



**QUALITY OF LIFE** 

**OF LIVING WITH SPINAL CORD INJURY** 



REHABILITATION DESIGN CHALLENGES & SOLUTIONS

> Editor - Dr. Ketna L. Mehta Founder Trustee - Nina Foundation





TATA MUMBAI MARATHON 19TH JAN. 2020

April. 2020 Vol. 18, Issue 35



Nina Foundation group participated for the 15th year in the wheelchair race on 19th January, 2020. We have seen:

- Lives Transforming.
- · Personal struggles of living with a devastating spinal cord injury have been overcome by taking this one small step of agreeing to participate.
- New horizons have been conquered by being in the midst of winners.
- · Achievement of Life goals have been made possible by this sporting event.
- · It's the best thing to happen in the lives of our friends with disability.

A big shout-out for Procam, Tata Group, ADAPT & all the other organizers.



#### BHAVNA CHHEDA LED OUR NINA FOUNDATION INITIATIVE ABLY

BHAVNA CHHEDA spearheaded the entire Marathon project & operations fabulously. Thanks to her tremendous persuasion, coordination & timely efforts we had a record group of 75 participants, 13 participated for the very first time for an unforgettable life-changing experience.













TATA MUMBAI MARATHON 19<sup>TH</sup> JAN. 2020

























TATA MUMBAI MARATHON 19TH JAN. 2020













## WISHES EVERYONE CONGRATULATIONS!!!

#### NINA FOUNDATION

Ajay Savla Ajaykumar Singh Parmar Akashdeep Gupta Alka Nikam Anthony John Bharti Chavan Bhawana Chheda Bijoli Shah **Dhaval Shah Hadis Mohammad** 

Hutaib Adib Joseph Rodrigues Ketna Mehta Kishor Meswani Mamta Sharma Manjout Kaur Matts Mayank Gandhi Mohammad Quralshi Nikhil Bodke

Harshad Shinde

Nikunj Bhutta Nisha Gupta Oliver Dsouza Rahil Shaikh Rajeshwari Mane Rajshri Patil Ritu Tiwari Sadik Nakade Salman Khan Samina Shaikh

Sanika Shasane Shadaab Sarang Shamshad Hashmi Sudhanshu Patel Sumalya Khan Sunil Jawkar Suraj Prajapati Surendra Kasare Tabassum Shaikh Tarandeep Singh



TATA MUMBAI MARATHON 19<sup>TH</sup> JAN. 2020

























TATA MUMBAI MARATHON 19<sup>™</sup>JAN. 2020 - MEDIA COVERAGE



20-Jan-2020 મુંબઇ Page 2

## મુંબઇ મેરેથોનમાં કચ્છી-ગુજરાતી દોડવીરોએ ઉત્સાહભેર ભાગ લીધો

દેશની સાર્થિક પ્રજયાની મુંબીમાં રાટા

મિનેશ છેલા (મુંબઇ-અપેરી ક્રમક-પામીરની, એમુ છેલા (મુંબઇ-મલાદા સ્થ ભષ્યછે, મનોજ ગાલા (મુંગઇ-દિવાજી દાર્ક કચ્છ-ખારોદીઅને પર્વેશ સાવલા યાક ક્લામ્પ્રેન્સારાપ્રિયમ પંચા શાલા (પૂંચ ને મોર્ટલર્સ, ક્લામ નવારાપ્રેનાલ પ્રેર્ધાન પૂર્વ કરી હતી. યાગાના કર વર્ષના સત્ત્રણ કાર્યા છે કર્ય પ્રેર્ધાન સાંતરૂત, ક્લામ ભ્યારો ફુલ પૈરેશનમાં ભાગ લીધે હતો. ૨૫ વર્ષના ચીઠિંગ શાહે (મુંબઈ-દાદર, કંચક -પુરત્વ સંગો) તાક વેડેમાંન પૂર્ણ કરી હતો, આ ઉપરાંત રિચી ગાા (ચીમ મધ્યમ આપોઈ) અને ભાવના અભ્યસ્થી છેવાએ (ધારકોયર-લાકદિયા) Boxin Martini son allei am 12 યુંગઈ વહારોવાને માને તાર વર્ષના વિજય





















