# Juvenile Dermatomyositis Cohort Biomarker Study and Repository

## Form 2: Clinic Visit Form

**Patient Reference Number:** **Date of visit:**

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

### A. History since last Clinic Visit (or in last 3 months – whichever is most recent)

**1. Clinical History**

I. General Symptoms

| | *Absent* | *Present* |
|---|---|---|
| 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

| | *Absent* | *Present* |
|---|---|---|
| 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 | *Absent* | *Present* |
|---|---|---|
| Chest Pain | 0 | 1 |
| Abdo Pain | 0 | 1 |
| Diarrhoea | 0 | 1 |
| Melaena | 0 | 1 |
| Haematuria | 0 | 1 |
| Facial/body swelling | 0 | 1 |

**2. Measurements**

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 visit; please check box

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

### B. Examination Findings

I. Skin

| | *Absent* | *Present* |
|---|---|---|
| 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

| | *Absent* | *Present* |
|---|---|---|
| Periorbital (heliotrope) | 0 | 1 |
| Periungal | 0 | 1 |
| Trunk | 0 | 1 |
| Small Joints | 0 | 1 |
| Large Joints | 0 | 1 |
| Other | 0 | 1 |

Specify/Describe: ____________________________

III. Joints

| | *Absent* | *Present* | *Please specify:* |
|---|---|---|---|
| Arthritis | 0 | 1 | ______________________ |
| Pain on motion | 0 | 1 | ______________________ |
| Joints with limited ROM | 0 | 1 | ______________________ |
| Contractures | 0 | 1 | ______________________ |

| IV.Oedema | Absent | Present |
|---|---|---|
| Periorbital/facial | 0 | 1 |
| Limb | 0 | 1 |
| Trunk | 0 | 1 |

| V. Abdomen | Absent | Present |
|---|---|---|
| Abdominal masses | 0 | 1 |
| Tenderness | 0 | 1 |
| Hepatomegaly | 0 | 1 |
| Splenomegaly | 0 | 1 |

VI. Respiration

Please circle one: 0 1 2 3 4 5

0= normal, 1=SOBE, 2=tachypnoea, 3=accessory muscle use, 4=requires oxygen, 5=ventilated

VII. Muscle Assessment

| | *No* | *Yes* | |
|---|---|---|---|
| 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 |

VIII. Outcome Measures

Physicians Global Assessment: Disease least active 0 ——————————————— 10 Disease most active

| Patient Reported Outcome Measures (PROMs): | | *No* | *Yes* | |
|---|---|---|---|---|
| | CHAQ | 0 | 1 | Score:___________/3 (0-3) 3 decimal points |
| | 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*

| | *Absent* | *Present* | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 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** | |
| **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 Antibodies | | | | | Specify: |
| C3 | | | | | |
| C4 | | | | | |
| IgG | | | | | |
| IgA | | | | | |
| IgM | | | | | |
| ASOT | | | | | |

## F. Therapy Information

**I. Corticosteroids**

| | No | Yes | Current Dose |
|---|---|---|---|
| Oral Steroids | 0 | 1 | _______mg/day |
| IV Steroids | 0 | 1 | _______mg/day |

**Overall is the Oral Steroid dose reducing:**

**Yes / No**

**II. DMARDs**

| | No | Yes | Dose and type administered | Dates if started or stopped in the last 3 months |
|---|---|---|---|---|
| Methotrexate | 0 | 1 | | |
| Ciclosporin | 0 | 1 | | |
| Azathioprine | 0 | 1 | | |
| Cyclophosphamide | 0 | 1 | | |
| Hydroxychloroquine | 0 | 1 | | |
| IV-IG | 0 | 1 | | |
| Plasmapheresis | 0 | 1 | | |
| Mycophenolate mofetil | 0 | 1 | | |
| Other (non biologic) | 0 | 1 | | |
| Etanercept | 0 | 1 | | |
| Infliximab | 0 | 1 | | |
| Adalimumab | 0 | 1 | | |
| Rituximab | 0 | 1 | | |
| Other (biologic) | 0 | 1 | | |

**III. NSAIDs**

| | No | Yes | Dose on day attending clinic |
|---|---|---|---|
| Ibuprofen | 0 | 1 | |
| Naproxen | 0 | 1 | |
| Other specify: ____________ | 0 | 1 | |

**IV. Drugs**

| | No | Yes | Dose on day attending clinic |
|---|---|---|---|
| Calcium/Vit D | 0 | 1 | |
| Folic Acid | 0 | 1 | |
| Gastroprotectant | 0 | 1 | |
| Vasodilator | 0 | 1 | |
| Anti-HT | 0 | 1 | |
| Other Specify: ______________ | 0 | 1 | |

**V. Physiotherapy/Occupational Therapy**

| | No | Yes | Please circle |
|---|---|---|---|
| Dry Land | 0 | 1 | Daily/Weekly/Other |
| Hydrotherapy | 0 | 1 | Daily/Weekly/Other |
| Splinting | 0 | 1 | Specify:__________ |

## G. Research Investigations Samples

*Were the following blood samples taken today:*

| | No | Yes |
|---|---|---|
| White capped PFH bottle | 0 | 1 |
| Clotted serum tube | 0 | 1 |
| ETDA tube | 0 | 1 |
| Saliva | 0 | 1 |

## H. Other Information

Specify:

| | |
|---|---|
| **Signature:** | **Position:** |
| **Print Name:** | **Date:** |
| **E-mail:** | |