Indicate reason** (check all that apply)**:** ❑ Services not available ❑ Insurance would not cover services ❑ Subject/family not interested ❑ Most or all recommendations were pursued ❑ Recommendations made today ❑ Unknown
8 **Has subject used other therapies?**	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Acupuncture/acupressure ❑ Craniosacral therapy ❑ Mindfulness/meditation ❑ Therapeutic massage ❑ Physical therapy ❑ Dietary supplements/herbal remedies ❑ Hypnosis ❑ Yoga ❑ Chiropractor ❑ Other ❑ No ❑ Unknown

SLE / MCTD / Sjögren's Disease Specific Form — Baseline

1 **Check all of the 1997 ACR criteria for Systemic Lupus Erythematosus (SLE) that the subject has ever met** *(SLE subjects must meet at least 3)*:

- ❑ None
- ❑ Malar rash
- ❑ Discoid rash
- ❑ Photosensitivity
- ❑ Oral ulcers
- ❑ Arthritis
- ❑ Serositis (pleuritis or pericarditis)
- ❑ Renal disorder
- ❑ Neurological disorder (seizures or psychosis)
- ❑ Hematological disorder (thrombocytopenia, hemolytic anemia, leukopenia, or lymphopenia)
- ❑ Immunological disorder (positive anti-Smith, anti-ds DNA, antiphospholipid or anti-cardiolipin antibodies or lupus anticoagulant)
- ❑ Positive ANA

2 **Disease manifestation present?** (Please answer all questions.)

Seizure*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Psychosis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Organic Brain Syndrome*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Visual Disturbance*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Cranial Nerve Disorder*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Other neurological manifestation (other than seizure, psychosis, organic brain syndrome, visual disturbance or cranial nerve disorder)	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Lupus headache*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Cerebral vascular accident*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Arthritis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown

**** Questions are from SLEDAI; EDC will calculate and display the total score.***

SLE / MCTD / Sjögren's Disease Specific Form — Baseline (continued)	
Myositis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Sclerodactyly or swollen hands	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Raynaud's	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Esophageal dysmotility	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Vasculitis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Rash*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Alopecia*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Mucosal ulcers*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
SICCA syndrome	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Fever > 38° C*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Pleurisy*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Pericarditis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown
Myocarditis	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown

**** Questions are from SLEDAI; EDC will calculate and display the total score.***

SLE / MCTD / Sjögren's Disease Specific Form — Baseline (continued)	
Pulmonary involvement	❑ Yes, in the last 10 days ➔ **If Yes: Check all that apply:** ❑ Decreased adjusted DLCO (diffusion capacity) ❑ Pneumonitis ❑ Pulmonary hypertension ❑ Lung biopsy performed ❑ Other ❑ Yes, in the last 11 days thru 6 months ➔ **If Yes: Check all that apply:** ❑ Decreased adjusted DLCO (diffusion capacity) ❑ Pneumonitis ❑ Pulmonary hypertension ❑ Lung biopsy performed ❑ Other ❑ No ❑ Unknown
Dialysis	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru 6 months ❑ No ❑ Unknown

3 Has subject ever had an arterial thrombotic event?	❑ Yes ❑ No ❑ Unknown
4 Has subject ever had a venous thrombotic event?	❑ Yes ❑ No ❑ Unknown
5 Has subject ever been diagnosed with coronary heart disease?	❑ Yes ❑ No ❑ Unknown
6 Has subject ever had imaging evidence of avascular necrosis of any joint?	❑ Yes ❑ No ❑ Unknown
7 Does subject have renal disease?	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Glomerulonephritis ❑ Nephrotic syndrome ❑ Interstitial nephritis ❑ Other ❑ No ❑ Unknown
8 Has subject ever had a renal transplant?	❑ Yes ❑ No ❑ Unknown

SLE / MCTD / Sjögren's Disease Specific Form — Baseline (continued)

Biopsies

9 **Has the subject had any non-renal biopsies consistent with disease diagnosis?**	❑ Yes **If Yes: Check all that apply:** ❑ Skin ❑ Lacrimal gland ❑ Conjuctiva ❑ Liver ❑ Lung ❑ Other ❑ No ❑ Unknown

10 **Has subject ever had one or more renal biopsies?** ❑ Yes → **If Yes: Answer questions below** ❑ No ❑ Unknown

Biopsy Date:	**WHO Class (I–VI)** *Check all that apply*	**And/OR ISN/RPS Class (I–VI)** *Check all that apply*
__ __ __ / __ __ __ __ *month* *year* **OR** ***Record "UNK" for portion of date unknown***	❑ I ❑ II ❑ III ❑ IV ❑ V ❑ VI ❑ Unknown ❑ Not done	❑ I ❑ II ❑ III → **Check one:** ❑ Active ❑ Active/chronic ❑ Chronic ❑ Unknown ❑ IV → **Check one:** ❑ Segmented (active) ❑ Global (active) ❑ Segmented (active/chronic) ❑ Segmented (chronic) ❑ Global (chronic) ❑ Unknown ❑ V ❑ VI ❑ Unknown ❑ Not done
__ __ __ / __ __ __ __ *month* *year* **OR** ***Record "UNK" for portion of date unknown***	❑ I ❑ II ❑ III ❑ IV ❑ V ❑ VI ❑ Unknown ❑ Not done	❑ I ❑ II ❑ III → **Check one:** ❑ Active ❑ Active/chronic ❑ Chronic ❑ Unknown ❑ IV → **Check one:** ❑ Segmented (active) ❑ Global (active) ❑ Segmented (active/chronic) ❑ Segmented (chronic) ❑ Global (chronic) ❑ Unknown ❑ V ❑ VI ❑ Unknown ❑ Not done
__ __ __ / __ __ __ __ *month* *year* **OR** ***Record "UNK" for portion of date unknown***	❑ I ❑ II ❑ III ❑ IV ❑ V ❑ VI ❑ Unknown ❑ Not done	❑ I ❑ II ❑ III → **Check one:** ❑ Active ❑ Active/chronic ❑ Chronic ❑ Unknown ❑ IV → **Check one:** ❑ Segmented (active) ❑ Global (active) ❑ Segmented (active/chronic) ❑ Segmented (chronic) ❑ Global (chronic) ❑ Unknown ❑ V ❑ VI ❑ Unknown ❑ Not done

11 **Serologies** (Please answer all questions.)

Positive Anti-Smith (Sm) **antibodies** (ever)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-RNP antibodies (ever)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-Ro antibodies (ever)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-La antibodies (ever)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive anti-phospholipid antibodies (including anti-cardiolipin antibodies), **anti-β2 glycoprotein 1 antibodies or positive lupus anticoagulant** (ever)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Anti-double stranded DNA antibodies in the past 10 days?*	❑ Yes → **If Yes: Was the test positive?** ❑ Yes ❑ No ❑ No → **If No: Has test been performed in the past 6 months?** ❑ Yes → **If Yes: Was the test positive?** ❑ Yes ❑ No ❑ Unknown ❑ No ❑ Unknown

SLE / MCTD / Sjögren's Disease Specific Form — Baseline (continued)		
	Complement levels (C3, C4, CH50) **in the past 10 days?***	❑ Yes → **If Yes: Are any of the levels below the lower limits of normal?** ❑Yes ❑No ❑ No → **If No: Have these tests been performed in the past 6 months?** ❑ Yes → **If Yes: Were any of the levels below the lower limits of normal?** ❑ Yes ❑ No ❑ Unknown ❑ No ❑ Unknown
12	**Cytopenias (in the last 10 days)** (Please answer all questions.)	
	Anemia hemoglobin (< 11 g/dL)	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
	Leukopenia (< 3000 white blood cells/mm^3*)	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
	Thrombocytopenia (< 100K platelets/mm^3*)	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
13	**Urinalysis and Renal Function Tests** (Please answer all questions.)	
	Urinary casts*	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
	Hematuria (> 5 red cells)*	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
	Pyuria (> 5 white cells)*	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
	Proteinuria (> 0.5 protein/creatinine ratio or > 500 mg protein/24 h) **in last 10 days?***	❑ Yes → **If Yes: Is this a new onset or increase of > 0.5 protein/creatinine ratio or > 500 mg protein/24h?** ❑ Yes ❑ No ❑ No → **If No: Has proteinuria** (> 0.5 protein/creatinine ratio pr > 500 mg protein/24h) **been present in the past 6 months?** ❑ Yes ❑ No ❑ Not done ❑ Unknown ❑ Not done ❑ Unknown
	Sample from the first void of the day?	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Serum creatinine (most recent)	_____ mg/dL **OR** ❑ Not done ❑ Unknown