- arên aren da
- Dell our
- Brid tild
- Roman Treat
- ચેતા ભરત ગા પ્રતિસ્થાન માટે
- North sons
- area area

- Scient and emphasis
- EVÉ ME
- भारीन गाम
- યાગા કિરનેશના કન્યોનથી વિશાસ માટ
- વિજય ભૂવા સંભા વિજય સાત
- DER KIM

દારાના સામક પાજપાના જુવારાના ટાટા યુવાં મેમેલોનની 17 મી સારાનિયાં દર વર્ષની જેમ ક્લાઇ-ટુજરાતી સ્પર્ધકોએ ક્લાહાલેર ભાગ શીધો હતો, વાગદ કિટનેશના ઇન્સેનડી C.A.

ભાગિત જેમાં ક્રિયા નાની તુંચી મુંચઈ-પાકોપા) લેનેમે તાક પેરેલનમાં



ભાગ લીધો હતો.

દિવાન પટેલે (યુંબઈ- વાટકોપર, કચ્છ

-ગાંધામાં) કુલ પૈરેયોન 5 કલાક 40 પિનિટમાં પૂર્વ કરી હતી. 40 પર્યના કમ્લી

કાલવામાં સાતીના હિલાંશ વિચાર

(મુંબઈ-ચાટકોયદ, કચ્છ નુલી) નવમી વખત કુથ મેરેથીન પૂર્ણ કરી હતી, 42

when the Pers and Court, and







ભાગ લીધો તતો. કા વર્ષના બો જ્ઞતીના લેતા ભાત ગાા (

મુંલઈ વાટકોરર, કચ્છ -વારી) એ ૧૯મી. મોલોનમાં ક્રિકિવર ક્રિકેટલ કેટેવરીમાં

તાર મેરીયોન આપ લઈ 2.12 મિનિટમાં





મેરેલોના 4 કલાક 13 મિનિક 13 દેકનામાં ह्ये हरे जी.

and (active, see condition) ga

યુવા કર્ય હતા. ગુજરાતીઓમાં 25 વર્ષના રાજેશ લાભા (નુંભઈ- પ્લાકોપર, ગુજરાત-મગદાશા લાલુકાનું કુંબરીયા)એ મીજ ત્રભત લાલ મેરેમોનમાં ભાગ નીંધી હતા.

ડક વર્ષના સ્થાનકવાસી જેને નિકેશ સાથિતીએ (યુંસઈ-વાદકોપર, ગુજરાત-વાંગામાં લુંવાન વાંડકારર, વૃત્ર લાન વાંગુર) તાક પેરેથોનનાં ભાગ શીધો તતો, 42 વર્ષના રેણાક પ્રખેશ શાર્તના ત્રિતા મહેલા તિથી મુંબઈ- ગુપદાન ભાગનગરોએ તાક પેરેથોનમાં પાની દશા મહેલા શાંદે દોર્યા ભાગ શીધો તતો. લ્ડ વર્ષના ગુજરાતી ભાદિયા શાહેના મિનાથી આંદર (મુંબઈ ચારકોપર,

ગુજરાત ગામમાં આવીઓ, ૩૯ વર્ષની દથી જો વિદારોયર, ગુજરાત સરકાર્થી જબાના દેશેઇ ગામના વર્ત્સી દિલ્હાંય કેટનરીમાં ભાગ શીધો હતો. 53 વર્ષના ગલાવાદી દેશા સ્વાનકવાલી જેવ જાહેનામાઈ શહે (મુંબઈ- ધાટકોપર, ગુજરાત- શુરેન્દ્રમાં પર જાભાનું સામગ્રા ) કુલ મેરેલાન ૩, ૩૩ મિનિકમાં પૂરી stad.

