

## Profile



The Founding Day of The Spinal Foundation is May 26, the birthday of Dr Mary Vergheese, seen in this 1963 image with the then President of India, Dr Sarvapalli Radhakrishnan at the inauguration of Physical Medicine & Rehabilitation Department in Christian Medical College, Vellore.

The Spinal Foundation is a India Self-Help Group for persons with spinal cord injury.

We have recorded instances of spinal cord injury (SCI) for more than 60 years now. Several small groups / individuals have been working to support persons with SCI in different parts of India. There has, however, been no concerted effort to push for improved quality of life for persons with SCI at a national level.

As an umbrella organisation, The Spinal Foundation seeks to combine efforts, be more effective, improve reach, have unified voice for advocacy, share best-practices and address the daunting challenges faced by persons with SCI, especially those who are also economically challenged, and living in rural areas.

The Spinal Foundation aspires to improve quality of rehabilitation, guide persons with spinal cord injury to a healthy life of dignity and improve advocacy.

**Living Well with SCI** is the motto of The Spinal Foundation. For each person with SCI, this has to be in the face of multiple disabilities such as loss of:

- Sensation
- Mobility (legs, hands and fingers)
- Bladder control
- Bowel control
- Sexual function
- Temperature control
- Ease of respiration
- Attendant psychological stress

These are accentuated by mishandling after injury, poor

rehabilitation, recourse to unscientific treatments, high cost of rehabilitation and post-injury complications such as pressure ulcers, urinary tract infections, loss of vocation / jobs as well as sizeable ongoing medical costs for life.

There is no cure for spinal cord injury. It leads to lifelong disability. Conservative estimates suggest that the incidence of spinal injuries would be about 10 per million. An estimated 10,000 fresh cases are added every year.

Appropriate and timely rehabilitation help lead a healthy, successful and productive life. Two exemplary individuals who epitomise this definite possibility are central to The Spinal Foundation.

May 26 has been chosen as the Founding Day for The Spinal Foundation, as it is the birthday of Padma Shri Dr Mary Vergheese, an alumnus of Christian Medical College, Vellore, a great doctor, and the visionary who championed India's first specialised centre for rehabilitation 50 years ago. She became a paraplegic in a road accident in 1954 and a wheelchair user for life.

The Spinal Foundation is headed by Padma Bhushan Major H P S Ahluwalia, a Mount Everest climber, a hero of 1965 India-Pakistan war in which he sustained a spinal cord injury, founder, Indian Spinal Injuries Centre, Delhi, one of three quality rehab centres in India, adventurer and author of Higher Than Everest among several books.

The Spinal Foundation is registered as a Society. The Governing Board, responsible for the overall management comprises SCI persons from across the country with a deep commitment to the cause.



Major HPS Ahluwalia is at the helm of The Spinal Foundation. A trailblazer in several respects, he has worked for the cause of SCI, played a major role in advocacy and is highly regarded by peer organisations worldwide. His leadership gives The Spinal Foundation a head start.

## Patrons



**Major HPS Ahluwalia** is a hero from the 1965 India-Pakistan war in which he sustained a spinal cord injury. A few months earlier he had scaled Mount Everest. Subsequently, he founded Indian Spinal Injuries Centre in the late 1990s, and is a leading advocate for the SCI community. He is the Patron-in-Chief & the first President of The Spinal Foundation. (New Delhi, 74 years).

**S Ramakrishnan** sustained a cervical spinal cord injury during naval officer selection. Facing the most acute challenges, he forged ahead, founding Amar Seva Sangam in Ayikudy, Tirunelveli, Tamil Nadu. His organisation offers vocational training, schools, in-patient facility for spinal injured and works in 600 nearby villages. He pioneered networking SCI persons in India. (Tamil Nadu, 58)



**Nazeema Hurzuk** had a spinal injury at 16, but it did not hold her back. Be it education, job, career growth & international sports, she embraced 'em all. She is the Founder and President of Helpers of the Handicapped. She has been actively championing the cause of physically challenged for almost three decades now. Nazeema is a go-getter, whatever be the hurdles. (Maharashtra, 64).