**** Questions are from SLEDAI; EDC will calculate and display the total score.***

Sarcoid Disease Specific Form — Baseline

1	**Is disease manifestation present at today's study visit?** Please answer all questions.	
	Lymphadenopathy	❑ Yes → **If Yes: Check all that apply:** ❑ Abdominal/pelvic ❑ Mediastinal ❑ Peripheral ❑ Other ❑ No ❑ Unknown
	Skin lesions	❑ Yes → **If Yes: Check all that apply:** ❑ Livedo reticularis ❑ Macules ❑ Papules ❑ Nodules ❑ Ulcers ❑ Erythema nodosum ❑ Other ❑ No ❑ Unknown
	Hepato- or splenomegaly	❑ Yes ❑ No ❑ Unknown
	Arthritis	❑ Yes ❑ No ❑ Unknown
2	**Has subject had any of the following disease manifestations within the last 6 months?**	
	Pulmonary disease	❑ Yes → **If Yes: Check all that apply:** ❑ Pleural disease ❑ Parenchymal pulmonary disease ❑ Restrictive lung disease ❑ Other ❑ No ❑ Unknown
	Hepatic involvement	❑ Yes ❑ No ❑ Unknown
	Uveitis	❑ Yes ❑ No ❑ Unknown
	Cardiac involvement	❑ Yes ❑ No ❑ Unknown
	Renal involvement	❑ Yes ❑ No ❑ Unknown
	Bone lesions	❑ Yes ❑ No ❑ Unknown
	Neurologic involvement	❑ Yes ❑ No ❑ Unknown
3	**Results of diagnostic tests done at today's study visit or within the last month:**	
	Hypercalcuria or hypercalcemia	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Elevated ACE	❑ Yes ❑ No ❑ Not done ❑ Unknown
4	**Has the subject ever had a biopsy with histology consistent with sarcoid?**	❑ Yes → **If Yes: Check all that apply:** ❑ Bone ❑ Lymph node ❑ Conjunctiva ❑ Parotid ❑ Lung ❑ Skin ❑ Kidney ❑ Synovium ❑ Liver ❑ Other ❑ Biopsies performed, but not consistent with sarcoid ❑ No biopsies performed ❑ Unknown

Vasculitis Disease Specific Form — Baseline

1	**Vasculitis diagnosis (must meet diagnostic criteria)** (check only one)**:**	❑ Childhood Wegener's Granulomatosis ❑ Childhood Systemic Polyarteritis Nodosa, systemic ❑ Childhood Takayasu's Arteritis ❑ Microscopic Polyangitis ❑ Primary Central Nervous System Vasculitis ❑ Cutaneous Polyarteritis Nodosa ❑ Behcet's Syndrome ❑ Churg-Strauss Syndrome
2	**Which of these is diagnosis based on** (check all that apply)**?**	❑ Clinical findings ❑ Tissue pathology ❑ Imaging ❑ Serology ❑ Other
3	**Has subject had any of the following disease manifestations in the last 6 months?** Please answer all questions.	
	Hypertension (or on chronic antihypertensive medications)	❑ Yes ❑ No ❑ Unknown
	Skin lesions	❑ Yes ❑ No ❑ Unknown
	Mucosal involvement	❑ Yes ❑ No ❑ Unknown
	Eye involvement	❑ Yes ❑ No ❑ Unknown
	Upper respiratory tract involvement	❑ Yes ❑ No ❑ Unknown
	Lower respiratory tract involvement	❑ Yes ❑ No ❑ Unknown
	Renal involvement	❑ Yes ❑ No ❑ Unknown
	Renal insufficiency	❑ Yes ➔ **If Yes: Check treatment:** ❑ On dialysis ❑ Not on dialysis ❑ Received renal transplant ❑ Other ❑ No ❑ Unknown
	Liver involvement	❑ Yes ❑ No ❑ Unknown
	Intestinal involvement	❑ Yes ❑ No ❑ Unknown
	Cardiovascular involvement	❑ Yes ❑ No ❑ Unknown
	Central nervous system involvement	❑ Yes ❑ No ❑ Unknown
	Peripheral nervous system involvement	❑ Yes ❑ No ❑ Unknown
	Arthritis	❑ Yes ❑ No ❑ Unknown
	Positive c-ANCA or anti-PR3 ever	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Positive p-ANCA or anti-MPO ever	❑ Yes ❑ No ❑ Not done ❑ Unknown

Autoinflammatory Disease Specific Form — Baseline	
1 Current diagnosis (check all that apply)**:**	❑ CH **(**Cyclic hematopoiesis) ❑ CINCA **(**Chronic infantile neurological cutaneous and articular syndrome) / NOMID **(**Neonatal-onset multisystem inflammatory disease) ❑ CRMO (Chronic recurrent multifocal osteomyelitis) ❑ DIRA **(**Deficiency of interleukin-1 receptor antagonist) ❑ FCAS(Familial cold autoinflammatory syndrome **)** ❑ FMF (Familial Mediterranean fever) ❑ HIDS (Hyperimmunoglobulin (Ig) D syndrome) ❑ Majeed syndrome ❑ MWS **(**Muckle-Wells syndrome) ❑ PAPA **(**Pyogenic arthritis, pyoderma gangrenosum, and acne syndrome) ❑ PFAPA (Periodic fever, aphthous stomatitis, pharyngitis, adenitis syndrome) ❑ SAPHO (Synovitis, acne, pustulosis, hyperostosis, osteitis) ❑ TRAPS (TNF receptor-associated periodic syndrome) ❑ Unknown origin ❑ Other
2 Has subject had positive genetic test(s) confirming diagnosis?	❑ Yes ❑ No ❑ Not applicable ❑ Unknown
3 Has there been disease activity in the last six months?	❑ Yes ❑ No ❑ Unknown

Uveitis Disease Specific Form — Baseline

1	**Uveitis type** (*check only one)*:	❑ Anterior uveitis (includes: iritis, iridocyclitis, anterior cyclitis) ❑ Intermediate uveitis (includes: pars planitis, posterior cyclitis, hyalitis) ❑ Posterior uveitis (includes: choroiditis, chorioretinitis, retinochorioditis, retinitis, neuroretinitis) ❑ Panuveitis (anterior uveitis, + intermediate and/ or posterior uveitis
2	**Which eye(s) has uveitis affected** *(check all that apply)***?**	❑ Right ❑ Left ❑ Unknown
3	**What is the length of the current episode of active uveitis** (*check only one)***?**	❑ In remission ❑ < 3 months ❑ ≥ 3 months ❑ Unknown
4	**Current uncorrected vision:**	**Right eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown **Left eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown
5	**Current corrected vision:**	**Right eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown **Left eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown
6	**Eye complications to date** *(check all that apply)*:	❑ None ❑ Increased intraocular pressure ❑ Keratic precipitates ❑ Posterior synechia ❑ Cataract(s) ❑ Macular edema ❑ Epiretinal membrane ❑ Snowbanks ❑ Snowballs ❑ Retinal vasculitis ❑ Macular atrophy ❑ Hypopyon ❑ Iris nodules ❑ Band keratopathy
7	**Has subject ever used topical steroid drops?**	❑ Yes → If Yes: **What was maximum frequency** *(check one)***?** ❑ Hourly ❑ 2 times per day ❑ Every 2 hours ❑ Once per day ❑ 6 times per day ❑ Once every other day ❑ 4 times per day ❑ Unknown ❑ 3 times per day ❑ No ❑ Unknown
8	**Is subject currently using topical steroid drops?**	❑ Yes → If Yes: **What is current frequency** *(check one)***?** ❑ Hourly ❑ 2 times per day ❑ Every 2 hours ❑ Once per day ❑ 6 times per day ❑ Once every other day ❑ 4 times per day ❑ Unknown ❑ 3 times per day **How long has subject been on this dose?** ❑ < 1 month ❑ 1-3 months ❑ >3-6 months ❑ >6-12 months ❑ >12 months ❑ Unknown ❑ No ❑ Unknown
9	**Has subject ever used topical mydriatics?**	❑ Current ❑ Past ❑ No ❑ Unknown
10	**Has subject ever used topical anti-glaucoma drops?**	❑ Current ❑ Past ❑ No ❑ Unknown
11	**Has subject ever had eye surgery?**	❑ Yes ❑ No ❑ Unknown

Subject Status

1 Subject status at this visit *(check only one)*:

❑ Active *(future follow-up expected)*	
❑ Inactive *(follow-up not expected, but subject still participating in registry)* →	❑ Referred elsewhere for ongoing care ❑ 2nd opinion visit ❑ Subject moved to non-CARRA registry pediatric rheumatologist ❑ Transitioned to adult rheumatology ❑ Lost to follow-up ❑ Other *(specify)*: _____
❑ Discontinuation *(alive but no longer participating in registry)* →	**Date of discontinuation**: __ __ __ / __ __ / __ __ __ __ (*month* / *day* / *year*) **Reason for discontinuation:** ❑ Withdrew consent ❑ Site decision *(specify)*: _____ ❑ Other *(specify)*: _____
❑ Deceased →	**Date of death:** __ __ __ / __ __ / __ __ __ __ (*month* / *day* / *year*) **Cause of death:** _____ **Was death related to rheumatic disease?** ❑ Yes ❑ No

2 Check if subject/parent was unable to provide at least one contact outside the home: ❑

3 Check if subject received a protocol waiver for enrollment: ❑

Visit date: __ __ / __ __ __ / __ __ __ __
day month year

Subject Data

1 Height: __ __ __ . __ cm **OR** ☐ Not done

2 Weight: __ __ __ . __ kg **OR** ☐ Not done

3 Blood pressure: __ __ __ / __ __ __ **OR** ☐ Not done

4 Does the subject smoke? ☐ Yes ☐ No ☐ Unknown

5. **Does anyone else in the subject's household smoke?** ☐ Yes ☐ No ☐ Unknown

Insurance Status

Does subject have health insurance?
☐ Yes
☐ No
☐ Unknown

Health Related Quality of Life Score (from Parent/Subject Worksheets)

