UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078

F. No. GGSIPU/UIAC /2024/020 Date: 30th July 2024

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL

NOTIFICATION

Subject: August is observed as Spinal Muscular Atrophy (SMA) Awareness Month 2024

The University Inclusion & Accessibility Cell (UIAC-UTTHAAN), Guru Gobind Singh Indraprastha University, New Delhi, **is dedicated to promoting Disability Inclusion & Accessibility.**

Spinal muscular atrophy (SMA) is a genetic disorder caused by defective copies of SMN1 gene. The disease affects the nerve cells of the spinal cord. The damage to the nerve cells leads to weakness of muscles of all limbs and trunk of the body. It is one of the rare disorders where new treatment options are changing the paradigm of outcome.

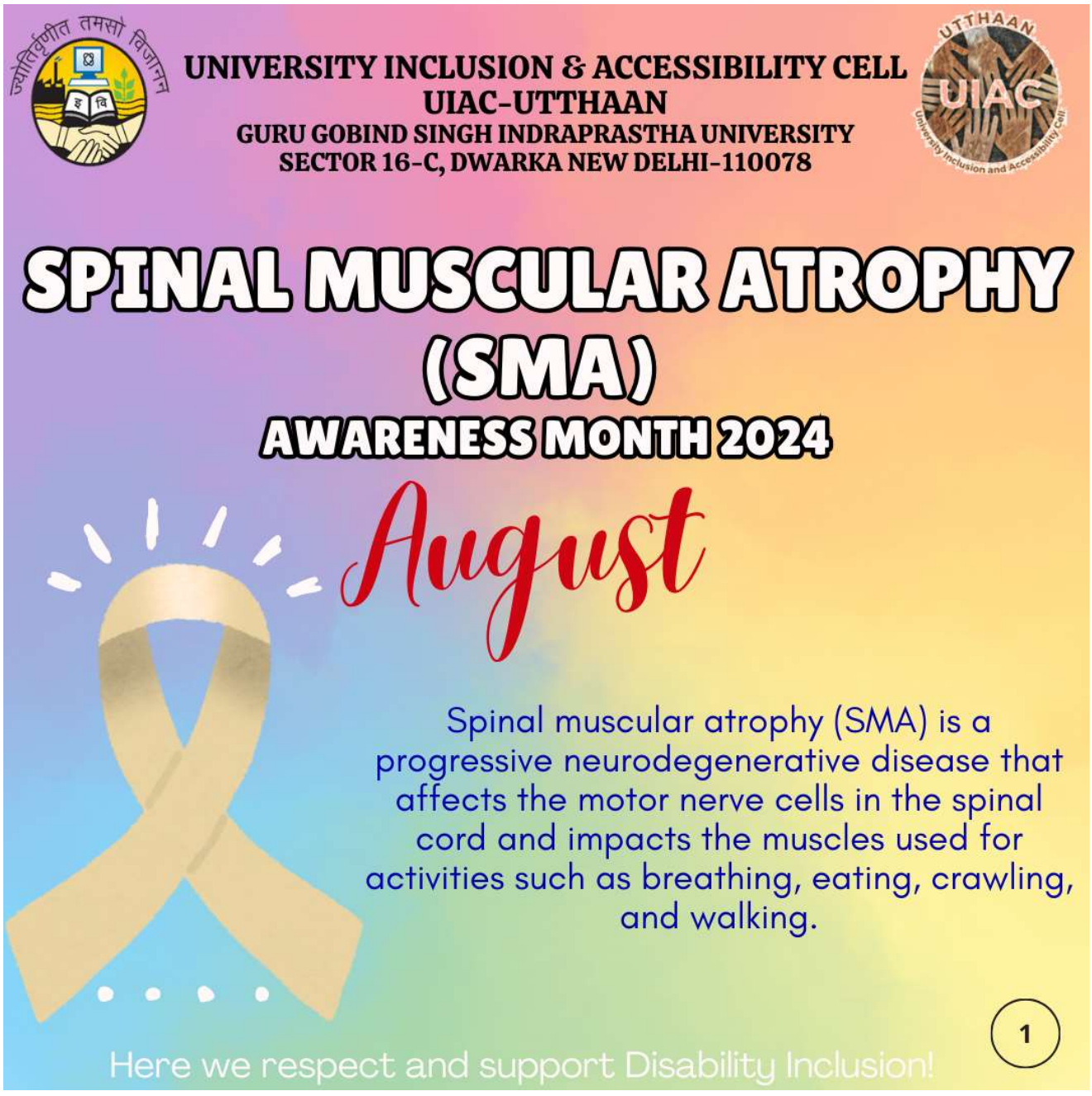
UIAC UTTHAAN aims to raise awareness and sensitize the community about SMA and its impact on individuals and families. UIAC-UTTHAAN facilitates this effort and seeks the support and cooperation of all.

