

# Juvenile Dermatomyositis Cohort Biomarker Study and Repository

## Form 3: Clinic Visit Form

Patient Reference Number:

Date of clinic visit:

Date of last assessment:

Date of form completion:

Patient NHS Number (or CHI Number for Scotland):

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### A. History during previous year (since last annual assessment)

#### 1. Clinical History (at any point over last year)

##### I. General Symptoms

	<i>Absent</i>	<i>Present</i>
Rash	0	1
Weakness	0	1
Fever	0	1
Alopecia	0	1
Weight Loss	0	1
Fatigue	0	1
Mouth Ulcers	0	1
Headache	0	1
Irritability	0	1
Raynauds	0	1
Increased urinary frequency	0	1
Incontinence	0	1

##### II. Musculoskeletal

	<i>Absent</i>	<i>Present</i>
Myalgia	0	1
Joint Pain	0	1
Joint Stiffness	0	1
Joint Swelling	0	1
Dyspnoea	0	1
Dysphonia	0	1
Dysphagia	0	1

##### III. Systemic Features

	<i>Absent</i>	<i>Present</i>
Chest Pain	0	1
Abdo Pain	0	1
Diarrhoea	0	1
Melaena	0	1
Haematuria	0	1
Facial/body swelling	0	1

#### 2. Measurements (at time of annual assessment)

Current height: \_\_\_\_\_ cm (1 decimal point)

Current weight: \_\_\_\_\_ Kg (1 decimal point)

BP: \_\_\_\_\_ / \_\_\_\_\_

#### 3. Family History

Any new family History in the last 3 months: Yes / No  
Specify: \_\_\_\_\_

#### 4. Vaccination

Any vaccinations since last annual assessment; please check box

DTaP/IPV     MMR     HPV     Td/IPV     BCG     MenC conjugate     Influenza

#### 5. Flares *Please completed section below and go to Appendix 1 to complete a data set for each flare*

How many flares in the last year: \_\_\_\_\_ The 1' system involved: \_\_\_\_\_

What treatment was changes: \_\_\_\_\_

6. Pregnancy (if applicable):      Yes      No

### B. Examination Findings

##### I. Skin

	<i>Absent</i>	<i>Present</i>
Gottrons Papules	0	1
Ulceration	0	1
Lipoatrophy	0	1
Oedema	0	1
Nailfold Changes	0	1
Calcinosis	0	1
Other	0	1
Specify/Describe: _____		

##### II. Distribution of rash

	<i>Absent</i>	<i>Present</i>
Periorbital (heliotrope rash)	0	1
Periungal	0	1
Trunk	0	1
Small Joints	0	1
Large Joints	0	1
Other	0	1
Specify/Describe: _____		

<u>III. Joints</u>			
	<i>Absent</i>	<i>Present</i>	<i>Please specify:</i>
Arthritis	0	1	_____
Pain on motion	0	1	_____
Joints with limited ROM	0	1	_____
Contractures	0	1	_____

<u>IV. Oedema</u>		
	<i>Absent</i>	<i>Present</i>
Periorbital/facial	0	1
Limb	0	1
Trunk	0	1

<u>V. Abdomen</u>		
	<i>Absent</i>	<i>Present</i>
Abdominal masses	0	1
Tenderness	0	1
Hepatomegaly	0	1
Splenomegaly	0	1

<u>VI. Respiration</u>						
Please circle one:	0	1	2	3	4	5
0= normal, 1=SOBE, 2=tachypnoea, 3=accessory muscle use, 4=requires oxygen, 5=ventilated						

<u>VII. Muscle Assessment</u>												
	<i>No</i>	<i>Yes</i>										
CMAS	0	1	Score: _____/52 (0-52) No decimal point									
MMT8	0	1	Score: _____/80 (0-80) No decimal point									
Please complete MMT8 below by circling score:												
Neck flexors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Shoulder abductors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Elbow flexors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Wrist Extensors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Hip Extensors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Hip Abductors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Knee Extensors	0	1	2	3	4	5	6	7	8	9	10	Not Done
Ankle Dorsiflexors	0	1	2	3	4	5	6	7	8	9	10	Not Done

<u>VII. Physicians Global Assessment</u>				
Physicians Global Assessment:	Disease least active			Disease most active
	0 _____ 10			
		<i>No</i>	<i>Yes</i>	
CHAQ	0	1	Score: _____/3 (0-3) 3 decimal points	
Patient Reported Outcome Measures (PROMs):	CHQ	0	1	Physical Score: _____ Psychological Score: _____
	Parent VAS	0	1	Score: _____/10 (0-10) 1 decimal points
	Pain VAS	0	1	Score: _____/10 (0-10) 1 decimal point