Score *(check only one)*: ☐ Excellent ☐ Very good ☐ Good ☐ Poor ☐ Very poor **OR** ☐ Not done

Parent/Subject Assessments (from Parent/Subject Worksheets)

Overall well-being score: _____ **OR** ☐ Not done

Pain score (Parent completes if subject <4; Subject completes if >9): _____ **OR** ☐ Not done **OR** ☐ Not applicable at this age

Faces Pain Scale score (subject 4-9 years old)**:** _____ **OR** ☐ Not applicable at this age **OR** ☐ Not done

CHAQ (from Parent/Subject Worksheet)

CHAQ disability index score: _____ **OR** ☐ Not done

Physician Global Assessment (from Baseline Physician Worksheet)

Score: _____ **OR** ☐ Not done

ACR Functional Class Current (from Baseline Physician Worksheet)

Check only one:
☐ Class I *(completely able to perform usual daily activities)*
☐ Class II *(able to perform usual self-care and vocational activities, but limited in avocational activities)*
☐ Class III *(able to perform usual self-care activities, but limited in vocational and avocational activities)*
☐ Class IV *(limited ability to perform usual self-care, vocational, and avocational activities)*
☐ Not done
☐ Unknown

Parent/Subject Questionnaires

Date completed: __ __ __ / __ __ / __ __ __ __
month day year

Person completing form: ☐ Mother ☐ Father ☐ Subject ☐ Other *(specify)*: _____

Parent

1 **How do you rate your child's health?** ☐ Excellent ☐ Very good ☐ Good ☐ Poor ☐ Very poor

2 **Considering all the ways that your child's rheumatic condition affects your child, rate how your child is doing:**

0	1	2	3	4	5	6	7	8	9	10
Very Well										Very Poor

Please circle one number

3 **We are also interested in learning whether or not your child has been affected by pain because of his/her rheumatic condition.**

How much pain do you think your child had because of his/her rheumatic condition in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Pain									Very	Severe Pain

Please circle one number

OR Subject

1 **How do you rate your health?** ☐ Excellent ☐ Very good ☐ Good ☐ Poor ☐ Very poor

2 **Considering all the ways that your rheumatic condition affects you, rate how you are doing:**

0	1	2	3	4	5	6	7	8	9	10
Very Well										Very Poor

Please circle one number

3 **We are also interested in learning whether or not you have been affected by pain because of your rheumatic condition.**

How much pain have you had because of your rheumatic condition in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Pain									Very	Severe Pain

Please circle one number

Childhood Health Assessment Questionnaire (CHAQ)

Instructions

In this section we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response that best describes your child's usual activities (averaged over an entire day) **OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS THAT ARE DUE TO ILLNESS**. If most children at your child's age are not expected to do a certain activity, please mark it as "Not Applicable." **For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but not because he/she is RESTRICTED BY ILLNESS, please mark it as "Not Applicable."**

CHAQ Functional Ability Scoring and Coding

(Adapted from the scanned instructions received from Dr. Nicola Ruperto)

The DAILY FUNCTION section is designed to assess the patient's functional ability over the past week. It is composed of eight categories, each of which has at least two component questions. Parents are also asked to indicate the use of any aids or devices or if the child needs help from another person for any of these activities. The eight categories are: dressing & grooming, arising, eating, walking, hygiene, reach, grip, and activities.

Possible responses for the component questions are:

Without ANY difficulty	= 0
With SOME difficulty	= 1
With MUCH difficulty	= 2
UNABLE to do	= 3

The highest score for any component question determines the score for that category. If a component question is left blank or the response is too ambiguous to assign a score, then the score for the category is determined by the remaining completed question(s). If all component questions are blank/not applicable, then the category is not scored and not used in the calculation of the final disability index.

If the parent's mark is between the response columns, then move it to the closest one. If it's directly between the two, move it to the higher one.

If either devices and/or help from another person is checked for a category, the score=2. This may determine the score unless the score on any other component question=3. For example, the response to "Dress yourself…" is with SOME difficulty (score=1). The parent has checked the use of a device for dressing, thereby increasing the score to 2. The response to "Shampoo your hair" is UNABLE to do (score=3). Therefore, the score for the DRESSING category is 3.

Devices associated with each category:

DRESSING & GROOMING	Devices used for dressing (button hook, zipper pull, long handles shoe horn, etc.)
ARISING	Built up or special chair
EATING	Built up pencil or special utensils
WALKING	Cane, walker, crutches, wheelchair
HYGIENE	Raised toilet set, bathtub seat, bathtub bar, long-handled appliances in bathroom
REACH	Long-handled appliances for reach
GRIP	Jar opener (for jars previously opened)

Devices written in the "Other" sections are considered only if they would be used for any of the stated categories.

Disability Index Calculation

The index is calculated by adding the scores for each of the categories and dividing by the number of categories answered. If questions in each category were answered, divide by 8. This gives a score in the 0 to 3.0 range.

Scoring worksheet:

1. Dressing and Grooming:	____	5. Hygiene:	____
2. Arising:	____	6. Reach:	____
3. Eating:	____	7. Grip:	____
4. Walking:	____	8. Activities:	____

Add scores from 1-8 above to get TOTAL: _____

Divide above TOTAL by number of answered categories to get Disability Index (0.00-3.00): ___.___ ___

Enter value in the above box for CHAQ score

Childhood Health Assessment Questionnaire (CHAQ)

Date completed: __ __ __ / __ __ / __ __ __ __
month *day* *year*

Person completing form: ☐ Mother ☐ Father ☐ Subject ☐ Other *(specify)*: _____

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
Dressing and Grooming: Is your child able to…					
Dress, including tying shoelaces and doing buttons?	☐	☐	☐	☐	☐
Shampoo his/her hair?	☐	☐	☐	☐	☐
Remove socks?	☐	☐	☐	☐	☐
Cut fingernails?	☐	☐	☐	☐	☐
Arising: Is your child able to…					
Stand up from a low chair or floor?	☐	☐	☐	☐	☐
Get in and out of bed or stand up in a crib?	☐	☐	☐	☐	☐
Eating: Is your child able to…					
Cut his/her own meat?	☐	☐	☐	☐	☐
Lift up a cup or glass to mouth?	☐	☐	☐	☐	☐
Open a new cereal box?	☐	☐	☐	☐	☐
Walking: Is your child able to…					
Walk outdoors on flat ground?	☐	☐	☐	☐	☐
Climb up five steps?	☐	☐	☐	☐	☐

Please check any AIDS or DEVICES that your child usually uses for any of the above activities:			
Cane	☐	**Devices used for dressing** *(button hook, zipper pull, long-handled shoe horn, etc.)*	☐
Walker	☐	**Built up pencil or special utensils**	☐
Crutches	☐	**Special or built up chair**	☐
Wheelchair	☐	**Other** *(specify)*:	☐

Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:			
Dressing and grooming	☐	Eating	☐
Arising	☐	Walking	☐

Reprinted from Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of health status in children with juvenile rheumatoid arthritis. Arthritis Rheum 1994; 37: 1761–9. With permission.

Childhood Health Assessment Questionnaire (CHAQ)					
	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
Hygiene: Is your child able to…					
Wash and dry entire body?	☐	☐	☐	☐	☐
Take a tub bath (get in and out of tub)?	☐	☐	☐	☐	☐
Get on and off the toilet or potty chair?	☐	☐	☐	☐	☐
Brush teeth?	☐	☐	☐	☐	☐
Comb/brush hair?	☐	☐	☐	☐	☐
Reach: Is your child able to…					
Reach and get down a heavy object such as a large game or books from just above his/her head?	☐	☐	☐	☐	☐
Bend down to pick up clothing or a piece of paper from the floor?	☐	☐	☐	☐	☐
Pull on a sweater over his/her head?	☐	☐	☐	☐	☐
Turn neck to look back over shoulder?	☐	☐	☐	☐	☐
Grip: Is your child able to…					
Write or scribble with pen or pencil?	☐	☐	☐	☐	☐
Open car doors?	☐	☐	☐	☐	☐
Open jars that have been previously opened?	☐	☐	☐	☐	☐
Turn faucets on and off?	☐	☐	☐	☐	☐
Push open a door when he/she has to turn a door knob?	☐	☐	☐	☐	☐
Activities: Is your child able to…					
Run errands and shop?	☐	☐	☐	☐	☐
Get in and out of a car or toy car or school bus?	☐	☐	☐	☐	☐
Ride bike or tricycle?	☐	☐	☐	☐	☐
Do household chores (e.g., wash dishes, take out trash, vacuuming, yard work, make bed, clean room)?	☐	☐	☐	☐	☐
Run and play?	☐	☐	☐	☐	☐

Please check any AIDS or DEVICES that your child usually uses for any of the above activities:			
Raised toilet seat	☐	Bathtub bar	☐
Bathtub seat	☐	Long-handled appliances for reach	☐
Jar opener *(for jars previously opened)*	☐	Long-handled appliances in bathroom	☐

Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:			
Hygiene	☐	Gripping and opening things	☐
Reach	☐	Errand and chores	☐