### Media Coverage - Divya Bhaskar



The Nina Foundation, which works for the welfare of the disabled, brought together several wheelchairbound people. Among them was Sadik Nakade. wheelchair for 30 years. "We come every year. Our life goes on even If we can't walk. We want to spread the message of love and safe driving," sald Nakade.

Media Coverage - Mumbai Mirror

# 48, who has been using a

### શારીરિક અક્ષમતા વિકાસમાં બાધારૂપ ન બની શકે



તમારી શારીરિક ખામીને ક્યારેય તમારા જીવનની કારકિર્દી કે વિકાસમાં બાધારૂપ બનવા દેવી જોઇએ નહીં, એમ ડૉ. કેતના મહેતાનું માનવું છે. પેરાગ્લાઇડિંગ કરતી વખતે થયેલા અકસ્માતમાં તેઓ સ્પાઇનલ કોર્ડ

ુન્જરી (એસસીઆઇ)નો ભોગ બન્યા હતા. ત્યારબાદથી તેઓ વ્હીલચેર પર જ છે, પણ તેમણે ક્યારેય તેમની શારીરિક અશ્રમતાને તેમની કમજોરી બનવા દીધી નથી. કાઉન્ડેશનમાં સ્પાઇનલ કોર્ડ ઇન્જરીનો બોગ બનનાર લોકોને ઉત્સાહ-ઉમંગથી જીવવાને પ્રોત્સાહનનું કામ કરે છે. આ ફાઉન્ડેશનમાં કોઇ ક્રિકેટર છે તો કોઇ ડાન્સર, આ લોકોની શારીરિક ખામી તેમના સપનાને સાકાર કરવામાં અવરોધરૂપ બનતા નથી.

Media Coverage - Gujarati Mid-day









CELEBRATING DIVERSITY & REPUBLIC DAY ON 23<sup>RD</sup> JAN. 2020

Nina Foundation was once again invited by Cricket Club of India ( CCI ) on 23rd Jan. 2020.

Salubrious, breezy green East Lawns of the prestigious Cricket Club of India (CCI)
hosted 300 friends with disabilities across Mumbai to CELEBRATE DIFFERENCES
and commemorate Republic Day. A novel way indeed!

Gratitude to Mr. Ramesh Daswani,

Ms. Silloo Medhora & entire CCI team for this invitation & to present our publication One World to Hon. Chief Guest IG of Police Mr. Yashaswi Yadav.

> Nina Foundation's friends & family thoroughly enjoyed the wonderful, colourful, musical evening.









CELEBRATING DIVERSITY & REPUBLIC DAY ON 23RD JAN. 2020















#### AT ROTARY DISTRICT CONFERENCE 3142.

Nina Foundation team of friends with spinal cord injury were invited by Rotary District 3142 Conference on 1<sup>st</sup> Feb. 2020 at CIDCO Convention Centre, Vashi, New Mumbai.

The theme was 'Anant Drishti - Infinite Vision of doing Good in the World' and for the first time offered a platform to create awareness about impact of spinal cord injured.









#### AT ROTARY DISTRICT CONFERENCE 3142.

Nina Foundation team uniquely designed an entertaining, educational theatrical musical dance performance by an enthusiastic & confident team of 25 friends on wheelchairs with spinal cord injury & volunteers, interspersed with an inspirational talk by Dr. Ketna Mehta, Founder Trustee of Nina Foundation, the auditorium erupted with

The life journey of a young energetic girl 'Pari' the hearts & minds of the audience.

applause and a standing ovation.

who meets with a road accident and how her life changes positively with motivation, counselling and guidance from Nina Foundation's Support Group reigniting Pari's life was evocatively performed.

This twenty minute entertaining performance with Bollywood songs, energetic dance moves, wheelies & wheelchair acrobatics with punchy dialogues and superlative acting won the hearts & minds of the audience.





















