

# Association tunisienne d'amyotrophie spinale - SMA Tunisia

Tunisia



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**Inès Bagana**

President of SMA Tunisia

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## 1. About

The Tunisian Association of Spinal Muscular Atrophy (SMA Tunisia), is an association founded in January 2022 by a group of parents of patients who decided to join forces for the benefit of people with spinal muscular atrophy in Tunisia and their families to build a network of information, support and management.

This association brings together many patients and their families in collaboration with health professionals. It is open to the entire SMA community in Tunisia and around the world. Our motto:

**”Bien vivre avec la SMA en Tunisie” - “Living well with SMA in Tunisia”**

## 2. Mission

- Be an interlocutor and representative of patients and their families in Tunisia.
- Create partnerships and cooperation with scientific and social associations at the national and international level.
- Creation of a national registry for people with spinal muscular atrophy.
- Implementation of a multidisciplinary management program and complaint of introduction of available SMA treatments to health authorities in Tunisia.
- Creation of reference and competence centres for neuromuscular diseases in Tunisia and participation in therapeutic trials.

- Intervene at school, cultural and social level and with local communities to facilitate the integration of patients and offer them appropriate conditions

### 3. Your focus.

The Association's work in the first three years focuses on awareness-raising and mentoring efforts, so we sought to inform the patient of the disease and its seriousness in the first and second societies, through publications distributed in a series of disturbances organized or participated in by the Association, through programmes in audio and visual media and via social media, as well as by organizing conferences and sensitization days in hospitals and beyond.

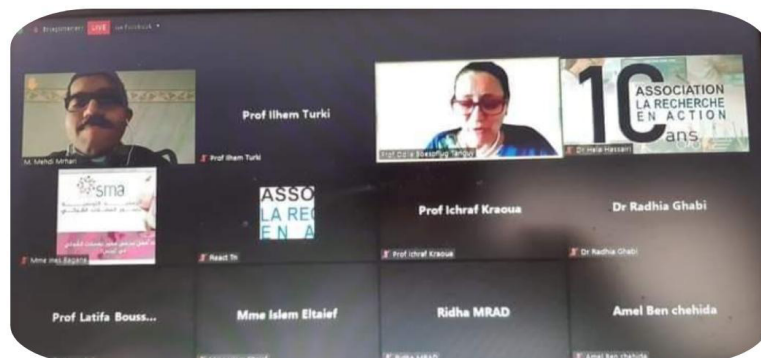
The Association also initiated the establishment of a database to record patients' cases in Tunisia until the census, identify the most prevalent areas and identify the needs of patients

The Association also requests the provision of medicines to the competent ministries of the Tunisian Government through correspondence and interviews to communicate patients' voices in claiming their right to medication.

### 4. Coming up

The Association requests the provision of medicines to the competent ministries of the Tunisian Government through correspondence and interviews to communicate patients' voices in claiming their right to medication.

Photos of the Association's activities during 2022 and 2023







  
 L'association Tunisienne d'amyotrophie spinale  
 organise en partenariat avec

  
 une journée de sensibilisation sur l'amyotrophie spinale infantile

## Brises d'espoir



<b>PEINTURE</b> Atelier animé par Le peintre <b>Mohsen Khataf</b>	<b>TECHNOLOGIE DIGITALE</b> Atelier animé par: Le centre de réhabilitation <b>RAED</b>	<b>BRICOLAGE ET MOTRICITE FINE</b> Atelier animé par L'industrielle <b>Mentem Tabtab</b>
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**Samedi 14 mai 2022**  
**9h00 à 12h00**

L'environnement du service de neurologie pédiatrique de CHU Hedi Cheker, Sfax

sponsorisé par: 

#spinalmuscularatrophy • 011 434 8371 • 011 2888 961 • association.tunisienne.sma@orange.tn • Association Tunisienne SMA






 Organise en partenariat avec :
 

# 1<sup>ER</sup> CONGRÈS MAGHRÉBIN SUR L'AMYOTROPHIE SPINALE

Thème de conférences  
 - Diagnostic  
 - Prise en charge  
 - Traitement  
 Ateliers & E-Posters

Soumission E-Poster :  
<http://amyotrophiespinale.wixsite.com/congresmaghrebinsma>  
 Dernier délai de soumission 15 octobre 2022  
[congresmaghrebinsma@gmx.com](mailto:congresmaghrebinsma@gmx.com)

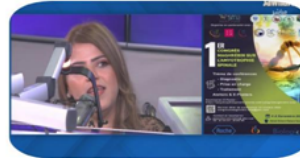
Contact et Inscription  
[association.sma.tunisie@gmail.com](mailto:association.sma.tunisie@gmail.com)  
 Tel : 53 434 377 - 26 888 464

**4-5 Novembre 2022**  
 Hôtel Orient Palace Sousse















organise :

# اليوم التوعوي: لضمور العضلات الشوكية

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السبت 9 سبتمبر



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GOLDEN TULIP  
EL MACHTEL TUNIS

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Association Amyotrophie Spinale Maroc  
 جمعية الضمور العضلي الشوكي المغرب

2<sup>ème</sup> الدورة  
 EDITION

CONGRÈS MAGHRÉBIN SUR L'AMYOTROPHIE SPINALE  
 المؤتمر المغاربي حول الضمور العضلي الشوكي

Sous le Thème  
 AMYOTROPHIE SPINALE DE L'ENFANCE À L'ÂGE ADULTE  
 ضمور العضلي الشوكي : التحول من الطفولة إلى سن البلوغ

MARRAKECH مراكش  
 03 - 04 . 11 . 2023

Roche NOVARTIS Biogen MASTE

SMMSNE  
 IRENA Organization for Rare Diseases

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