Follow-Up Physician Worksheet

Date completed: __ __ __ / __ __ / __ __ __ __
month day year

Rheumatologic Disease Diagnosis

What is the subject's rheumatologic disease diagnosis? *(If multiple, please select those that meet disease classification criteria.)*

☐ Mixed connective tissue disease
☐ Systemic lupus erythematosus
☐ Primary Sjögren's disease
☐ Systemic sclerosis
☐ Juvenile dermatomyositis
☐ Localized Scleroderma
☐ Juvenile idiopathic arthritis/Juvenile ankylosing spondylitis
☐ Chronic vasculitis (excluding Kawasaki and Henoch-Schönlein purpura)
☐ Sarcoid
☐ Auto-inflammatory disease (including fever syndromes, chronic recurrent multifocal osteomyelitis)
☐ Idiopathic uveitis (not associated with other rheumatologic disease)
☐ Juvenile primary fibromyalgia

Physician Global Assessment of Disease Activity

Instructions: Indicate the assessed level of this subject's disease activity. *(To be filled out the **same day** as subject's visit. Do not wait for laboratory results.)*

At this time, the overall disease activity is:

Not Active										Very Active
0	1	2	3	4	5	6	7	8	9	10

Please circle one number

ACR Functional Class

ACR functional class current *(check only one)***:**
☐ Class I *(completely able to perform usual daily activities)*
☐ Class II *(able to perform usual self-care and vocational activities, but limited in avocational activities)*
☐ Class III *(able to perform usual self-care activities, but limited in vocational and avocational activities)*
☐ Class IV *(limited ability to perform usual self-care, vocational, and avocational activities)*
☐ Not done
☐ Unknown

Disease Update

1 What is the subject's primary rheumatologic disease diagnosis? *(If multiple, please select those that meet disease classification criteria.)*

- ☐ Mixed connective tissue disease
- ☐ Systemic lupus erythematosus
- ☐ Primary Sjögren's disease
- ☐ Systemic sclerosis
- ☐ Juvenile dermatomyositis
- ☐ Localized scleroderma
- ☐ Juvenile idiopathic arthritis/ Juvenile ankylosing spondilitis
- ☐ Chronic vasculitis (excluding Kawasaki and Henoch-Schönlein purpura)
- ☐ Sarcoid
- ☐ Auto-inflammatory (including fever syndrome, Chronic recurrent multifocal osteomyelitis)
- ☐ Idiopathic uveitis (not associated with other rheumatologic disease)
- ☐ Juvenile primary fibromyalgia

2 Has the subject been hospitalized since the last study visit?

☐ Yes → **If Yes: Was this due to** *(check all that apply)***:**

- ☐ Flare of rheumatic disease
- ☐ Complication of disease
- ☐ Medication side effect
- ☐ Infection
- ☐ Malignancy
- ☐ Trauma/injury
- ☐ Other, specify: _____
- ☐ Unknown

☐ No
☐ Unknown

3 Has the subject had any newly diagnosed or acquired conditions since the last study visit?

☐ Yes → **If Yes: Check all that apply:**

- ☐ Autism spectrum disorder
- ☐ Auto-immune hepatitis
- ☐ Auto-immune thyroid disease
- ☐ Celiac disease
- ☐ Cerebral palsy
- ☐ Chronic asthma
- ☐ Congenital heart disease
- ☐ Cystic fibrosis
- ☐ Demyelinating disease
- ☐ Diabetes – Type 1
- ☐ Diabetes – Type 2
- ☐ Malignancy
- ☐ Primary immunodeficiency syndrome(s)
- ☐ Seizure disorder
- ☐ Other autoimmune disease *(specify)*: _____
- ☐ Other major congenital or acquired disease/condition *(specify)*: _____

☐ No
☐ Unknown

Medications Since Last Visit

Please indicate all sources of information used to answer medication items below:

☐ Family or subject recall ☐ Limited chart review ☐ Provider recall ☐ Complete chart review ☐ Other

Has the subject been in any blinded drug trial(s) where treatment assigned has not yet been revealed to physician or subject not yet transitioned to open-label phase?

☐ Yes → **Check all that apply:**

☐ Current study → **Specify drug(s):** _____

_____

☐ Post study → **Specify drug(s):** _____

_____

☐ No

☐ Unknown

1 Since the last study visit, has the subject taken any non-biologic immune modulators and disease-modifying antirheumatic drugs *(DMARDS)***:**

☐ No

☐ Yes → **If Yes: Check one answer per medication:**

Azathioprine *(Imuran)*	☐ Yes	☐ No	☐ Unknown
Cyclophosphamide oral *(Cytoxan)*	☐ Yes	☐ No	☐ Unknown
Cyclophosphamide pulse *(Cytoxan)*	☐ Yes	☐ No	☐ Unknown
Cyclosporine A *(Neoral, Sandimmune, Gengraf)*	☐ Yes	☐ No	☐ Unknown
Hydroxychloroquine *(Plaquenil)*	☐ Yes	☐ No	☐ Unknown
Leflunomide *(Arava)*	☐ Yes	☐ No	☐ Unknown
Methotrexate—oral	☐ Yes	☐ No	☐ Unknown
Methotrexate—subcutaneous	☐ Yes	☐ No	☐ Unknown
Mycophenylate mofetil *(CellCept, Myfortic)*	☐ Yes	☐ No	☐ Unknown
Sulfasalazine *(Azulfidine)*	☐ Yes	☐ No	☐ Unknown
Tacrolimus *(Prograf)*	☐ Yes	☐ No	☐ Unknown
Lenalidomide *(Revlimid)*	☐ Yes	☐ No	☐ Unknown
Thalidomide *(Thalomid)*	☐ Yes	☐ No	☐ Unknown
Colchicine *(Colcrys)*	☐ Yes	☐ No	☐ Unknown

Do not include drugs newly prescribed at this visit.

Medications Since Last Visit (continued)

2 Since the last study visit, has subject taken any Biologics?
☐ No ☐ Yes → **If Yes: Check one answer per medication:**

Abatacept *(Orencia)*	☐ Yes	☐ No	☐ Unknown
Adalimumab *(Humira)*	☐ Yes	☐ No	☐ Unknown
Anakinra *(Kineret)*	☐ Yes	☐ No	☐ Unknown
Belimumab *(Benlysta)*	☐ Yes	☐ No	☐ Unknown
Canakinumab *(Ilaris)*	☐ Yes	☐ No	☐ Unknown
Certolizumab *(Cimzia)*	☐ Yes	☐ No	☐ Unknown
Epratuzumab *(LymphoCide)*	☐ Yes	☐ No	☐ Unknown
Etanercept *(Enbrel)*	☐ Yes	☐ No	☐ Unknown
Golimumab *(Simponi)*	☐ Yes	☐ No	☐ Unknown
Infliximab *(Remicade)*	☐ Yes	☐ No	☐ Unknown
IVIG	☐ Yes	☐ No	☐ Unknown
Rilonacept *(Arcalyst)*	☐ Yes	☐ No	☐ Unknown
Rituximab (*Rituxan)*	☐ Yes	☐ No	☐ Unknown
Tocilizmab *(Actemra)*	☐ Yes	☐ No	☐ Unknown
Othe biologic *(specify)***:**	☐ Yes	☐ No	☐ Unknown
Other biologic *(specify)***:**	☐ Yes	☐ No	☐ Unknown

3 Since the last study visit has the subject taken any Glucocorticoids (other than inhaled and intranasal):
☐ No ☐ Yes → **If Yes: Check one answer per medication:**

Intraarticular corticosteroids	☐ Yes	☐ No	☐ Unknown
IV pulse steroids	☐ Yes	☐ No	☐ Unknown
Systemic corticosteroids long term daily	☐ Yes →	☐ No	☐ Unknown
If Yes: What is cumulative exposure?	☐ < 1 month	☐ ≥ 1 month	☐ Unknown
Intraocular injections	☐ Yes	☐ No	☐ Unknown
Steroid eye drops	☐ Yes	☐ No	☐ Unknown

4 Since the last study visit has the subject taken any of these other drugs of interest?
☐ No ☐ Yes → **If Yes: Check one answer per medication:**

Daily nonsteroidal anti-inflammatory drugs *(NSAIDs)*	☐ Yes	☐ No	☐ Unknown
Selective serotonin reuptake inhibitors *(SSRIs)*	☐ Yes	☐ No	☐ Unknown
Tri-cyclic antidepressants	☐ Yes	☐ No	☐ Unknown
Serotonin norepinephrine reuptake inhibitors *(SNRIs)*	☐ Yes	☐ No	☐ Unknown
Gamma-amniobutyric acid *(GABA)* **analogues**	☐ Yes	☐ No	☐ Unknown
Opioids	☐ Yes	☐ No	☐ Unknown
Cimetidine	☐ Yes	☐ No	☐ Unknown
Herbals or non-vitamin supplements	☐ Yes	☐ No	☐ Unknown

Do not include drugs newly prescribed at this visit.