**C. System Review (where organ involvement due to Idiopathic Inflammatory Myopathy)**

*Were the following tests performed; please circle appropriate box*  
0=normal, 1=abnormal, 9=not done

	<i>Absent</i>	<i>Present</i>												
Interstitial Lung Disease	0	1	PFT (lung)	0	1	9	CXR	0	1	9	CT of chest	0	1	9
Cardiac Involvement	0	1	ECG/Echo	0	1	9	MRI/PET	0	1	9	Stress Test	0	1	9
Neurological involvement	0	1	EEG	0	1	9	MRI	0	1	9	CT	0	1	9
GI Disease	0	1	Radiology	0	1	9	Endoscopy	0	1	9	Biopsy	0	1	9
Pancreatic disease	0	1	Bloods	0	1	9	CT/MRI abdo	0	1	9				
Eyes (glaucoma/cataracts)	0	1	none											

### D. Overall Clinical Impression

Please tick one box for each clinical feature

	Not Present	New	Improving	Same	Worsening	Were below tests performed, please circle appropriate box; 0=normal, 1=abnormal, 9=not done			
Myositis						MRI	0	1	9
Calcinosis						XRay	0	1	9
Skin disease (including nail fold capillaries)									
Other: please specify: _____									

### E. Investigation Results:

0=normal, 1=abnormal, 9=not done: Please tick the appropriate box for each test

Investigations	Date	Result			Further Information: Please record any significant information
		0	1	9	
<b>Haematology</b>					
Hb					
WBC					
Platelets					
WBC Diff: Neut					
WBC Diff: Lymph					
ESR					
<b>Biochemistry</b>					
CRP					
Urea					
Creatine					
CK					
LDH					
ALT					
AST					
Albumin					
Other					Specify:
<b>Immunology</b>					
RF					
ANA					
ENA					
dsDNA					
Other Antibodies					Specify:
C3					
C4					
IgG					
IgA					
IgM					
ASOT					

## **F. Therapy Information**

<u>I. Corticosteroids</u>	No	Yes		
Currently on oral steroids	0	1	Dose received _____mg/day	<b>Overall is the Oral Steroid dose reducing: Yes / No</b>
Oral steroids over last year	0	1	Maximum dose received _____mg/day	
IV steroids over last year	0	1		

<u>II. DMARDs</u>	<b>Today</b>		<b>Previous Year</b>	
	No	Yes	No	Yes
Methotrexate	0	1	0	1
Ciclosporin	0	1	0	1
Azathioprine	0	1	0	1
Cyclophosphamide	0	1	0	1
Hydroxychloroquine	0	1	0	1
IV-IG	0	1	0	1
Plasmapheresis	0	1	0	1
Mycophenolate mofetil	0	1	0	1
Other (non biologic)	0	1	0	1
Etanercept	0	1	0	1
Infliximab	0	1	0	1
Adalimumab	0	1	0	1
Rituximab	0	1	0	1
Other Biologic	0	1	0	1

<u>III. NSAIDs</u>	<b>Today</b>		<b>Previous Year</b>	
	No	Yes	No	Yes
Ibuprofen	0	1	0	1
Naproxen	0	1	0	1
Other specify: _____	0	1	0	1

<u>IV. Drugs</u>	<b>Today</b>		<b>Previous Year</b>	
	No	Yes	No	Yes
Calcium/Vit D	0	1	0	1
Folic Acid	0	1	0	1
Gastroprotectant	0	1	0	1
Vasodilator	0	1	0	1
Anti-HT	0	1	0	1
Other Specify: _____	0	1	0	1

<u>V. Physiotherapy/Occupational Therapy</u>	No	Yes	
Dry Land	0	1	Daily/Weekly/Other
Hydrotherapy	0	1	Daily/Weekly/Other
Splinting	0	1	Specify: _____

Does the child or parent say that medication is not taken as prescribed and/or is there clinician concern regarding adherence to medication? Yes / No

## **G. Research Investigations Samples**

<i>Were the following blood samples taken today:</i>	No	Yes
White capped PFH bottle	0	1
Clotted serum tube	0	1
ETDA tube	0	1
Saliva	0	1

## **H. Other Information**

Specify:

<b>Signature:</b>	<b>Position:</b>
<b>Print Name:</b>	<b>Date:</b>
<b>E-mail:</b>	