*For more information, please refer to the attached handout.

Together, let's work towards a more inclusive and accessible world

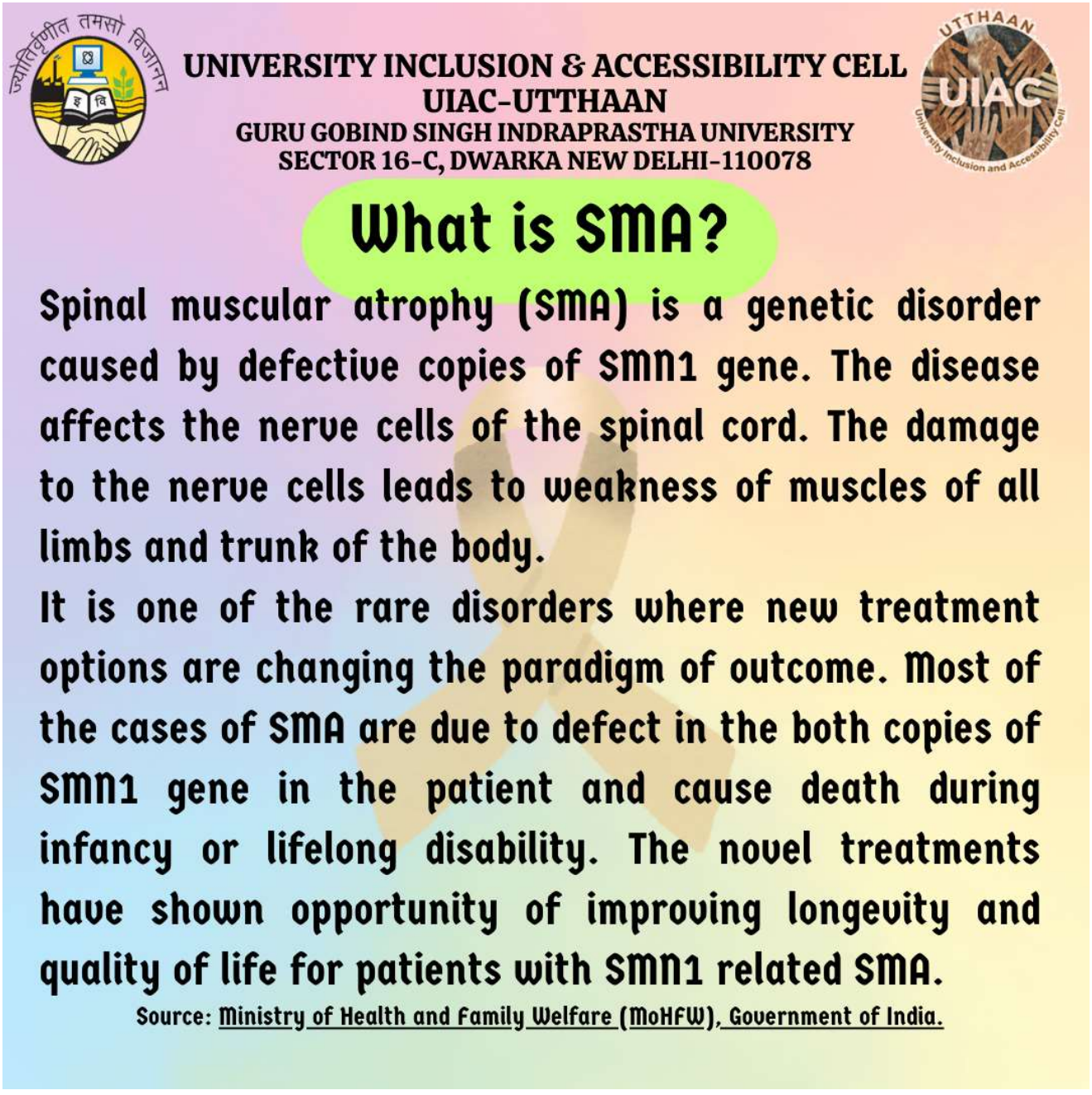
Prof. (Dr) Shalini Garg
University Grievance Redressal Officer – Disability Matters
Chairperson University Inclusion & Accessibility Cell (UIAC)
GGSIPU

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078



This information is extracted from the publicly available open sources.