#### AT ROTARY DISTRICT CONFERENCE 3142.

Rotary Excellence Award was conferred on Dr. Ketna Mehta by Rotary International Presidents Representative Mr. Dushan Souza and wife Ms. Manorie from Sri Lanka.

Nina Foundation's spinal cord injury awareness through an entertaining theaterical musical dance performance idea was wholeheartedly accepted by Rotary district conference DG, committee members and superbly written & executed by our ace creative team comprising of Sunita Sancheti & Eysha Khialani (Choreographer).













AT ROTARY DISTRICT CONFERENCE 3142.

















AT ROTARY DISTRICT CONFERENCE 3142.

NINA FOUNDATION ACE TEAM:

Creative Concept, Script & Lead Performer: Sunita Sancheti Choreography, Costumes & Concept: Evsha Khialani Narration: Ravi Iver

#### PERFORMERS

Madhu Singh Bhavna Chheda

Rajshri Patil

Mamta Sharma

Samina Sheikh Manjeet Kaur Matta Ramila Chheda

Mohammed Yousuf Jignya Shah

Harmeet Kaur Matta

Disha Sancheti

Shabnam Sheikh

Surendra Kasare Sudhanshu Patel

Rahil Sheikh

Hadis Sheikh

Ketna Mehta

#### YOUTUBE ENTIRE DANCE

https://www.youtube.com/watch?v=VoOErJ4t9ys

KETNA MEHTA INTRO (GOOGLE DRIVE LINK)

https://drive.google.com/file/d/1z8IQUPAur0f\_3q5Nis7x CISqdB6BxID-/view?usp=sharing

MEDIA COVERAGE NMTV LINK

https://www.youtube.com/watch?v=VoOErJ4t9ys



- Connect with all Piotary Intends in district Intriguing thems based causiers Amazing performances Lacky draw and prizes

- Fontantic rotorta
- Exotic cuitine and spirits Flash Mob.

ROTARY CLUB OF THANE NORTH Register Now!











# REHEARSALS OUR FRIEND ARVIND PRABHOO & HIS ACCESSIBLE AEROBICS HALL & PRABODHANKAR THACKERAY KRIDA SANKUL - VILE PARLE

Our 6 dance practice sessions were enabled, thanks to our friend Arvind Prabhoo's accessible aerobics hall. The enthusiasm and effort of travelling long distances by road from Dahisar, Mira Road, Andheri, Crawford Market, Ghatkopar, etc. did not dampen the smiles and spirit during the many rehearsals nor the final performance by our friends & volunteers. A special thank you to Rtn. Santosh Bhide (with the entire DISCON team) & the NASH Events team for their excellent cooperation.





















#### NINA FOUNDATION



A NINETEEN YEAR OLD NGO ESTABLISHED IN THE MEMORY OF DR. NINA DOSHI FOR REHABILITATION OF FRIENDS WITH SPINAL CORD INJURY IN INDIA



There are over 1.5 million friends with spinal cord injury in India, making it the capital for the disability in the world. Major causes are Road Traffic Accidents, Falls, Sports, Violence including Terror Attacks and Diseases of the Spine. Spinal cord injury is a permanent disability transforming a person's life and rehabilitation is the key to facing life with dignity. WHO (World Trade Organisation) has declared Spine Injury as the most devastating disability in the world. Our Foundation has been encouraging friends enabling them to excel in their respective fields.

#### VISION

To spread optimism and hope of good health to friends with spinal cord injury by offering innovative rehabilitation solutions.

#### MISSION

To offer world-class spinal cord injury solutions encompassing physical, psychological, vocational, social, recreational & spiritual rehabilitation for overall well-being.