Juvenile Idiopathic Arthritis/ Juvenile Ankylosing Spondylitis Disease Specific Form Follow-up

1 **Physician assigned category** *(check only one)*:

- ❑ Systemic JIA
- ❑ Polyarticular RF (–)
- ❑ Polyarticular RF (+)
- ❑ Oligoarticular persistent
- ❑ Oligoarticular extended
- ❑ Psoriatic
- ❑ ERA
- ❑ Undifferentiated
- ❑ Juvenile Ankylosing Spondylitis (JAS)
- ❑ Other

2 **Total number of joints affected with arthritis since last study visit:** ❑ None ❑ 1-4 joints ❑ ≥ 5 joints

3 **Total number of currently active joints:** _____

4 **Has subject had any of the following disease manifestations since the last study visit:**

Quotidian fever attributable to JIA	❑ Yes ❑ No ❑ Unknown
Evanescent rash	❑ Yes ❑ No ❑ Unknown
Generalized lymphadenopathy	❑ Yes ❑ No ❑ Unknown
Hepatomegaly	❑ Yes ❑ No ❑ Unknown
Splenomegaly	❑ Yes ❑ No ❑ Unknown
Serositis	❑ Yes ❑ No ❑ Unknown
Nail pitting	❑ Yes ❑ No ❑ Unknown
Dactylitis	❑ Yes ❑ No ❑ Unknown
Leg length discrepancy	❑ Yes ❑ No ❑ Unknown
Psoriasis	❑ Yes ❑ No ❑ Unknown
Enthesitis	❑ Yes ❑ No ❑ Unknown
Sacroiliac joint tenderness and/or inflammatory lumbosacral pain	❑ Yes ❑ No ❑ Unknown
Limited lumbosacral mobility (modified Schober test)	❑ Yes ❑ No ❑ Unknown
Inflammatory bowel disease	❑ Yes ❑ No ❑ Unknown
Uveitis	❑ Yes ❑ No ❑ Unknown *If Current, complete Follow-Up Uveitis form*
Pulmonary hypertension	❑ Yes ❑ No ❑ Unknown
Rheumatoid nodules	❑ Yes ❑ No ❑ Unknown
Interstitial lung disease	❑ Yes ❑ No ❑ Unknown

5 **Has the subject had any of the following positive diagnostic tests since the last study visit:**

Positive Anti-CCP	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive IgM RF	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive HLAB27	❑ Yes ❑ No ❑ Not done ❑ Unknown

6 **Has the subject had any joint imaging done since the last study visit?**

❑ Yes → **if Yes: Indicate findings** (check all that apply)**:**

- ❑ Normal
- ❑ Joint space narrowing
- ❑ Erosion
- ❑ Ankylosis
- ❑ Sacroiliac involvement
- ❑ Other

❑ No

❑ Unknown

7 **Parent/subject assessment of disease activity** (from worksheet)**:** _____ **OR** ❑ Not done

RHEUMATOLOGIC JOINT ASSESSMENT (page 1 of 2)

Date of visit (dd/mmm/yyyy): __ __ /__ __ __ / __ __ __ __	**Visit: _____**

RIGHT SIDE				UPPER	LEFT SIDE			
Swelling	POM	Tend	LOM	Joint	Swelling	POM	Tend	LOM
				Temp. Mand.				
			N/A	**Sterno.clav**				N/A
			N/A	**Acro. Clav.**				N/A
				Shoulder				
				Elbow				
				Wrist				
				MCP I				
				MCP II				
				MCP III				
				MCP IV				
				MCP V				
				PIP I				
				PIP II				
				PIP III				
				PIP IV				
				PIP V				
				DIP II				
				DIP III				
				DIP IV				
				DIP V				

RHEUMATOLOGIC JOINT ASSESSMENT (page 2 of 2)

Date of visit (dd/mmm/yyyy): __ __ /__ __ __ / __ __ __ __

RIGHT SIDE				LOWER	LEFT SIDE			
Swelling	POM	Tend	LOM	Joint	Swelling	POM	Tend	LOM
N/A				**Hip**	N/A			
				Knee				
				Ankle				
N/A				**Subtalar**	N/A			
				Tarsi				
				MTP I				
				MTP II				
				MTP III				
				MTP IV				
				MTP V				
				Toes (PIP) I				
				Toes (PIP) II				
				Toes (PIP) III				
				Toes (PIP) IV				
				Toes (PIP) V				
NA			N/A	**Sacroiliac**	N/A			N/A
				Cervical spine	N/A			
				Thoracic spine	N/A			
				Lumbar spine	N/A			

_____ (to be signed by assessor)

Parent/Subject Disease Activity Assessment (JIA only)

Date completed: __ __ __ / __ __ / __ __ __ __
month day year

Person completing form: ☐ Mother ☐ Father ☐ Subject ☐ Other *(specify)*: _____

Parent

How do you rate your child's disease activity in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Disease										Very Active

Please circle one number

OR Subject

How do you rate your disease activity in the past week?

0	1	2	3	4	5	6	7	8	9	10
No Disease										Very Active

Please circle one number

Juvenile Dermatomyositis Disease Specific Form — Follow-up

1 **JDM category** (check one): ❑ Definite ❑ Probable ❑ Amyopathic

2 **Childhood Myositis Assessment Scale** (CMAS) **score** (0–52)**:** ___ ___ **OR** ❑ Not done

3 **Manual muscle test (MMT-8**) **score** (0–80)**:** ___ ___ **OR** ❑ Not done

4 **Does the subject have any of the following disease manifestations at today's study visit** (please answer all questions)**:**

Symmetric proximal muscle weakness	❑ None ❑ Mild ❑ Moderate ❑ Severe ❑ Not done
Gottren's sign, papules or heliotrope	❑ Yes ❑ No ❑ Not done ❑ Unknown
Malar or facial erythema	❑ Yes ❑ No ❑ Not done ❑ Unknown
V or shawl sign	❑ Yes ❑ No ❑ Not done ❑ Unknown
Lipodystrophy	❑ Yes ❑ No ❑ Not done ❑ Unknown
Skin ulcers	❑ Yes ❑ No ❑ Not done ❑ Unknown
Periungual telangiectasia (nailfold capillary changes)	❑ Yes ❑ No ❑ Not done ❑ Unknown
Contractures	❑ Yes ❑ No ❑ Not done ❑ Unknown

5 **Has the subject had documented evidence of the following since the last study visit:**

Calcinosis	❑ Yes ❑ No ❑ Unknown
Small joint arthritis	❑ Yes ❑ No ❑ Unknown
Large joint arthritis	❑ Yes ❑ No ❑ Unknown
Dysphagia or dysphonia	❑ Yes ❑ No ❑ Unknown
Muscle enzyme elevation	❑ Yes ❑ No ❑ Unknown
Cardiac involvement	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Arrhythmia ❑ Decreased cardiac output ❑ Myocarditis ❑ Other ❑ No ❑ Unknown
Interstitial lung disease	❑ Yes ❑ No ❑ Unknown
GI ulceration due to JDM	❑ Yes ❑ No ❑ Unknown

6 **Has the subject had any of the following diagnostic assessments since the last study vist:**

Pulmonary function testing (PFTs)	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Normal ❑ Decreased FVC ❑ Decreased DLCO ❑ Reversible airway disease ❑ Other ❑ No ❑ Not done ❑ Unknown
MRI consistent with inflammatory muscle disease	❑ Yes ❑ No ❑ Not done ❑ Unknown
EMG consistent with inflammatory myopathy	❑ Yes ❑ No ❑ Not done ❑ Unknown
Muscle biopsy consistent with inflammatory muscle disease	❑ Yes ❑ No ❑ Not done ❑ Unknown

CHILDHOOD MYOSITIS ASSESSMENT SCALE (CMAS) SCORING SHEET

1. HEAD LIFT:
   0 = Unable 3 = 30-59
   1 = 1-9 sec 4 = 60-119 sec
   2 = 10-29 5 = > 2 min
   Score ____

2. LEG RAISE/TOUCH OBJECT:
   0 = Unable to lift leg off table.
   1 = Able to clear table, but cannot touch object (examiner's hand).
   2 = Able to lift leg high enough to touch object (examiner's hand).
   Score ____

3. STRAIGHT LEG LIFT/DURATION:
   0 = Unable 3 = 30-59 sec
   1 = 1-9 sec 4 = 60-119 sec
   2 = 10-29 sec 5 = > 2 min
   Score ____

4. SUPINE TO PRONE:
   0 = Unable. Has difficulty even turning onto side; able to pull right arm under torso only slightly or not at all.
   1 = Turns onto side fairly easily, but cannot fully free right arm and is unable to fully assume a prone position.
   2 = Easily turns onto side; has some difficulty freeing arm, but fully frees arm and fully assumes a prone position.
   3 = Easily turns over, fully frees right arm with no difficulty.
   Score ____

5. SITS-UPS:
   Hands on thighs, with counterbalance ____
   Hands across chest, with counterbalance ____
   Hands behind head, with counterbalance ____
   Hands on thighs, without counterbalance ____
   Hands across chest, without counterbalance ____
   Hands behind head, without counterbalance ____
   Score (0-6) ____

6. SUPINE TO SIT:
   0 = Unable by self.
   1 = Much difficulty. Very slow, struggles greatly, barely makes it. Almost unable.
   2 = Some difficulty. Able, but is somewhat slow, struggles some.
   3 = No difficulty.
   Score ____

