General Instructions

Thank you for taking time to complete this lengthy questionnaire for the Utah Dystrophinopathy Project (UDP). Please fill out the form to the best of your ability.

When filling in the form out always use a black medium tipped pen, with either a felt tip or ball point. Do not use either blue ink or pencil.

There are 3 types of questions on the form, please complete them as shown in the example below:

1) Bubble Responses are to be filled in.

Shade circles like this: ●
Not like this: ×

2) Constrained Text Fields must be filled in using UPPERCASE LETTERS and the uppercase letters or numbers should not touch the sides of the box or go out of the boxes.

For optimum accuracy, please print in capital letters and avoid contact with the edge of the box.
The following will serve as an example:

∅ Not like this: (use uppercase letters only and do not touch the sides)

Date: 5/2003

3) Open Text Fields are specific locations on the form where you can hand write more information. Please take care to print or write your answers in these sections neatly and legibly.

Other:

Open text field, please write neatly

∅ Not Like this:

Don't write in cursive
4) Making corrections
If you make a mistake while filling out the form, please do the following:

- To correct a bubble field, draw and “X” through the incorrect mark and then fill in the correct bubble.

  **Example:**
  ![Image](image1.png)

- To correct letters or numbers in text fields, simply draw a line through the incorrect character and print the correct character above or below the box.

  **Example:**
  ![Image](image2.png)

∅ **Do not** use white out.

∅ **Do not** write near the 4 small black boxes in the four corners of each page or the rectangular box at the bottom right hand corner of each page. These boxes are used by TELEFORM to align and identify the form. Doing so may make the form unreadable and all the data on the form will have hand entered onto a new form.

**Specific Instructions**

For your information we have provided a sample form with detailed instructions. Please use this guide to help you as you complete the questionnaire. Answer the questions to the best of your ability. If you are not sure of exact dates, use your best estimate.

**Pages 1 & 2 Demographics**

1. Fill in the patient’s (your son’s) name, birthday and sex
2. Fill in your son’s current mailing address
   (note: if there is a change in address please notify us)

   **Address**
   
   Street 1
   Street 2
   Street 3
   City
   Country or State
   Zip or Routing Number
   Phone

3. If your son has a relative enrolled in the UDP study, please fill in their name. If there is more
   than one relative, use the name of the closest relative.

   Do you know if a relative has joined the study? ○ Yes □ No
   If yes, how many? __________

   First Name
   Last Name

4. Provide a secondary contact in case we are unable to contact your son by the primary address

   **Secondary Contact Person:**
   
   First Name
   Last Name
   Street
   City
   State
   Zip Code
   Phone
   Relation to Patient

5. Do you wish to be notified of other studies for which your child may be a candidate for? If yes
   we will notify you and you will need to contact those researchers. This does not guarantee
   that your child will be enrolled in that study. If you do not wish to participate in other studies,
fill in the bubble for “no”.

6. Please provide your son’s MDA doctor, clinic, the address and phone

Muscular Dystrophy Doctor:

Name: 

Name of Clinic: 

Street: 50 North Medical Dr

City: Salt Lake City

State: UT

Zip Code: 84112

Phone: 801-555-6666

**Page 3 Historical Data**

1. What age did your son first show symptoms?

   **Age of First Symptoms** (Enter age to nearest 0.5 year)

   [5.0] OR ○ Not Applicable (no symptoms)

2. What was the first part of the body that you noticed these symptoms?

   **Body region first affected:**
   ○ Not Applicable (no symptoms)
   ○ Legs: Pelvis
   ● Legs: Calf muscles
   ○ Arms
   ○ Cardiac (heart)
   ○ Cognitive (mind)
   ○ Other
   Region if OTHER:

3. What symptoms does your son currently have?

   **Presenting Symptoms:**
   (check all that apply)

   ● Weakness
   ○ Muscle hypertrophy (enlarged calf muscles for example)
   ● Toe Walking
   ○ Myalgias/ Cramping
   ○ Myoglobinuria (cola or tea colored urine)
   ○ Cognitive Dysfunction
   ○ Developmental Delay
   Asymptomatic hyperCKemia (elevated serum CK)
   ○ tested in the setting of family history of disease
   ○ as an incidental finding (found when testing for something else)
   ○ Anesthetic Complications
   ○ Prenatal Diagnosis
1. How old was your son when diagnosed with muscular dystrophy by a doctor?