#### PUBLICATION ME WORLD

(34 issues since 2000)

#### SUPPORT GROUP

. Created a chain of positively charged Buddy Network to touch more lives

- UNIQUE PROJECTS . A free OPD for underprivileged friends with Spine Injury - Project Nirmaan
  - · End-to-end solutions for complete rehabilitation
  - · Education Scholarships
  - · Wheelchair Sports & Marathon

- · Dance Therapy
- · Spiritual Trips on Founder's Day 9th March
- · Advocacy through Articles & Talks
- · Educational & Wellness Seminars
- · Guest Editorship: Design for All Institute's Publication on Spinal Cord Injury

#### INNOVATIONS

- . Spinal Injury Day 25th June
- SCI Helpline
- · PhD Research "Market potential study for a world-class Spinal Injury Rehab Centre in Mumbai"
- · Holistic Medical Camps in Rural Areas
- · Inspirational Talks

- · Rockstar, Will Star & Angel Champion Awards
- · NGO Partner for the first India Rehab & Care Expo
- · Give the Best Quality Counselling & Products to all
- Outbound Program
- Prestigious Bombay Times Fashion Show
- · Social Awareness through Dance & Drama

#### NINA FOUNDATION ADVOCATES FOR



WORLD-CLASS SPINAL CORD INJURY REHAB CENTRE in Mumbai, other cities & villages



SPINAL CORD INJURY REGISTRY pan India

#### NINA FOUNDATION

of India

Regd. Address: 240/11, 1" Floor, Shankar Sadan, Sion (E), Mumbai - 400 022. INDIA. Tel.: +91 22 2409 4319, +91 22 2407 1952 • Helpline: +91 97696 80820

nmafoundation@gmail.com • www.ninafoundation.org

The Trust's Registration Number is E 23804 (Mumba). The Foundation is registered with the Chanties Commissioner's Office, Government of Mahaeashtra, INDIA. Donations are exempt under Sec 80G of Income Tax.







#### NINA FOUNDATION





#### TRUSTEES

#### DR. (Ms.) KETNA L. MEHTA MMM, FIMC, PhD, Founder Trustee

Editor & Management Advisor

DR. S. Y. BHOJRAJ MS, FCPS (ORTHO), D (ORTHO) Consultant Spine Surgeon

DR. RITEN R. PRADHAN M.S. ORTH. FRCS (Ed), FRCS Tr. & Ortho, Orthopedic Surgeon, UK

#### MR. DHAVAL L. MEHTA B.Com, DTM, DMM,

Founder - kreate&young Advertising

DR. PARINAZ HUMRANWALA DHMS, MD.

Consultant Homocopath

DR. HIMANSHU DOSHI MBBS

#### DR. V. C. JACOB

BSc., D.P.T., MIAP, Physiotherapist

#### LATE DR. SHARAD N. SAGADE

MS (General Surgery), MCH (Urology), Consultant Urologist

#### SPECIAL PROJECTS TEAM

YOUTH VOLUNTEERS

- Anupama Ganesh
- · Dr. Dhruy Mehta · Aditi Moorthy
- · Neenu Kewlani · Sunita Sancheti
- · Pranay Raman
- · Bhawana Manral
- Namrata Mehta
- · Dev Mehta
- · Harrsh Mehta
- · Rushil Mehta
- Khushboo Gadda
- · Shwetha Iver
- · Aditi Mehta
- · Surabhi Narang
- · Vinay Mehta

#### PROJECT NIRMAAN MANAGING TEAM

(Counselling, Rehab, Physiotherapy, Assistive Technology, Medication & Supplies, Bladder & Bowel Management, Bedsore Management, Home Based Rehabilitation)

- · Rajshri Patil
- · Bhavna Chheda
- · Madhu Singh
- · Oliver D'souza
- · Mrs. Renuka Sagade Vivek
- · Meera Mehta
- · Hardik Dholabhai
- . Dr. Rama Vora
- Dr. Aashish Kumar Dubey
- · Mohammed Soni
- · Ajay Mahadik
- · Mohammed Sheikh

#### WHEELCHAIR SPORTS MANAGING TEAM

 BASKETBALL : Nisha Gupta (Women) | Oliver D'souza (Men) | Rajshri Patil (Rural)

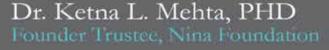
 CRICKET : Surendra Kasare BADMINTON : Anup Chandran SWIMMING : Oliver D'souza DANCE : Sanika Shasane

 MARATHON : Bhayna Chheda





# EDITORIAL



Nina my elder sister (an ace Homoeopath doctor) and myself as children, loved reading mystery books. We voraciously read popular authors like Agatha Christie, Arthur Conan Doyle, Alfred Hitchcock and many others. More complex the problem higher our interest levels.