7. ARM RAISE/STRAIGHTEN:
   0 = Cannot raise wrists up to the level of the A-C joint.
   1 = Can raise wrists at least up to the level of the A-C joint, but not above top of head.
   2 = Can raise wrists above top of head, but cannot raise arms straight above head so that elbows are in full extension.
   3 = Can raise arms straight above head so that elbows are in full extension.
   Score ____

8. ARM RAISE/DURATION: Can maintain wrists above top of head for:
   0 = Unable 3 = 30-59 sec
   1 = 1-9 sec 4 = > 60 sec
   2 = 10-29 sec
   Score ____

9. FLOOR SIT: Going from a standing position to a sitting position on the floor:
   0 = Unable. Afraid to even try, even if allowed to use a chair for support. Child fears that he/she will collapse, fall into a sit, or harm self.
   1 = Much difficulty. Able, but needs to hold onto a chair for support during descent. Unable, or unwilling to try if not allowed to use a chair for support.
   2 = Some difficulty. Can go from stand to sit without using a chair for support, but has at least some difficulty during descent. May need Gower's. Descends somewhat slowly and/or apprehensively; may not have full control or balance as maneuvers into a sit.
   3 = No difficulty. Requires no compensatory maneuvering.
   Score ____

10. ALL FOURS MANEUVER:
    0 = Unable to go from a prone to an all-fours position.
    1 = Barely able to assume and maintain an all-fours position. Unable to raise head to look straight ahead.
    2 = Can maintain all-fours position with back straight and head raised (so as to look straight ahead). But, cannot creep (crawl) forward.
    3 = Can maintain all-fours, look straight ahead and creep (crawl) forward.
    4 = Maintains balance while lifting and extending one leg.
    Score ____

11. FLOOR RISE: Going from a kneeling position on the floor to a standing position:
    0 = Unable, even if allowed to use a chair for support.
    1 = Much difficulty. Able, but needs to use a chair for support. (Unable if not allowed to use a chair.)
    2 = Moderate difficulty. Able to get up without using a chair for support, but needs to place one or both hands on thighs/knees or floor. (Unable without using hands.)
    3 = Mild difficulty. Does not need to place hands on knees, thighs or floor, but has at least some difficulty during ascent.
    4 = No difficulty.
    Score ____

12. CHAIR RISE:
    0 = Unable to rise up from chair, even if allowed to place hands on sides of chair seat.
    1 = Much difficulty. Able, but needs to place hands on sides of seat. Unable if not allowed to place hands on sides of seat.
    2 = Moderate difficulty. Able, but needs to place hands on knees/thighs. Does not need to place hands on sides of seat.
    3 = Mild difficulty. Does not need to place hands on seat, knees or thighs but has at least some difficulty during ascent.
    4 = No difficulty.
    Score ____

13. STOOL STEP:
    0 = Unable.
    1 = Much difficulty. Able, but needs to place one hand on exam table (or examiner's hand).
    2 = Some difficulty. Able, does not need to use exam table for support, but needs to use hand on knee/thigh.
    3 = Able. Does not need to use exam table or hand on knee/thigh.
    Score ____

14. PICK-UP:
    0 = Unable to bend over and pick up pencil off floor.
    1 = Much difficulty. Able, but relies heavily on support gained by placing hands on knees/thighs.
    2 = Some difficulty. Has some difficulty (but not "much-difficulty"). Needs to at least minimally and briefly place hand(s) on knees/thighs for support. Is somewhat slow.
    3 = No difficulty. No compensatory maneuver necessary.
    Score ____

TOTAL CMAS SCORE: _____

The maximum possible total score for the 14 maneuvers is 52

Systemic Sclerosis Disease Specific Form — Follow-up

1 Is disease manifestation present at today's study visit? Please answer all questions.

Skin changes	❑ Yes → **If Yes: Check all that apply:** ❑ Face ❑ Trunk ❑ Sclerodactyly ❑ Calcinosis ❑ Proximal to MCPs ❑ Proximal to elbow ❑ Telangiectasia ❑ Other ❑ No
Nail-bed capillary abnormalities	❑ Yes ❑ No
Digital ulceration/gangrene	❑ Yes ❑ No
Raynaud's	❑ Yes ❑ No
Musculoskeletal disease	❑ Yes → **If Yes: Check all that apply:** ❑ Contractures ❑ Myositis ❑ Tendinopathy ❑ Other ❑ Arthritis ❑ No

2 Has the subject had any of the following disease manifestations since the last study visit?

Pulmonary involvement: Were any studies done?	❑ Yes → **If Yes: Check all abnormalities noted:** ❑ None ❑ Dyspnea ❑ Decreased DLCO/hypoxemia ❑ Parenchymal pulmonary disease ❑ Restrictive lung disease ❑ Radiologic or pathologic evidence of fibrosis ❑ Pulmonary hypertension ❑ Other ❑ No
Cardiac disease	❑ Yes → **If Yes: Check all that apply:** ❑ Pericardial effusion ❑ Angina ❑ Arrhythmia ❑ Other ❑ Myocardiopathy ❑ No
Renal disease	❑ Yes → **If Yes: Check all that apply:** ❑ Abnormal urinary sediment ❑ Renovascular hypertension ❑ Elevated creatinine ❑ Imaging abnormality ❑ Fibrosis on biopsy ❑ Other ❑ No
GI disease	❑ Yes → **If Yes: Check all that apply:** ❑ Dysphagia ❑ Documented GERD ❑ GI dysmotility ❑ Esophagitis ❑ Stricture ❑ Malabsorption ❑ Other ❑ No

Localized Scleroderma Disease Specific Form — Follow-up

1 **Localized scleroderma subtype** (check all that apply)**:**

- ❑ Circumscribed morphea → **Check all that apply:** ❑ Superficial ❑ Deep
- ❑ Linear scleroderma → **Check all that apply:** ❑ Linear involving trunk/limbs ❑ Linear involving face/scalp (En coup de saber, Parry-Romberg)
- ❑ Generalized morphea
- ❑ Pansclerotic morphea
- ❑ Eosinophilic fascilitis
- ❑ Other

2	**Location of lesions** (check all that apply)**:**	❑ Scalp ❑ Chest ❑ Arm ❑ Thigh ❑ Face ❑ Back ❑ Forearm ❑ Leg ❑ Neck ❑ Buttock ❑ Hand ❑ Foot ❑ Abdomen ❑ Other, specify: _____
3	**Does the subject have any of the following disease manifestations on today's study visit or documented since the last study visit?** Please answer all questions.	
	New lesion(s)	❑ Yes ❑ No ❑ Unknown
	Extension of previous lesion(s)	❑ Yes ❑ No ❑ Unknown
	Erythematous/violaceous lesion color	❑ Yes ❑ No ❑ Unknown
	Lesion warmth	❑ Yes ❑ No ❑ Unknown
	Skin Induration perimeter lesion	❑ Yes ❑ No ❑ Unknown
	Skin Thickening center of lesion	❑ Yes ❑ No ❑ Unknown
	Dermal atrophy	❑ Yes ❑ No ❑ Unknown
	Subcutaneous atrophy	❑ Yes ❑ No ❑ Unknown
	Hyperpigmentation	❑ Yes ❑ No ❑ Unknown
	Hypopigmentation	❑ Yes ❑ No ❑ Unknown
	Hair loss associated with lesion	❑ Yes ❑ No ❑ Unknown
	Muscle atrophy	❑ Yes ❑ No ❑ Unknown
	Extremity shortening	❑ Yes ❑ No ❑ Unknown
	Joint contracture	❑ Yes → **If Yes: Specify number of joints affected:** ❑ 1 ❑ 2 ❑ 3 ❑ 4 ❑ 5 ❑ > 5 ❑ None ❑ Unknown
	Hemifacial atrophy	❑ Yes ❑ No ❑ Unknown
4	**Does the subject have any extracutaneous manifestations on today's study visit or documented since the last study visit?**	❑ Yes → **If Yes: Check all that apply:** ❑ Arthritis ❑ GI involvement ❑ Neurological involvement ❑ Eye involvement ❑ Other ❑ No ❑ Unknown
5	**Has the subject had any laboratory findings or imaging abnormalities since the last study visit?** Please answer all questions below.	
	Abnormal CK	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Abnormal aldolase	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Presence of eosinophilia	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Elevated IgG	❑ Yes ❑ No ❑ Not done ❑ Unknown
	CNS imaging abnormality	❑ Yes ❑ No ❑ Not done ❑ Unknown
	GI study abnormality	❑ Yes ❑ No ❑ Not done ❑ Unknown

Juvenile Primary Fibromyalgia Syndrome Disease Specific Form — Follow-up

1	**Has this subject had any of the following symptoms within the last month** (please answer all questions)**?**	
	Widespread pain?	❑ Yes ❑ No ❑ Unknown
	Disordered sleep?	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Non-restorative ❑ Increased sleep latency ❑ Hypersomnia ❑ Frequent wakings ❑ Other ❑ No ❑ No, on medication ❑ Unknown
	Frequent headaches?	❑ Yes ❑ No ❑ Unknown
	Irritable bowel syndrome (IBS) symptoms with prior physician diagnosis?	❑ Yes ❑ No ❑ Unknown
	Subjective soft tissue swelling of the extremities?	❑ Yes ❑ No ❑ Unknown
	Numbness and tingling of the extremities?	❑ Yes ❑ No ❑ Unknown
	Pain modulated by physical activity?	❑ Yes ❑ No ❑ Unknown
	Pain modulated by weather?	❑ Yes ❑ No ❑ Unknown
	Pain modulated by stress/anxiety?	❑ Yes ❑ No ❑ Unknown
	Fatigue?	❑ Yes ❑ No ❑ Unknown
2	**Has subject participated in organized physical activity since last study visit?**	❑ Yes ❑ Yes, but curtailed due to pain ❑ No ❑ Unknown
3	**Has subject been diagnosed with depression and/or anxiety disorder since last study visit?**	❑ Yes ❑ No ❑ Unknown