   **Age at Clinical Diagnosis**
   (Enter age to nearest 0.5 year)  
   [ ] 5.0  
   OR   
   **Date of Clinical Diagnosis (mo/yr):**
   [ ] / [ ]

2. Is your son currently walking without help? If yes, mark “walks unassisted”. If he walks with help, mark “walks with assistance” and indicate what kind of assistance he uses to walk.

   **Walking**
   ○ Walks unassisted
   ○ Walks with assistance
   **Type of Assistance**
   ○ braces or other devices
   ○ walks only with someone's help
   ○ Does not walk

3. At what age did your son first use a wheelchair? (if your son has not used a wheelchair, mark not applicable)

   And what age did your son start using a wheelchair full-time? If your son does not use a wheelchair full-time, mark not applicable.

   **Age at Loss of Ambulation**
   At what age did the patient first use:
   (Enter age to nearest 0.5 year)  
   [ ] 1.0
   ○ Not Applicable
   Wheelchair Full-Time
   [ ] 1
   ○ Not Applicable

4. How many brothers and sisters does your son have? If the he does not know (ie: they are adopted), mark no family history.

   **Family History**
   ○ No family history (adopted)
   Does this patient have brothers? How many?
   [ ] 0 1
   Does this patient have sisters? How many?
   [ ] 0 1

5. Mark “yes” if any of your son’s following family members have muscular dystrophy. Mark “no” if they do not.

   ○ Yes  ● No  X-Linked Family History (uncles, cousins)?
   ○ Yes  ● No  Is the Patient's Father symptomatic?
   ○ Yes  ● No  Is the Patient's Mother symptomatic?
   ● Yes  ○ No  Is (are) the Patient's Brother(s) symptomatic?
   ○ Yes  ● No  Is (are) the Patient's Sister(s) symptomatic?

**Page 5 Method of Diagnosis**

1. Has your son had a muscle biopsy?
2. If yes, enter the date of the biopsy or the age of your son when the biopsy was done.

- **Biopsy Date**
  - 01/01/2001

  **OR**

- **Age at Biopsy**
  - (nearest 0.5 year mark)
  - 5.5

3. If your son had a muscle biopsy, what did the report say?

- **Results:**
  - Dystrophin reduced

*Note: Please sign and return the medical release form, found at the end of this document, so that we may obtain a copy of the biopsy results; or, if you have a copy, please send the copy along with this completed data form.*

4. Has your son had DNA testing?

- **DNA Testing?**
  - Yes
  - No

5. If yes, what were the results?

- **DNA Testing Results:**
  - Exon Deletion
  - Exon Duplication
  - Stop Codon
  - Insertion
  - Subexonic Deletion
  - Missense
  - No Mutation Detected
  - Other

6. If you son had DNA testing and a formal report is available, please send us a copy or sign the medical release form for us to get a copy.
1. Please fill in the appropriate response about your son’s cognitive function.

**Cognitive Function:**

- Has IQ testing ever been performed?  ● Yes  ○ No  ○ Not Available
- Does your child attend a special classroom or have any classes outside of his regular classroom?  ○ Yes  ● No  ○ Unknown
- Does this patient have any special needs or services provided in the classroom?  ● Yes  ○ No  ○ Unknown
- Behavioral problems?  ○ Yes  ● No

<table>
<thead>
<tr>
<th>Current Grade</th>
<th>Last Grade Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 2</td>
<td>0 1</td>
</tr>
</tbody>
</table>

Was the child (or adult subject) delayed in his early language development?  ○ Yes  ● No  ○ Unknown

2. Has your son ever been diagnosed with any of the following? If not, leave blank.

- Has the child (or adult subject) ever been given a diagnosis by a health care professional of
  ○ Language Impairment
  ○ Mental Retardation
  ○ Learning Disability
  ○ Attention Deficit Disorder
  ○ Autism
  ○ Pervasive Developmental Disability
  ○ Depression

3. Indicate other cognitive or behavioral problems here, not covered in the previous questions.
1. Does your son or has he in the past, used incentive spirometry? If yes, how often and when did he first use it? Incentive spirometry is designed to mimic natural sighing or yawning by encouraging the patient to take long, slow, deep breaths. This is done by using a device that provides patients with visual or other positive feedback when they inhale at a set flow rate or volume and hold the inflation for a minimum of 3 seconds.

