This document should be completed by the Paediatric Neurologist and shared with the Adult Neurologist.

Date completed:	Date revised:
Form completed by:	

CONTACT INFORMATION

Patient name:

Date of birth:	Preferred language:

Parent/caregiver name:

Relationship to patient:

Address:

Phone (mobile):	Phone (home):	Best time to reach:
Email:		Best way to reach: Text Phone Email

Emergency contact name:

Relationship to patient:	Phone:

Preferred emergency care location:

Advance directive: Yes No

Parent/caregiver/guardian or power of attorney for healthcare: Yes No *If yes, please provide details below.*

Is there any special information the patient or family would like healthcare professionals to know?
Please use the space below. Examples might include details of advance directives, special assistance, or medical information.

Please rate the patient's understanding of the DMD diagnosis and its long-term health implications:
very good good fair poor

DIAGNOSES

Primary diagnosis: **Duchenne muscular dystrophy (DMD)**

Secondary diagnoses *(check all that apply)*

Orthopaedic/musculoskeletal
- Contractures, multiple joints
- Immobility, loss of ambulation
- Osteoporosis
- Scoliosis
- *Surgically fused?* Yes No
- Vertebral/compression fractures

Cardiac
- Cardiomyopathy
- Heart failure
- Tachycardia, sinus

Respiratory*
- BiPAP dependent
- Chronic respiratory failure
- Ineffective airway clearance
- Obstructive sleep apnoea
- Restrictive lung disease
- Ventilator dependent via tracheostomy

Neurology/psychology
- Anxiety disorder
- Autism
- Learning disability
- *Please specify:*
- Obsessive-compulsive disorder
- Other
- *Please specify:*

Gastrointestinal and genitourinary
- Constipation
- *Gastroparesis?* Yes No
- GERD
- Kidney stones, recurrent
- Nutritional concerns
- *Gastrostomy tube?* Yes No
- *Assistance with eating or drinking?* Yes No
- Urinary frequency, urgency, hesitation

Additional diagnoses not listed above
- Delayed puberty
- Cataract
  - Right Left
- Other
- *Please specify:*

*CAUTION: Oxygenation should be accompanied by adequate ventilation. Airway clearance requires cough-assist device, followed by suctioning, due to muscle weakness.
BiPAP, bilevel positive airway pressure; GERD, gastroesophageal reflux disorder.

PRECAUTIONS AND SPECIAL CONSIDERATIONS

Corticosteroid use, chronic: Yes No

Stress dose coverage plan:

Sedation risk[†]

Allergies *List or attach list:*

Fall or transfer precautions

Clinical trial participation? *Please specify:*

[†]Avoid analgesics or sedatives that may reduce respiratory drive, unless breathing is supported (with BiPAP or other support). Avoid inhaled anaesthesia, which can cause adverse effects in patients with DMD.

MEDICATIONS	DOSE	FREQUENCY

Medication notes:

HEALTHCARE PROVIDERS, AGENCIES, AND EQUIPMENT SUPPLIERS

Please include all providers involved in prescribing, ordering, or assisting with equipment, as well as care coordinators and social workers.

PROVIDER/CONTACT	SPECIALITY	CLINIC/HOSPITAL/LOCATION	PHONE	FAX
	Primary care			
	Neuromuscular			
	Pulmonary			
	Cardiology			
	Physical therapy			
	Occupational therapy			
	Psychiatrist/psychologist			
	Case worker/social worker			
	Home healthcare agency			
	Durable medical equipment			
	Orthotics			
	Home healthcare agency			
	Other:			

EQUIPMENT, ORTHOTICS, ASSISTIVE TECHNOLOGY, SUPPLIES

List type, brand, size, and weight if available.

Wheelchair or other power mobility Type: Year purchased:	**Stander** Type: Used hours/day	**Orthotic devices** Type: Year purchased: Used hours | Used day night
BiPAP CPAP *(please choose one)* Type: Interface (eg, mask): Used hours | Used day night Frequency of tubing changes: Settings:	**Sip/puff (mouthpiece) ventilation** Used hours/day Frequency of tubing changes: Settings:	**Tracheostomy with ventilation** Tracheostomy type: Vent type: Used hours | Used day night Frequency of tubing changes: Settings:
Suction machine and catheters, cough-assist device Settings:	**Nebuliser**	**Oxygen and tubing**
Gastrostomy	**Oximeter** Parameters:	**Communication device**
Supplemental nutrition Formula:	**Lift/transfer technique/equipment**	

BASELINE VITAL SIGNS AND MEASURES

Height:	Weight:	Heart rate:	Respiration rate:	Blood pressure:

MEDICAL HISTORY

Date	Surgery, procedure, or hospitalisation

Date	Test	Result
	ECG	
	Echocardiogram	
	Cardiac MRI	
	Spine X-ray	
	DEXA scan	
	Pulmonary function tests: Forced vital capacity Peak cough flow Resting oxygen saturation (spO_2) Partial pressure of CO_2 (pCO_2) Other:	
	Vitamin D	
	Other:	

DEXA, dual-energy X-ray absorptiometry; ECG, electrocardiogram; MRI, magnetic resonance imaging.

SCHOOL OR WORK INFORMATION

School	Contact person	Phone	Fax
Work	**Contact person**	**Phone**	**Fax**

OTHER IMPORTANT CONTACTS

Include case manager, education consultants, benefits coordinators, and advocacy organisations.

Organisation	Contact person	Phone	Fax

Please attach immunisation record and recent clinic notes to this form for future reference.

This material has been developed and funded by PTC Therapeutics. It is intended for healthcare professionals only.

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PTC THERAPEUTICS