4 **What treatments have been recommended/prescribed/provided by a pediatric rheumatologist to the subject since the last study visit** (check all that apply)**?**

❑ Education regarding fibromyalgia and chronic pain	❑ Referral for psychotropic medications
❑ Sleep hygiene	❑ Pain clinic ➔ **Choose type of pain clinic:** ❑ Pediatric pain clinic ❑ Adult pain clinic
❑ Graduated aerobic exercise program	
❑ Physical therapy for stretching and strengthening	
❑ General counseling	❑ Integrative medicine clinic referral
❑ Cognitive behavioral therapy	❑ Rehabilitation clinic referral
❑ Biofeedback	❑ Other
❑ Medications	❑ None

Juvenile Primary Fibromyalgia Syndrome Disease Specific Form — Follow-up (continued)	
5 **Did subject pursue these recommendations since the last study visit?**	❑ None of recommendations were pursued ➔ **If None: In dicate reason** (check all that apply)**:** ❑ Services not available ❑ Insurance would not cover services ❑ Subject/family not interested ❑ Other ❑ Only some recommendations were pursued ➔ **If Only some: In dicate reason** (check all that apply)**:** ❑ Services not available ❑ Insurance would not cover services ❑ Subject/family not interested ❑ Other ❑ Most or all recommendations were pursued ❑ Recommendations made today ❑ Unknown
6 **Has subject used other therapies since the last study visit?**	❑ Yes ➔ **If Yes: Check all that apply:** ❑ Acupuncture/acupressure ❑ Craniosacral therapy ❑ Mindfulness/meditation ❑ Therapeutic massage ❑ Physical therapy ❑ Dietary supplements/herbal remedies ❑ Hypnosis ❑ Yoga ❑ Chiropractor ❑ Other ❑ No ❑ Unknown

SLE / MCTD / Sjögren's Disease Specific Form — Follow-up

1 Disease manifestation present? (Please answer all questions.)

Seizure*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Psychosis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Organic Brain Syndrome*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Visual Disturbance*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Cranial Nerve Disorder*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Other neurological manifestation (other than seizure, psychosis, organic brain syndrome, visual disturbance or cranial nerve disorder)	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Lupus headache*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Cerebral vascular accident*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Arthritis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Myositis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Sclerodactyly or swollen hands	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Raynaud's	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Esophageal dysmotility	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown

SLE / MCTD / Sjögren's Disease Specific Form — Follow-up (continued)	
Vasculitis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Rash*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Alopecia*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Mucosal ulcers*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
SICCA syndrome	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Fever > 38° C*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Pleurisy*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Pericarditis*	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Myocarditis	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown
Pulmonary involvement	❑ Yes, in the last 10 days ➔ **If Yes: Check all that apply:** ❑ Decreased adjusted DLCO (diffusion capacity) ❑ Pneumonitis ❑ Pulmonary hypertension ❑ Lung biopsy performed ❑ Other ❑ Yes, in the last 11 days thru last study visit ➔ **If Yes: Check all that apply:** ❑ Decreased adjusted DLCO (diffusion capacity) ❑ Pneumonitis ❑ Pulmonary hypertension ❑ Lung biopsy performed ❑ Other ❑ No ❑ Unknown
Dialysis	❑ Yes, in the last 10 days ❑ Yes, in the last 11 days thru last study visit ❑ No ❑ Unknown

**** Questions are from SLEDAI; EDC will calculate and display the total score.***

SLE / MCTD / Sjögren's Disease Specific Form — Follow-up (continued)

2	**Has subject had an arterial thrombotic event since the last study visit?**	❑ Yes ❑ No ❑ Unknown
3	**Has subject had a venous thrombotic event since the last study visit?**	❑ Yes ❑ No ❑ Unknown
4	**Has subject been diagnosed with coronary heart disease since the last study visit?**	❑ Yes ❑ No ❑ Unknown
5	**Has subject had imaging evidence of avascular necrosis of any joint since the last study visit?**	❑ Yes ❑ No ❑ Unknown
6	**Has subject had a renal transplant since the last study visit?**	❑ Yes ❑ No ❑ Unknown
7	**Has subject been diagnosed with renal disease since the last study visit?**	❑ Yes **If Yes: Check all that apply:** ❑ Glomerulonephritis ❑ Nephrotic syndrome ❑ Interstitial nephritis ❑ Other ❑ No ❑ Unknown
Biopsies		
8	**Has the subject had any non-renal biopsies consistent with disease diagnosis since the last study visit?**	❑ Yes → **If Yes: Check all that apply:** ❑ Skin ❑ Lacrimal gland ❑ Conjuctiva ❑ Liver ❑ Lung ❑ Other ❑ No ❑ Unknown

9 **Has subject had one or more renal biopsies since last study visit?** ❑ Yes → **If Yes: Answer questions below** ❑ No

Biopsy Date: MMM/YYYY	WHO Class (I–VI) *Check all that apply*	And/OR ISN/RPS Class (I–VI) *Check all that apply*
__ __ __ / __ __ __ __ *month* *year* ***OR record UNK for portion of date unknown***	❑ I ❑ II ❑ III ❑ IV ❑ V ❑ VI ❑ Unknown ❑ Not done	❑ I ❑ II ❑ III → **Check one:** ❑ Active ❑ Active/chronic ❑ Chronic ❑ Unknown ❑ IV → **Check one:** ❑ Segmented (active) ❑ Global (active) ❑ Segmented (active/chronic) ❑ Segmented (chronic) ❑ Global (chronic) ❑ Unknown ❑ V ❑ VI ❑ Unknown ❑ Not done
__ __ __ / __ __ __ __ *month* *year* ***OR record UNK for portion of date unknown***	❑ I ❑ II ❑ III ❑ IV ❑ V ❑ VI ❑ Unknown ❑ Not done	❑ I ❑ II ❑ III → **Check one:** ❑ Active ❑ Active/chronic ❑ Chronic ❑ Unknown ❑ IV → **Check one:** ❑ Segmented (active) ❑ Global (active) ❑ Segmented (active/chronic) ❑ Segmented (chronic) ❑ Global (chronic) ❑ Unknown ❑ V ❑ VI ❑ Unknown ❑ Not done
__ __ __ / __ __ __ __ *month* *year* ***OR record UNK for portion of date unknown***	❑ I ❑ II ❑ III ❑ IV ❑ V ❑ VI ❑ Unknown ❑ Not done	❑ I ❑ II ❑ III → **Check one:** ❑ Active ❑ Active/chronic ❑ Chronic ❑ Unknown ❑ IV → **Check one:** ❑ Segmented (active) ❑ Global (active) ❑ Segmented (active/chronic) ❑ Segmented (chronic) ❑ Global (chronic) ❑ Unknown ❑ V ❑ VI ❑ Unknown ❑ Not done

SLE / MCTD / Sjögren's Disease Specific Form — Follow-up (continued)

10 Serologies (Please answer all questions.)

Positive Anti-Smith (Sm) **antibodies since last study visit?**	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-RNP antibodies since last study visit?	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-Ro antibodies since last study visit?	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive Anti-La antibodies since last study visit?	❑ Yes ❑ No ❑ Not done ❑ Unknown
Positive anti-phospholipid antibodies (including anti-cardiolipin antibodies), **anti-β2 glycoprotein 1 antibodies or positive lupus anticoagulant since last study visit?**	❑ Yes ❑ No ❑ Not done ❑ Unknown
Anti-double stranded DNA antibodies in the past 10 days?*	❑ Yes → **If Yes: Was the test positive?** ❑ Yes ❑ No ❑ No → **If No: Has test been performed since the last study visit?** ❑ Yes → **If Yes: Was the test positive?** ❑ Yes ❑ No ❑ Unknown ❑ No ❑ Unknown
Complement levels (C3, C4, CH50) **in the past 10 days?***	❑ Yes → **If Yes: Are any of the levels below the lower limits of normal?** ❑ Yes ❑ No ❑ No → **If No: Have these tests been performed since the last study visit?** ❑ Yes → **If Yes: Were any of the levels below the lower limits of normal?** ❑ Yes ❑ No ❑ Unknown ❑ No ❑ Unknown

11 Cytopenias (Please answer all questions.)

Anemia hemoglobin (< 11 g/dL)	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
Leukopenia (< 3000 white blood cells/mm ^{3}*)	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
Thrombocytopenia (< 100K platelets/mm ^{3}*)	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown

SLE / MCTD / Sjögren's Disease Specific Form rm — Follow-up (continued)