**Respiratory Function:**

<table>
<thead>
<tr>
<th>Does this patient use incentive spirometry?</th>
<th>Frequency</th>
<th>Date first used: (mo/yr)</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Yes</td>
<td>● Daily</td>
<td>03 / 2003</td>
</tr>
<tr>
<td>○ No</td>
<td>○ Weekly</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Monthly</td>
<td></td>
</tr>
</tbody>
</table>

2. Has your son ever had an overnight oximetry study? If yes, when? An overnight oximetry study measures blood oxygen levels by a small clip (called an oximeter) placed on the tip of the index finger.

<table>
<thead>
<tr>
<th>Has this patient ever had an overnight oximetry study?</th>
<th>Date of most recent test: (mo/yr)</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Yes</td>
<td></td>
</tr>
<tr>
<td>● No</td>
<td></td>
</tr>
</tbody>
</table>

**Results of most recent test:**
3. Has your son ever had a PSG (polysonmography)? If yes, when? What were the results?

PSG is a procedure that records a variety of body functions during sleep, including electrical activity of the brain, eye movement, muscle activity, heart rate, breathing, air flow through the nose and mouth, and blood oxygen levels.

Has this patient had a polysonmography study?  
☐ Yes  
☐ No  

Results of most recent test:  

Date of most recent test: (mo/yr)  

4. Does your son ever feel short of breath?

At present, does this patient have complaints of shortness of breath?  
☐ Yes  
☐ No

5. If yes, when does it happen? Does your son snore? Have morning headaches? Sleep apnea (a condition that occurs when you regularly stop breathing for 10 seconds or longer during sleep)?

IF YES Then:

<table>
<thead>
<tr>
<th>With Activity?</th>
<th>With Rest?</th>
<th>When lying down?</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>☐ No</td>
<td>☐ No</td>
<td>☐ No</td>
</tr>
</tbody>
</table>

Complaints of:

<table>
<thead>
<tr>
<th>Snoring?</th>
<th>Morning Headaches?</th>
<th>Apnea?</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>☐ No</td>
<td>☐ No</td>
<td>☐ No</td>
</tr>
</tbody>
</table>

---

1. Does your son use oxygen while sleeping? If yes, how long and what for?

Does this patient currently use ventilatory support?  
☐ Yes  
☐ No  

If YES:

Current # of hours/day on ventilatory support:  

Ventilatory support initiated due to:

☐ Decreased FVC  
☐ Nocturnal hypercapnia (increased carbon dioxide levels)  
☐ Nocturnal hypoxia (decreased oxygen levels)  
☐ Symptoms alone - no oxygen or carbon dioxide testing performed
2. Indicate if you son has used any of the following and if so the date he started.

**Ventilatory History:**

<table>
<thead>
<tr>
<th>Curare</th>
<th>Date Started</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ○</td>
<td></td>
</tr>
<tr>
<td>No ●</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BiPAP: Nasal Pillows</th>
<th>Date Started</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ○</td>
<td></td>
</tr>
<tr>
<td>No ●</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BiPAP: Mask</th>
<th>Date Started</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ○</td>
<td></td>
</tr>
<tr>
<td>No ●</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CPAP</th>
<th>Date Started</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ○</td>
<td></td>
</tr>
<tr>
<td>No ●</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tracheostomy</th>
<th>Date Started</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ○</td>
<td></td>
</tr>
<tr>
<td>No ●</td>
<td></td>
</tr>
</tbody>
</table>

**Other:**

<table>
<thead>
<tr>
<th>Date Started</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Page 9**

1. Has your son complained of the following?

<table>
<thead>
<tr>
<th>Complaints of</th>
<th>Chest Pains?</th>
<th>Yes ○ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palpitations?</td>
<td>Yes ○ No</td>
<td></td>
</tr>
<tr>
<td>Peripheral edema attributed by a physician to cardiac failure</td>
<td>○ Yes ● No</td>
<td></td>
</tr>
</tbody>
</table>

2. Has your son had an EKG of the heart?

- **EKG**
  - ● Not Done
  - ○ Net Available
  - ○ Normal
  - ○ Abnormal, Clinically Insignificant
  - ○ Abnormal, Clinically Significant

- **Describe Abnormal Results:**

3. Has your son had any of the following heart procedures?

<table>
<thead>
<tr>
<th>Has this patient had any of the following?</th>
<th>Cardiac Transplant?</th>
<th>Yes ○ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac Pacemaker?</td>
<td>Yes ○ No</td>
<td></td>
</tr>
<tr>
<td>Cardiac Ablation?</td>
<td>Yes ○ No</td>
<td></td>
</tr>
</tbody>
</table>