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078



This information is extracted from the publicly available open sources.

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078

UNIVERSITY INCLUSION & ACCESSIBILITY CELL
UIAC-UTTHAAN
GURU GOBIND SINGH INDRAPRASTHA UNIVERSITY
SECTOR 16-C, DWARKA NEW DELHI-110078

Spinal Muscular Atrophy (SMA)
What You Need to Know

- Spinal muscular atrophy (SMA) is a disorder affecting the motor neurons—nerve cells that control voluntary muscle movement. These cells are located in the spinal cord.
- Because the muscles cannot respond to signals from the nerves, they atrophy — weaken and shrink — from inactivity.
- One in every 6,000 babies is born with SMA. It is one of the most prevalent genetic disorders affecting young children and a major cause of death in infancy.
- SMA can strike children at any age. SMA in infancy and early childhood is associated with worse outcomes, while patients who develop symptoms later in childhood or in adolescence usually have a more positive prognosis.
- SMA does not affect sensory nerves or intellect, but it has been observed that many patients with SMA are highly intelligent.

Source: https://www.hopkinsmedicine.org/health/conditions-and-diseases/spinal-muscular-atrophy-sma#:~:text=What%20You%20Need%20to%20Know,weaken%20and%20shrink%20%E2%80%94%20from%20inactivity.

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078

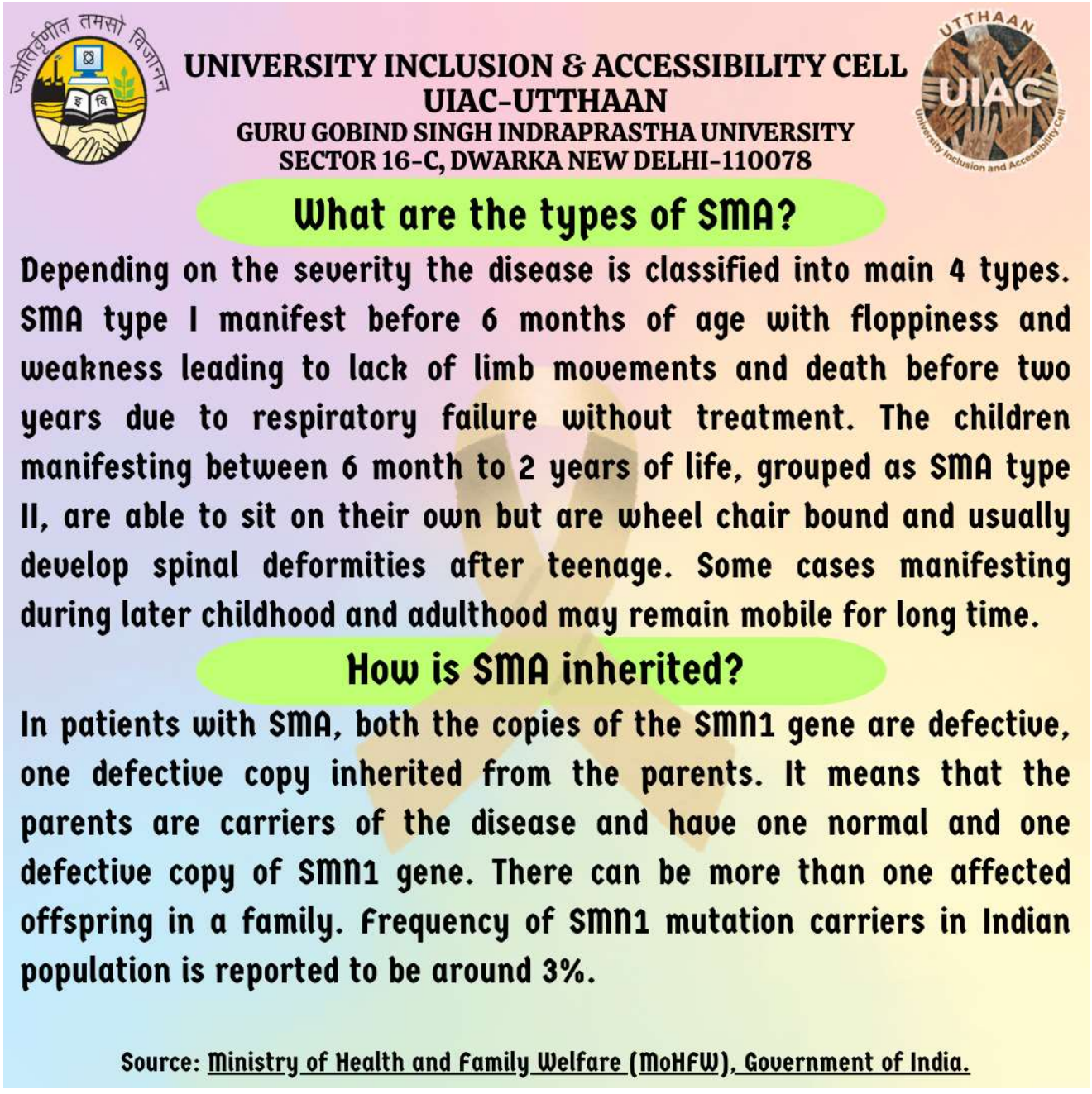
UNIVERSITY INCLUSION & ACCESSIBILITY CELL
UIAC-UTTHAAN
GURU GOBIND SINGH INDRAPRASTHA UNIVERSITY
SECTOR 16-C, DWARKA NEW DELHI-110078