12 Urinalysis and renal function tests (Please answer all questions.)

Urinary casts*	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
Hematuria (> 5 red cells)*	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
Pyuria (> 5 white cells)*	❑ Yes, in the last 10 days ❑ No ❑ Not done ❑ Unknown
Proteinuria (> 0.5 protein/creatinine ratio or > 500 mg protein/24 h) **in last 10 days?***	❑ Yes → **If Yes: Is this a new onset or increase of > 0.5 protein/creatinine ratio or > 500 mg protein/24h?** ❑ Yes ❑ No ❑ No → **If No: Has proteinuria** (> 0.5 protein/creatinine ratio pr > 500 mg protein/24h) **been present since the last study visit?** ❑ Yes ❑ No ❑ Not done ❑ Unknown ❑ Not done ❑ Unknown
Sample from the first void of the day?	❑ Yes ❑ No ❑ Not done ❑ Unknown
Serum creatinine (most recent)	_____ mg/dL OR ❑ Not done ❑ Unknown

**** Questions are from SLEDAI; EDC will calculate and display the total score.***

Sarcoid Disease Specific Form — Follow-up

1	**Is disease manifestation present at today's study visit?** Please answer all questions.	
	Lymphadenopathy	❑ Yes → **If Yes: Check all that apply:** ❑ Abdominal/pelvic ❑ Mediastinal ❑ Peripheral ❑ Other ❑ No ❑ Unknown
	Skin lesions	❑ Yes → **If Yes: Check all that apply:** ❑ Livedo reticularis ❑ Macules ❑ Papules ❑ Nodules ❑ Ulcers ❑ Erythema nodosum ❑ Other ❑ No ❑ Unknown
	Hepato- or splenomegaly	❑ Yes ❑ No ❑ Unknown
	Arthritis	❑ Yes ❑ No ❑ Unknown
2	**Has subject had any of the following disease manifestations since the last study visit?**	
	Pulmonary disease	❑ Yes → **If Yes: Check all that apply:** ❑ Pleural disease ❑ Parenchymal pulmonary disease ❑ Restrictive lung disease ❑ Other ❑ No ❑ Unknown
	Hepatic involvement	❑ Yes ❑ No ❑ Unknown
	Uveitis	❑ Yes ❑ No ❑ Unknown
	Cardiac involvement	❑ Yes ❑ No ❑ Unknown
	Renal involvement	❑ Yes ❑ No ❑ Unknown
	Bone lesions	❑ Yes ❑ No ❑ Unknown
	Neurologic involvement	❑ Yes ❑ No ❑ Unknown
3	**Results of diagnostic tests done at today's study visit or within the last month:**	
	Hypercalcuria or hypercalcemia	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Elevated ACE	❑ Yes ❑ No ❑ Not done ❑ Unknown
4	**Has the subject had a biopsy with histology consistent with sarcoid since the last study visit?**	❑ Yes → **If Yes: Check all that apply:** ❑ Bone ❑ Lymph node ❑ Conjunctiva ❑ Parotid ❑ Lung ❑ Skin ❑ Kidney ❑ Synovium ❑ Liver ❑ Other ❑ Biopsies performed, but not consistent with sarcoid ❑ No biopsies performed ❑ Unknown

Vasculitis Disease Specific Form — Follow-up

1	**Vasculitis diagnosis** (check only one)**:**	❑ Childhood Wegener's Granulomatosis ❑ Childhood Systemic Polyarteritis Nodosa ❑ Childhood Takayasu's Arteritis ❑ Microscopic Polyangitis ❑ Primary Central Nervous System Vasculitis ❑ Cutaneous Polyarteritis Nodosa ❑ Behcet's Syndrome ❑ Churg-Strauss Syndrome
2	**Has subject had any of the following disease manifestations since the last study visit?** Please answer all questions.	
	Hypertension (or on chronic antihypertensive medications)	❑ Yes ❑ No ❑ Unknown
	Skin lesions	❑ Yes ❑ No ❑ Unknown
	Mucosal involvement	❑ Yes ❑ No ❑ Unknown
	Eye involvement	❑ Yes ❑ No ❑ Unknown
	Upper respiratory tract involvement	❑ Yes ❑ No ❑ Unknown
	Lower respiratory tract involvement	❑ Yes ❑ No ❑ Unknown
	Renal involvement	❑ Yes ❑ No ❑ Unknown
	Renal insufficiency	❑ Yes ➔ **If Yes: Check treatment** ❑ On dialysis ❑ Not on dialysis ❑ Received renal transplant ❑ Other ❑ No ❑ Unknown
	Liver involvement	❑ Yes ❑ No ❑ Unknown
	Intestinal involvement	❑ Yes ❑ No ❑ Unknown
	Cardiovascular involvement	❑ Yes ❑ No ❑ Unknown
	Central nervous system involvement	❑ Yes ❑ No ❑ Unknown
	Peripheral nervous system involvement	❑ Yes ❑ No ❑ Unknown
	Arthritis	❑ Yes ❑ No ❑ Unknown
	Positive c-ANCA or anti-PR3	❑ Yes ❑ No ❑ Not done ❑ Unknown
	Positive p-ANCA or anti-MPO	❑ Yes ❑ No ❑ Not done ❑ Unknown

Autoinflammatory Disease Specific Form — Follow-up	
1 Current diagnosis (check all that apply)**:**	❑ CH **(**Cyclic hematopoiesis) ❑ CINCA **(**Chronic infantile neurological cutaneous and articular syndrome) / NOMID **(**Neonatal-onset multisystem inflammatory disease) ❑ CRMO (Chronic recurrent multifocal osteomyelitis) ❑ DIRA **(**Deficiency of interleukin-1 receptor antagonist) ❑ FCAS(Familial cold autoinflammatory syndrome **)** ❑ FMF (Familial Mediterranean fever) ❑ HIDS (Hyperimmunoglobulin (Ig) D syndrome) ❑ Majeed syndrome ❑ MWS **(**Muckle-Wells syndrome) ❑ PAPA **(**Pyogenic arthritis, pyoderma gangrenosum, and acne syndrome) ❑ PFAPA (Periodic fever, aphthous stomatitis, pharyngitis, adenitis syndrome) ❑ SAPHO (Synovitis, acne, pustulosis, hyperostosis, osteitis) ❑ TRAPS (TNF receptor-associated periodic syndrome) ❑ Unknown origin ❑ Other
2 Has subject had positive genetic test(s) confirming diagnosis since last study visit?	❑ Yes ❑ No ❑ Not applicable ❑ Unknown
3 Has there been disease activity in the last six months?	❑ Yes ❑ No ❑ Unknown

Uveitis Disease Specific Form — Follow-Up

1 Uveitis type *(check only one)*:	❑ Anterior uveitis (includes: iritis, iridocyclitis, anterior cyclitis) ❑ Intermediate uveitis (includes: pars planitis, posterior cyclitis, hyalitis) ❑ Posterior uveitis (includes: choroiditis, chorioretinitis, retinochorioditis, retinitis, neuroretinitis) ❑ Panuveitis (anterior uveitis, + intermediate and/ or posterior uveitis)
2 Since the last study visit, has the uveitis changed in terms of involvement of additional eye?	❑ Yes → **If Yes: Which eye(s) ever involved** *(check all that apply)*? ❑ Right ❑ Left ❑ Unknown ❑ No
3 What is the length of the current episode of active uveitis (*check only one)*?	❑ In remission ❑ < 3 months ❑ ≥ 3 months ❑ Unknown
4 Current uncorrected vision:	**Right eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown **Left eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown
5 Current corrected vision:	**Right eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown **Left eye:** ❑ Normal ❑ Abnormal ❑ Blind ❑ Unknown
6 Since the last study visit, have there been any new eye complications?	❑ Yes → **If Yes: Check all that apply:** ❑ Increased intraocular pressure ❑ Snowballs ❑ Keratic precipitates ❑ Retinal vasculitis ❑ Posterior synechia ❑ Macular atrophy ❑ Cataract(s) ❑ Hypopyon ❑ Macular edema ❑ Iris nodules ❑ Epiretinal membrane ❑ Band keratopathy ❑ Snowbanks ❑ No ❑ Unknown
6 Has subject used topical steroid drops since the last study visit?	❑ Yes→ **If Yes: What was maximum frequency since last study visit?** ❑ Hourly ❑ 2 times per day ❑ Every 2 hours ❑ Once per day ❑ 6 times per day ❑ Once every other day ❑ 4 times per day ❑ Unknown ❑ 3 times per day ❑ No ❑ Unknown
7 Is subject currently using topical steroid drops?	❑ Yes → **If Yes: What is current frequency** *(check one)*? ❑ Hourly ❑ 2 times per day ❑ Every 2 hours ❑ Once per day ❑ 6 times per day ❑ Once every other day ❑ 4 times per day ❑ Unknown ❑ 3 times per day **How long has subject been on this dose?** ❑ < 1 month ❑ 1-3 months ❑ >3-6 months ❑ >6-12 months ❑ >12 months ❑ Unknown ❑ No ❑ Unknown

8 Has subject used topical mydriatics since the last study visit?	❑ Yes ❑ No ❑ Unknown
9 Has subject used topical anti-glaucoma drops since the last study visit?	❑ Yes ❑ No ❑ Unknown
10 Has subject had eye surgery since the last study visit?	❑ Yes ❑ No ❑ Unknown