This fascination for solving mysteries as well as real problems and challenges, I retain at my young age of only 57 years with 25 years of living with spinal cord injury in India and as many years understanding, empathizing, problem-solving, counselling several other friends with spinal cord injury as part of our NGO, Nina foundation.

My approach towards spinal cord injury has been that of wonder, curiosity, mysticism encompassing the realm of anatomy to the cosmic and the spiritual. The most mystical mystery is why did humans supposedly the highest evolutionary mammal discontinue and stop regenerating our nerves in the spinal cord, the main communicating medium between the brain and the rest of our body? Squirrels, also mammals, fall on their spine several times while climbing trees and yet regenerate their nerves thus going about their life as usual?





#### CAUSES OF SPINAL CORD INJURIES ARE

For those uninitiated about the impact and severe implications of spinal cord injury allow me to enlighten you.













#### SPINAL CORD INJURY

A spinal cord injury usually begins with a sudden, traumatic blow to the spine that fractures or dislocates the vertebrae. The damage begins at the moment of injury when displaced bone fragments, disc material, or ligaments, bruise or tear into spinal cord tissue. Most injuries to the spinal cord don't completely sever it. Instead, an injury is more likely to cause fractures and compression of the vertebrae, which then crush

and destroy axons -- extensions of nerve cells that carry signals up and down the spinal cord between the brain and the rest of the body. An injury to the spinal cord can damage a few, many, or almost all of these axons. Some injuries will allow almost complete recovery. Others will result in complete paralysis, medically termed paraplegia or quadriplegia.

#### How does Spinal Cord Injuries affect the Body?

- It affects the Motor System (movement of toes, ankles, knees, legs, arms, shoulders, fingers)
- Sensory System (touch, ant bites, etc.)
- Bladder Incontinence (catheterisation to be done in order to avoid)
- Bowel Incontinence (either train or digital stimulation)
- Temperature Regulation (Autonomic Functions)
- Sexual Function
- Mind Psychological Trauma & Depression

Infact no other injury affects so many parts of the body as a spinal cord injury - Mobility, Hot-Cold-Bite Sensation, Skin, Bones, Muscle Strength, Urine and Stool Control.

There are over 1.2 million friends with Spinal

Cord Injury in India (in 2019) making it the capital with this disability in the world. Spinal cord Injury is a permanent disability transforming a person's life and comprehensive rehabilitation is the key to facing life with dignity in the world.

WHO (World Health Organization) has declared Spinal Cord Injury as the most devastating disability in the world. (https://www.who.int/disabilities/policies/spinal\_cord\_injury/en)



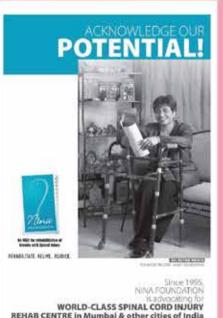


#### PROBLEMS FACED SPECIFICALLY BY OUR INDIAN FRIENDS WITH SPINAL CORD INJURY ON WHEELCHAIRS ARE

- Lack of world-class holistic rehabilitation facilities even in Mumbai and most cities & towns. Rural areas are worse.
- The Rights of Persons with Disabilities Bill (Act) does not list spinal cord distinctly as a SEPARATE disability giving it the importance in policy and plans.
- There is no spinal cord injury Registry on causes, incidence and prevalence which collates and shares real time data for future action.
- Lack of complete rehabilitation team to provide guidance. Till date Occupation Therapy, Assistive Technologist & Rehabilitation specialist majorly missing.
- Lack of trained rehabilitation professionals to guide in the entire journey of life.
- No awareness about prevention of spinal cord injury. Even now we observe construction sites workers work without a safety harness.
- Post road accidents the 'golden hour' precautions need to be taught to every citizen like CPR. Poor handling by well meaning