## Objectives

- Identify and reach out to people with spinal cord injury with a focus on connecting with the newly injured as early as possible after the injury date.
- Advocate and facilitate the right to rehabilitation after a spinal cord injury.
- Support and monitor the spread of quality rehabilitation facilities.
- Improve quality of treatment and rehabilitation for persons with spinal cord injury through creation and implementation of evidence-based indigenized medical protocols.
- Establish a robust peer network and a knowledge bank with a special emphasis on serving populations from rural areas, lower-income groups and persons with no access to contemporary communication facilities.
- Facilitate the establishment of a high-quality registry of persons with spinal cord injury with the support of the government.
- Enable enhancement in quality of life for persons with spinal cord injury through:
  - Advocacy against unscientific so-called treatments.
  - Fight incidence and encourage proper management of pressure ulcers, commonly known as bedsores.
  - Inclusive education, training, empowerment and guidance on vocation / employment.
  - Social integration, recreation and sports leading to general health and fitness.
  - Promoting, tracking and reporting research.
  - Aiding information and availability of aids, implements and medical supplies.
- Follow the social, economic and family lives of persons with spinal cord injury so as to be able to provide support where needed and possible, especially by connecting the spinal cord injured person, his family and friends with support systems at multiple levels in a geographic sense.
- Sensitise and build awareness about spinal cord injury and its multi-faceted implications.
- Mould public policy at multiple levels of government.
- Champion initiatives to reduce incidence of spinal cord injury.
- Promote accessibility by removing mental and physical barriers.

## The Governing Board



**Chandra Rama Rao**, injured at 10, is a Chartered Accountant. She rose to top positions in banking. She leads a vibrant life associating herself with NGOs and is a disability activist. She is a peer counsellor at ISIC, Delhi. (Uttar Pradesh, 65).



**Komal Kamra** is an Associate Professor of Zoology, a peer counsellor and a volunteer in good causes. Komal works closely with government and regulators on disability issues. Her clarity of thought shapes several initiatives. (Delhi, 59)



**Dilip Patro**, is President of The Ability People, which offers support for physically challenged, especially for mobility. Dilip networks with government and is setting up a rehabilitation centre for SCI. (Andhra Pradesh, 42)



**Nitin Goyal**, a senior finance professional, spearheads the SCI Yahoo email group. He provides outstanding guidance to SCI community. Nitin, a peer counsellor, works extensively on patient education materials. (Haryana, 41).



**Javed Ahmad Tak** is active in advocacy, as well as in working for needy children and SCI persons by using local facilities. Javed is also the Founder & Chairman of Humanity Welfare organisation HELpline. (Jammu & Kashmir, 40).



**Preethi Srinivasan's** soaring cricket ambitions were cut short by a cervical level injury. She works using a voice-operated software, is a brilliant speaker, and founder of Soulfree to especially support women SCI. (Tamil Nadu, 34).



**Ketna Mehta** is founder trustee of Nina Foundation, one of the more active NGOs for SCI persons. She is active in advocacy. She is Editor and Associate Dean, Research at a Management Institute. (Maharashtra, 51).



**Parvinder Singh** has been instrumental in networking for persons with SCI in Punjab as President of The Spinal Cord Injury Association in Punjab. His ground level work is considered exemplary and a model for the rest. (Punjab, 60).

## The Governing Board



**Salil Chaturvedi** runs a corporate consultancy outfit. He is active in sports, culture, writing, media work, creative assignments, accessibility and advocacy. He is associated with a couple of NGOs and leads by example (Goa, 42).



**Sruti Mohapatra's** budding civil services aspirations were ended by a hostile environment in the late 1980s. She did a PhD. She spearheads Swabhiman, an advocacy group for the physically challenged. (Orissa, 49)



**Sashank Vaibhav Allu**, an alumnus of IIT Madras, is a very independent and is set for Masters in Robotics from a top-rung U S university. He writes an outstanding, blog called quadriplegichronicles. (Andhra Pradesh, 24)



**P.Suresh Krishna** has braved challenges of a brain injury and spinal cord injury sustained in the US while working. Through plegia.org, he works at grassroots level enabling rehabilitation for many. (Chennai, Tamil Nadu, 41)



**Shikha Jain**, injured at 7, has relentlessly pursued education and is a multiple postgraduate. She works as a teacher in Manipur. Shikha brings insights about the North East and related accessibility issues well. (Manipur, 26).



**S Vaidyanathan** is a Peer Counsellor at Mary Verghese Institute of Rehabilitation, a part of Christian Medical College, Vellore. Inspired by Dr Suranjan Bhattacharji, he co-founded The Ganga Trust (Vellore, 48)



**Shivjeet Singh Raghav** is a Peer Counsellor and Patient Educator at ISIC, Delhi. He inspires by his active life despite acute challenges. He is widely travelled and brings networking skills with global peer groups. (Haryana, 56)

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