4. Has your son had an echocardiogram (ultrasound of the heart)? If yes, please indicate the most recent one and the first abnormal one.
Page 10

1. Has your son broken his arm or leg? If yes, which one and which side?

Fracture of long bones
- Yes
- No

Check all that apply:
- Humerus (upper arm) – L (left) R (right)
- Femur (thigh) – L R
- Tibia (inside of lower leg) – L R
- Fibula (outside of lower leg) – L R
- Others – L R

2. Has your son fractured any bones in his back? If yes, which one(s)?

Vertebral fractures (spine)
- Yes
- No

Vertebral Fracture Level:
- C5 T1 T5 T9 L1 S1
- C6 T2 T6 T10 L2 S2
- C7 T3 T7 T11 L3 S3
- C8 T4 T8 T12 L4
- L5

3. Was your son taking steroids when he broke his arm, leg, or spine? If yes, which ones?

Was patient on steroids at the time of initial diagnosis of fractures?
- Yes
- No
- Unknown
- Not Applicable

If so, which fractures?

4. How old was your son when he had his first broken bone? If he has had more than one fracture, when was his most recent one (how old was he)?

(To nearest 0.5 years)
Age at 1st fracture 6.0
Age at most recent fracture 6.0
Page 11

1. Has your son had any of the following? If yes, what age did they start?

GI complaints which required medical evaluation or treatment:

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Yes</th>
<th>No</th>
<th>Age at onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bloating</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Urinary complaints which required medical evaluation or treatment:

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Yes</th>
<th>No</th>
<th>Age at onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incontinence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urgency</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney Stones</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Any other treatments or diagnosis?

Other Medical History:

These are any other important treatments or diagnosis not covered in the previous questions.

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1. If your son is or has been on steroids, please complete the following. If he has been on more than one steroid treatment or dose, enter the 2nd regimen after the first.

Steroids:
- Prednisone
- Deflazacort
- Oxandrolone

Daily
- Intermittent
- Every other day
- 10 days/month
- 10 days on / 10 days off
- Weekly
- Single dose
- 2 days / week
- Other

Dosage: [ ] mg/kg OR [ ] Unknown

Date On: 02/2002
Date Off: 03/2002

○ Currently taking
If the patient has been on more than one regimen, enter the second regimen here:

<table>
<thead>
<tr>
<th>Steroids:</th>
<th>Dosage:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prednisone</td>
<td>Daily</td>
</tr>
<tr>
<td>Deflazacort</td>
<td>Intermittent</td>
</tr>
<tr>
<td>Oxandrolone</td>
<td>Every other day</td>
</tr>
<tr>
<td></td>
<td>10 days/month</td>
</tr>
<tr>
<td></td>
<td>10 days on/ 10 days off</td>
</tr>
<tr>
<td></td>
<td>Weekly</td>
</tr>
<tr>
<td></td>
<td>Single dose</td>
</tr>
<tr>
<td></td>
<td>2 days/ Week</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

Date On: [__/___] Date Off: [__/___] Or Currently taking [ ]

Comments regarding steroid regimen:

---

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1. Has any of the following occurred while your son has been on steroids? If yes, indicate the date.

<table>
<thead>
<tr>
<th>Cushingoid Features:</th>
<th>Diabetes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ☐ No ●</td>
<td>Date of Diagnosis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hypertension:</th>
<th>Avascular Necrosis:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ☐ No ●</td>
<td>Date of Diagnosis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavioral Disturbance:</th>
<th>Cataracts:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ☐ No ●</td>
<td>Date of Diagnosis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Acne:</th>
<th>Gastric Ulcers:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ☐ No ●</td>
<td>Date of Diagnosis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skin fragility:</th>
<th>Fungal Infection:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes ☐ No ●</td>
<td>Date of Diagnosis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other:</th>
</tr>
</thead>
</table>

Date of Diagnosis [__/___]
1. What was the weight of your son when he first started steroids and the date he was weighed?

   Weight at start of therapy: 70.0 kg  
   Date Evaluated: 02/02/2002  
   ○ Unknown

2. What was his weight when he stopped taking steroids or his current weight if he is still taking steroids and the date he was weighed?