- samaritans like rushing the victim in a rickshaw causes further damage and a permanently disability. Scoop stretchers are invisible in India which can save lives.
- Schools, colleges, offices, government buildings, movie halls, restaurants, hotels, public washrooms and every infrastructure is NOT wheelchair accessible. Surprisingly even the new structures violate the guidelines and laws. The parents, family members and the wheelchair users all have to suffer very much due to this apathy and disdain towards this huge population.
- Medical curriculum does not have descriptive spinal-cord injury rehabilitation details. Thus cases are not properly managed.
- Lack of information & access to good quality affordable customised wheelchairs, cushions, etc. locally.
- Disability pension ranges from a meagre ₹800-₹1200 per month which does not cover most of the cost of living for 80% of friends with spinal cord injuries thus burdening the NGOs and social charities.











My rehabilitation in Mumbai was totally at home with minimal equipments but top class, highly experienced physiotherapist Dr. V. C. Jacob leading the 'Challenge Walk' ably supported by Dr. Milka Vivek (Nina's friend), Sharone, Vijayalaxmi and many others from the talented team.

The compounded complexity was we stayed on the first floor without an elevator. I used to be willingly carried piggyback by my kind hearted, athletic brother-in-law Dr. Himanshu Doshi for hospital visits.

An idea of adjusting the walker given by Dr. Riten Pradhan and enthusiastically accepted & actioned by Dr. V. C. Jacob (with Dr. Himanshu Doshi waiting like a cricket fielder, arms positioned at the foot of the stairs, just in case;). Such and many more ideas ensured that I learnt to climb & descend the entire two flights of stairs independently - enabling me to reclaim my freedom and life!

Nina taught me CIC and with family support I learnt other activities of daily living. Nina also got me some basic computer based part time work for the Homoeopathic journal she was contributing to. This turned out to be a real game changer immersing me in work, my elixir.







## THE WIDE SPECTRUM OF KNOWLEDGE ON SPINAL CORD INJURY I OWE TO A FABULOUS TEAM AROUND ME

My late parents for instilling the never-say-die confident spirit, independence and giving a quality education with ethical values.

My loving late sister Dr. Nina Doshi for making me believe in my talent, abilities & dreams to boldly stride full steam ahead and with twinkling eyes prophetically challenging me 'prove the medical books wrong and achieve the impossible.' Well today she is not physically with me but the NGO Nina Foundation that my younger brother Dhaval & I set up 19 years ago in her memory has empowered thousands of lives already.

My positive, handsome, magnanimous younger brother Dhaval has a heart of gold and has looked after me throughout my life fulfilling all my desires. The day tour that we jointly took to Swiss Rehab Centre, Nottwil, Switzerland still inspires gasps, awe & wonder at the 7 star spinal cord injury rehabilitation facility and the value of a human life accorded by them. Dhaval also funded the seed money to start Nina Foundation - the purpose of my life. His advertising agency kreate&young and efficient team provides creative, design communication as well as timely administrative support.



The astuteness, depth and superlative communication command that Dr Riten Pradhan (a fantastic human being coupled with vast knowledge and creative wisdom) an Orthopedic surgeon based in UK now, who saved my life post my paragliding accident on 12th Feb. 1995 is unmatched. His genuine interest and constant solutions for my various questions and issues which he brilliantly explained and solved on an ongoing basis through my entire rehabilitation enabled me to quickly scale unsurmountable peaks. He continues to do so even now. His personal visits, timely phone calls, fax, letters and emails has shaped my thinking as well as approach towards spinal cord injury rehabilitation.

