وزارة الصحة
Ministry of Health

Referral letter of SMA patients for National Spinal Muscular Atrophy program

(For Neurology Consultant use only)

Demographics and Personal details	
Patient Name (English): اسم المريض (اللغة العربية):	Gender: ☐ Male ☐ Female Family Contact Number: Additional contact number:
National ID #:	Date of birth (dd / mm / yyyy):
Type of application: ☐ New ☐ Follow up/ Re-submission If follow up, date of enrollment to the program:	
SMA type: ☐Pre-symptomatic ☐Type 1 ☐Type 2 ☐Type 3 ambulant ☐Type 3 non ambulant	If symptomatic please indicate type of SMA patient, please fill in the required details (as applicable): • SMA type: …… • Age at onset of symptoms: …… ☐ Month ☐ Years
Weight: KG Date:	Height: Cm Date:
Patient's educational level: Grade/Class: Date of completion:	Patient employment ☐Yes ☐ No ☐NA Joining date:
For adult patients only: BMI: Marital status: ☐Married ☐Single ☐Others:	Number of Children:
Referring physician:	Date of submission:
Referring hospital:	Date of Diagnosis of SMA:

Clinical details

Please complete the following information: Date of Evaluation (dd / mm / yyyy)

Gross motor skills:

Head control: ☐ Not achieved ☐ Achieved at age ……. months	Sitting with support: ☐ Not achieved ☐ Achieved at age …..... months
Sitting unsupported: ☐ Not achieved ☐ Achieved at age.....months achieved and lost at age (for all)	Standing without support: ☐ Not achieved ☐ Achieved at age …... months
Walking with assistance: ☐ Not achieved ☐ Achieved at age ..... months	Walking without support: ☐ Not achieved ☐ Achieved at age ……. yr

Pulmonary function test 5-6 years and above (12 months & 20 months)

Current Motor Status as of: Date(dd/mm/yyyy):

☐ Cannot sit un-supported ☐ Sitting independently ☐Independent ambulation ☐Dependent ambulation

Motor Abilities Assessment Scales with Videotaping: HFMSE /CHOPINTEND/HINE2/6MWT/CMAP/RULM motor assessment scales at baseline

☐ **CHOPINTEND (For type 1 SMA)**
Baseline score _____ Date Follow up score _____ Date

☐ **HINE2 (For type 1 SMA)**
Baseline score _____ Date Follow up score _____ Date

☐ **HFMSE (For type 2 and type 3 SMA)**
Baseline score _____ Date Follow up score _____ Date

☐ **6MWT (For Type 2 & Type 3 ambulant SMA patients)**
Baseline score _____ Date Follow up score _____ Date

☐ **CMAP (For Type 2 & Type 3 SMA patients)**
Baseline amplitude _____ Date Follow up Amplitude _____ Date

☐ **RULM (For type 2 and 3 SMA)**
Baseline score _____ Date Follow up score _____ Date

Respiratory status:

1. Has this patient been admitted for any respiratory infection requiring supportive ventilation (non-invasive or invasive intubation/mechanical ventilation: ☐ No ☐ Yes

- If yes, please indicate the age at which the first admission was:

2.Age of last respiratory related admission:

3. Current respiratory status of the patient as of: (dd/mm/yyyy):

☐On room air (no respiratory support)

☐Needs daily respiratory support: Please choose method: On oxygen nasal cannula during sleeping

☐Patients on Non-invasive ventilation (>11 hours/day > 1 month)

☐Use of invasive ventilatory support (tracheostomy with positive pressure) at assessment

☐Nocturnal ventilation support

SMA medication history:

1.The patient has been prescribed any therapy for Spinal muscular Atrophy before: ☐No ☐ Yes

2. If yes, please specify: ☐ Nusinersen ☐ onasemnogene abeparvovec ☐ Risdiplam ☐ Salbutamol

- Add treatment start date: Duration on treatment: ☐……. Months ☐ ……Years

Review of other systems:

1. Other comorbidities (choose all applicable – details must be included in separate report):
   - ☐ Liver disease
   - ☐ Renal disease
   - ☐ Cardiac disease
   - ☐ Seizures
   - ☐ Fractures / Recurrent Fractures
   - ☐ Active infection requiring systemic antibacterial or antiviral therapy
   - ☐ History of brain or spinal cord disease that would interfere with lumbar punctures or CSF circulation
   - ☐ Presence of an implanted CSF drainage shunt or CNS catheter
   - ☐ Hematology or clinical chemistry parameters at screening that would prevent inclusion
   - ☐ Cognitive impairment
   - ☐ Any other comorbidity that might affect the life expectancy of the patient and decrease the likelihood of response to therapy
   - · Specify: …….
   - ☐ None
2. Scoliosis:
   ☐ Yes ☐ No If yes, what is the cobb angle:
3. Spine surgery
   ☐ Yes ☐ No
4. Contractures
   ☐ Yes ☐No If yes, Where at and magnitude:

5. Nutritional condition:

Method of feeding:

