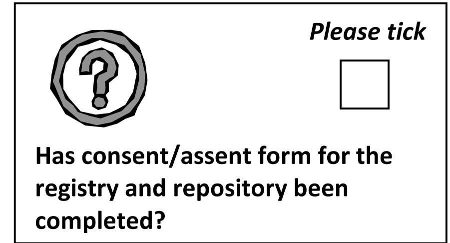
Juvenile Dermatomyositis Cohort Biomarker Study and Repository

Form 1: Initial Presentation Form



A: Demographics

Date of Visit: **Patient Ref Number:**

Patient Status*: **Gender:**

D.O.B:

Ethnicity 01 02 03 04 05 06 07 08 09

***(Please see guidelines for code. If 04 or 09, please specify)*____________________**

Postcode: **Occupation of parents:**

***1=Initial visit/diagnosis at contributing centre**
2=Primary contributing centre for JDM care after previous diagnosis elsewhere
3=Seen for occasional care/shared care only at the contributing centre
4=Other (please specify)

Patient NHS Number (or CHI Number for Scotland): ☐☐☐ - ☐☐☐ - ☐☐☐☐

B. History Up To Diagnosis

1. Background Data

Diagnosis: ____

Onset Date (mm/yyyy):______________________ **Diagnosis Date (mm/yyyy):**______________________

Please indicate which of the following contributed towards the patients diagnosis:

Proximal Muscle Weakness	**Yes / No**	**Not Done**
Rash suggestive of JDM	**Yes / No**	**Not Done**
Raised muscle enzymes	**Yes / No**	**Not Done**
Evidence of myositis on MRI	**Yes / No**	**Not Done**
Evidence of myositis on Muscle biopsy	**Yes / No**	**Not Done**
Evidence of myositis on EMG	**Yes / No**	**Not Done**

2. Clinical History

I. General Symptoms

	Absent	*Present*	*Not Known*
Rash	0	1	9
Weakness	0	1	9
Fever	0	1	9
Alopecia	0	1	9
Weight Loss	0	1	9
Fatigue	0	1	9
Mouth Ulcers	0	1	9
Headache	0	1	9
Irritability	0	1	9
Raynauds	0	1	9
Increased Urination	0	1	9
Incontinence	0	1	9

At diagnosis it available: *Not Known*

Height: _______________cm ☐

Weight: _______________Kg ☐

BP: ________/_______ ☐

II. Muscoskeletal

	Absent	*Present*	*Not Known*
Myalgia	0	1	9
Joint Pain	0	1	9
Joint Stiffness	0	1	9
Joint Swelling	0	1	9
Dyspnoea	0	1	9
Dysphonia	0	1	9
Dysphagia	0	1	9

III. Systemic Features

	Absent	*Present*	*Not Known*
Chest pain	0	1	9
Abdo pain	0	1	9
Diarrhoea	0	1	9
Melaena	0	1	9
Haematuria	0	1	9
Facial/Body Swelling	0	1	9

3. Vaccinations

Please check box if vaccine received

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

4. Past medical History	*Absent*	*Present*	*Not Known*	*Please specify where details known/relevant*
Specific viral infection	0	1	9	________________
Other autoimmune disease	0	1	9	________________
Other significant diagnosis	0	1	9	________________
Trauma/injury	0	1	9	________________
Immunisation in last 6/12	0	1	9	________________
School absence	0	1	9	________________
Stopped PE/Sport	0	1	9	________________
Respiratory Problems	0	1	9	________________
GI problems	0	1	9	________________
Neurological involvement	0	1	9	________________
Medication related problems	0	1	9	________________
FH of autoimmune disease	0	1	9	________________

C. Examination Findings At Diagnosis: (Tick this box and go to form 2 if patient recruited at diagnosis) [ ]

I. Skin	*Absent*	*Present*	*Not Known*
Gottrons Papules	0	1	9
Ulceration	0	1	9
Oedoma	0	1	9
Calcinosis	0	1	9
Nailfold Changes	0	1	9
Lipoatrophy	0	1	9
Heliotrope Rash	0	1	9
Other	0	1	9

Specify/describe:

____

	Absent	*Present*	*Not Known*
II. Arthritis	0	1	9
III. Muscle Weakness	0	1	9
IV. Other:	0	1	9

Specify:______________________________________

D. System Review (where organ involvement due to Idiopathic Inflammatory Myopathy) at diagnosis

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

	Absent	*Present*	Test				Test				Test			
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											

E. Overall Clinical Impression at diagnosis

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:_____________									

F. Clinical Course Since Diagnosis

I. General Symptoms

	Absent	Present	Not Known
Rash	0	1	9
Weakness	0	1	9
Fever	0	1	9
Alopecia	0	1	9
Weight Loss	0	1	9
Fatigue	0	1	9
Mouth Ulcers	0	1	9
Headache	0	1	9
Irritability	0	1	9
Raynauds	0	1	9
Increased Urination	0	1	9
Incontinence	0	1	9

II. Musculoskelatal

	Absent	Present	Not Known
Myalgia	0	1	9
Joint Pain	0	1	9
Joint Stiffness	0	1	9
Joint Swelling	0	1	9
Dyspnoea	0	1	9
Dysphonia	0	1	9
Dysphagia	0	1	9

III. Systemic Features

	Absent	Present	Not Known
Chest Pain	0	1	9
Abdo Pain	0	1	9
Diarrhoea	0	1	9
Melaena	0	1	9
Haematuria	0	1	9
Facial/Body Swelling	0	1	9
Calcinosis	0	1	9

G. Investigation Results at Diagnosis:

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

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

H. Therapy Information Since Diagnosis

I. Corticosteroids

	No	Yes	Not Known
Oral Steroids	0	1	9
IV Steroids	0	1	9

III.NSAIDs

	No	Yes	Not Known
Naproxen	0	1	9
Other (Specify): ______________	0	1	9

II.DMARDs

	No	Yes	Not Known
Methotrexate	0	1	9
Ciclosporin	0	1	9
Azathioprine	0	1	9
Cyclophosphamide	0	1	9
Hydroxycloroquine	0	1	9
IV-Immunoglobulin	0	1	9
Plasmapheresis	0	1	9
Mycophenolate mofetil	0	1	9
Other (non biologic)	0	1	9
Etanercept	0	1	9
Infliximab	0	1	9
Adalimumab	0	1	9
Rituximab	0	1	9
Other (biologic) ______________	0	1	9

IV. Other

	No	Yes	Not Known
Calcium Vit D	0	1	9
Folic Acid	0	1	9
Other (Specify): ______________	0	1	9

I. Physiotherapy/Occupational Therapy

	No	Yes	Not Known
Dry Land	0	1	9
Hydrotherapy	0	1	9
Splinting	0	1	9
Other (Specify):__________________	0	1	9

J. Other Information

	No	Yes
Specify:	0	1

Signature:	**Position:**
Print Name:	**Date:**
Email:	