



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

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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



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SPINAL MUSCULAR ATROPHY (SMA) AWARENESS MONTH 2024

August



Spinal muscular atrophy (SMA) is a progressive neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking.

Here we respect and support Disability Inclusion!

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What is SMA?

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. Most of the cases of SMA are due to defect in the both copies of SMN1 gene in the patient and cause death during infancy or lifelong disability. The novel treatments have shown opportunity of improving longevity and quality of life for patients with SMN1 related SMA.

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



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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.>



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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.>



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What are the types of SMA?

Depending on the severity the disease is classified into main 4 types. SMA type I manifest before 6 months of age with floppiness and weakness leading to lack of limb movements and death before two years due to respiratory failure without treatment. The children manifesting between 6 month to 2 years of life, grouped as SMA type II, are able to sit on their own but are wheel chair bound and usually develop spinal deformities after teenage. Some cases manifesting during later childhood and adulthood may remain mobile for long time.

How is SMA inherited?

In patients with SMA, both the copies of the SMN1 gene are defective, one defective copy inherited from the parents. It means that the parents are carriers of the disease and have one normal and one defective copy of SMN1 gene. There can be more than one affected offspring in a family. Frequency of SMN1 mutation carriers in Indian population is reported to be around 3%.

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



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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



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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.