SMA Signs and Symptoms

- Spinal muscle atrophy symptoms vary, and may be mild or disabling, but involve a weakness of the muscles that control movement. Involuntary muscles, such as those in the heart, blood vessels and digestive tract, are not affected.
- SMA weakens the muscles closest to the center of the body, including the shoulders, hips, thighs and upper back. The affected child may develop a curve in the spine (scoliosis) due to loss of size and strength of the back muscles.
- Progression of SMA can also affect breathing and swallowing, which can threaten the life of the patient.

Source: https://www.hopkinsmedicine.org/health/conditions-and-diseases/spinal-muscular-atrophy-sma#:~:text=What%20You%20Need%20to%20Know,weaken%20and%20shrink%20%E2%80%94%20from%20inactivity.

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078



This information is extracted from the publicly available open sources.

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078

UNIVERSITY INCLUSION & ACCESSIBILITY CELL
UIAC-UTTHAAN
GURU GOBIND SINGH INDRAPRASTHA UNIVERSITY
SECTOR 16-C, DWARKA NEW DELHI-110078

Govt of India: Supporting SMA

Read at:

Ministry of Health and Family Welfare (MoHFW), Government of India.
https://rarediseases.mohfw.gov.in/Documents

Spinal muscular atrophy (SMA)
https://rarediseases.mohfw.gov.in//uploads/Content/1627981400_Spinal_Muscular_Atrophy.pdf

Government of India has identified 12 institutions which are actively managing patients suffering from rare diseases. These institutes have been designated as Centres of Excellence(CoE).
https://rarediseases.mohfw.gov.in/Hospital_Treating_Rare_Diseases

This information is extracted from the publicly available open sources.

UNIVERSITY INCLUSION AND ACCESSIBILITY CELL
Guru Gobind Singh Indraprastha
Sector 16-C, Dwarka New Delhi-110078

UNIVERSITY INCLUSION & ACCESSIBILITY CELL
UIAC-UTTHAAN
GURU GOBIND SINGH INDRAPRASTHA UNIVERSITY
SECTOR 16-C, DWARKA NEW DELHI-110078

Where can I find more information about spinal muscular atrophy?

Information may be available from the following organizations and resources:

Ministry of Health and Family Welfare (MoHFW), Government of India.

Cure SMA

Genetic and Rare Diseases (GARD) Information Center
Muscular Dystrophy Association

Spinal Muscular Atrophy Foundation

Disclaimer:
This information is provided solely for awareness generation and has been obtained from publicly available open sources.