   Weight at Date #2:  
   Date Evaluated:  
   ● Unknown

3. Is or was your son participating in a steroid study? If yes, please indicate the start date and where the study is being done.

   Has this patient participated in a treatment trial?
   Currently in a trial:  ○ Yes  ● No
   Past Trials?  ○ Yes  ● No
   Start Date:  

   Trials and Institutions/Consortiums:
   

---

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1. List medications your son routinely takes and mark currently taking. Also list medications he has routinely taken in the past.

   1) Medication Name  
      Tylenol  
      ● Currently taking

   2) Medication Name  
      Claritin  
      ○ Currently taking

   3) Medication Name  
      Vitamin D  
      ● Currently taking
1. Does your son use any of the following braces or splints? Or has he in the past?

**KAFO Braces:**
- Yes •
- No ○
- Not Applicable ○

<table>
<thead>
<tr>
<th>If YES</th>
<th>Date Started</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>03/2003</td>
<td>03/2004</td>
</tr>
</tbody>
</table>

**AFO Braces:**
- Yes •
- No ○
- Not Applicable ○

<table>
<thead>
<tr>
<th>If YES</th>
<th>Date Started</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Body Jacket:**
- Yes •
- No ○
- Not Applicable ○

<table>
<thead>
<tr>
<th>If YES</th>
<th>Date Started</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Ankle Splinting:**
- Night-time use only •
- Night-time & Daytime ○
- Daytime only ○
- Not Applicable ○

<table>
<thead>
<tr>
<th>Date Started</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>03/2003</td>
<td>03/2004</td>
</tr>
</tbody>
</table>

**Hand Splinting:**
- Night-time use only ○
- Night-time & Daytime ○
- Daytime only ○
- Not Applicable ○

**Splinting (Other):**
- Comment:

---

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1. Has your son had a contracture release? If yes, please indicate where and which side.

**Contracture Release:**
- Yes •
- No ○

<table>
<thead>
<tr>
<th>Ankle</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right:</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>Left:</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Both:</td>
<td>●</td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knee</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right:</td>
<td>○</td>
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<td>Left:</td>
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<tr>
<td>Both:</td>
<td>●</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Hip Flexor</th>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
<tr>
<td>Right:</td>
<td>○</td>
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<table>
<thead>
<tr>
<th>Iliotibial Band</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right:</td>
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<td>Both:</td>
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</tr>
</tbody>
</table>
2. List the month and year of each release surgery.

Comments: Please list any other release surgeries, as well as the month and the year of each surgery checked off above.

3. Has your son had any of the following surgeries? If yes, please indicate the month and year.

Other Surgeries:
- Posterior Tibialis Tendon Transfer: ○ Yes ■ No
  Date: ___ / ___ ___
- Tonsillectomy/Adenoidectomy: ○ Yes ■ No
  Date: 02 / 2002
- Tympanostomy tube: ○ Yes ■ No
  Date: ___ / ___ ___
- PEG placement: ○ Yes ■ No
  Date: ___ / ___ ___

4. Any other surgeries not previously listed?

Other (include date):

5. Has your son ever had problems with anesthesia?

Has this patient ever had anesthetic complications? ○ Yes ■ No

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1. Has your son ever had an x-ray of his back? If yes, when was it and what was the result?

Has this patient had a spine X-Ray? ○ Yes ■ No

If YES:
- Date of most recent X-ray: 01 / 01 / 2001
- Result:
  ○ Normal
  ○ Abnormal (>30% curvature) ■ Sitting
  ○ Unknown ■ Standing
- Position:
  ○ Standing
  ○ Unknown

2. Has your son had spine surgery? If yes, how many times and what type?

Has this patient had spine surgery? ○ Yes ■ No

If Yes:
- How many times?:
- Type:
  ○ Harrington Rod: ○ Yes ■ No
  ○ Luque Rod: ○ Yes ■ No
  ○ Spinal Fusion: ○ Yes ■ No
  ○ Other: ○ Yes ■ No
3. Has your son had a bone density scan?

   [ ] Yes   [ ] No

   Has this patient had DEXA testing? (Bone Density Scan)

Thank you for taking time to complete this form. Please use the envelope provided to return the form. If you have any questions or concerns, please contact:

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   Utah Dystrophinopathy Project
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   Flanigan Neurogenetics Lab
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   Salt Lake City, UT 84112

   801-585-1299
   khart@genetics.utah.edu

   Thank you!