☐ Oral

☐ Nasogastric tube

☐ Gastrostomy tube

Last weight: …. (Percentile on growth chart: .....….) On (date): ……

Diagnosis:

Genetic testing date:

a) Type of mutation of SMN1: ☐ deletion ☐ Point mutation NAIP gene copy no#
b) Number of SMN2 copies:

Please attach the official laboratory result report with lab name

Family/ Psychosocial Status

Total no# of siblings (excluding / rather than the patient):	**No# of affected siblings:** **No# of healthy siblings:**
Please Specify if the Family / Patient has received Genetic counseling: ☐ **Yes** ☐ **No** **If you select No, please mention the reason:** ……..	**Consanguinity:** **Are the parents being relatives in any way?** ☐ **Yes** ☐ **No**

In case any of the siblings are affected please mention their names:

……..

Please specify if any of affected siblings are enrolled in NSMA Program

☐ **Yes** ☐ **No**

If yes, please enter the EMR code:

……..

City of residence:	**Parents' level of education** Father: Mother:
Do you have trained Physiotherapist/Rehab team to conduct required motor scales? ☐ Yes ☐ No	**Parental commitment to standard of care:** ☐ Committed ☐ Unknown ☐ Not committed

Patient's/ Family Preferences

The patient has completed counseling session about the disease	☐Yes ☐No
The patient is fully aware about the National SMA program and the process flow	☐Yes ☐No
The patient is fully aware about different treatment options for SMA	☐Yes ☐No

The patient has preferred Specific treatment option* **If yes, please specify** ☐Yes ☐No	☐Oral / Daily ☐ Intrathecal injection / loading dose then every 4 months ☐Infusion / one time
Please, Specify the reasons for the selection (which are applicable) **Explanation (Mandatory in case of preferred option selection)** ……	☐Medical condition ☐Residency ☐Occupation ☐Administration compliance ☐Others
Physician preferences	
The treating physician prefers Specific treatment option as a recommendation* **If yes, please specify** ☐Yes ☐No	☐Oral/Daily ☐ Intrathecal injection/ loading dose then every 4 months ☐Infusion/one time
Please, Specify the reasons for the selection (which are applicable) **Explanation (Mandatory in case of preferred option selection)** …… …… ……	
Please mention the reference / Supporting document name for your preferences and attach it to the patient's file	• …… • ……

I hereby, declare that the information provided here is true and correct. I also understand that any incorrect information or mismatch with supporting documents may delay the full submission of this application. In addition, **the patient doesn't have any active substances of alcohol or drug addiction.**

***I understand that if there is any delay in submission of all the accurate mandatory requirements and documents. This may affect the timeline frame of NMC decisions for both new patients' enrolment and Treatment continuation decision during treatment journey.**

*Treating physician and Patient's preferences are for recommendations and preferences purposes only and **should not be taken / communicated to the patient or caregivers** as a decision for approval or/ and Selection of specific treatment option. **The full authorization of both Approval decision and Treatment selection are owed only to Saudi Ministry of Health - The Scientific Committee of The National Neuromuscular Committee (NMC)**.

*These preferences **don't oblige the Saudi Ministry of Health with any duties towards treatment or follow-up** from a multidisciplinary team **except** after the decision of approval by the Scientific Committee on the treatment plan.

* The treating physician should ensure that both:

- Overall adherence rate is achieved for:
  - Treatment adherence
  - Minimum standards of Care of Multidisciplinary services
- The required Motor Function Assessments starting from Baseline assessment and going forward for all the Follow-up Evaluations and assessments during the treatment journey including the required mandatory information as below:
  - **Timeline assessment** and all the applicable mandatory motor Function scales according to SMA type
  - **Current Motor Status** at the time of the evaluation including if the patient is using any assistive devices. In case the motor status has been changed from the baseline during the treatment journey, the treating physician should provide the reasons of this change and to specify which scale is affected and the date of this change.

- **Current Respiratory status** and if the patient has been admitted during the treatment journey due to any respiratory reasons or receive ventilation support.
- **Current Scoliosis status if exiting and progress and degree if applicable.**
- **Spinal surgeries** with its indication, date and its affect on the overall patient's status if applicable.
- **Scoring sheets along with the videotaping according to the videotaping policy** are available and submitted as per assigned timelines.
- **Minimum required information**, for example but not limited to weight, height, employment, current education degree, marital status, and how many current number of children
- **A detailed medical report including the above current statutes information** for every evaluation, assessment, updated medical condition, or if requested by NMC.

Mandatory Supporting Documents	
Provided (Yes/No). If No, please add Comment	
Genetic test	☐Yes ☐No
Patient Consent Form	☐Yes ☐No
National ID copy	☐Yes ☐No
All mandatory required assessments as applicable with videotaping	☐Yes ☐No
Medical report	☐Yes ☐No
Complete and signed PAF form	☐Yes ☐No

Primary Physician who will be responsible for administering therapy and reporting follow up data to MOH:	
Name:	**Signature:**
Contact #:	
Email:	**Date:**