Dr. Himanshu Doshi my brother-in-law (Nina's husband) has with his actions, knowledge, medical wisdom, simple problem-solving approach and clarity been an integral part of my rehabilitation solving myraid problems as they arose always joking & smiling and making light of any situation. I owe it to him to have learnt self-catheterisation and many other life skills.





Through the years and my PhD research study I have had the blessings of so many eminent surgeons, academicians and people. Our other eminent Nina Foundation Board of Trustees Dr. S.Y. Bhojraj, Late Dr. S. Sagade, my dearest angel sister and internationally reputed Homoeopath Dr. Parinaz Humranwala who has played a role of mentor, supporter, family member and through all my health lows & ebbs stood like a rock of Gibraltar each time lifting my spirits to soar higher, Dr. Dhruv Mehta and Anupama Ganesh. My close circle of family and friends Rupal, Dev, Meera Mehta, Darshika Thacker, Divya Suvarna, Namrata Shah, Mr. G. Shanker, Mr. & Mrs. Vieira, Rohinton Surti, Satish Kulkarni, Dr. Razia Manjrekar, Mr. R. J. Khambatta, Late Mr. S. K. Nagpal, Soli Doctor, & several others have expanded my horizons about different aspects of rehabilitation.

Dr. H. S. Chhabra (ISIC), Dr. Patrick Kluger, my mentor late Dr. Vijaya Manerikar, Prof. Ernest Fernandes, Dr. N. H. Atthreya, my PhD guide Dr. Uday Salunkhe, all my esteemed physiotherapists, caregivers, family, associates and so many friends with spinal cord injury I proudly call them as my close knit family and whom I covered in my research sample.

Our NGO Nina Foundation activities has not only given me the opportunity to meet, talk & understand the primitive plight of our rural, urban poor and other friends with spinal cord injury but also to guide, mentor students, scholars from various academic fields like architecture, fashion, technology, physiotherapy, occupational therapy, assistive technology, media, advertising, management, medicine, design, disability studies, social sciences, sports, rehabilitation and many more.



PhD ON HEALTHCARE REHABILITATION MANAGEMENT BY DR. KETNA MEHTA

As a management professional I always focus on the other - the user experiences, user requirements and latent desires. The bandwidth of the lifecycle of a person with spinal cord injury has six levels of rehabilitation as devised by me through my PhD in healthcare spinal cord injury rehabilitation management in 2005.



In spinal cord injury there is need for understanding and association from various stakeholders in the society as the quality of life is highly dependent on the quality of rehabilitation and the quality of inter personal relationships.

PAINTING BY: DEV MEHTA

I'm extremely overwhelmed and grateful for this opportunity offered by Dr. Sunil Bhatia, editor of Design For All Institute, inviting me as the Guest Editor for this special December 2019 issue and granting me the freedom to pursue my passion & purpose in life of improving the quality of life of friends with spinal cord injury in India.



#### "QUALITY OF LIFE OF LIVING WITH SPINAL CORD INJURY IN INDIA REHABILITATION DESIGN CHALLENGES & SOLUTIONS"

Come to think of it I see a pattern with the way the Universe has given me such golden opportunities.

- First my PhD on healthcare spinal cord injury rehabilitation management in 2005.
- This led to me being invited as a Regional Consultant for WHO's (World Health Organization) IPSCI - International Perspectives on Spinal Cord Injury, the first ever global research study in 2010.
- The very first national mainline publication Success & Ability on the theme of spinal cord injury, they invited me as their Guest Editor in 2012.

And now this..... Thank you God. Thank you Dr. Bhatia.



#### SPINAL CORD INJURY (SCI) DESIGN LAB PROPOSAL

I see tremendous potential and possibilities across disciplines to work out affordable low-cost innovations, design and solutions for improving the life of Indians with spinal cord injury.

My Guest Editorial can be taken as a proposal for a spinal cord injury design lab to re-calibrate our thinking amongst academic institutions, schools, colleges, the government, institutions, makers lab, hackathons, and more.

This Guest Editorial can also be given as design innovation challenges or caselets to both young and experienced minds to find creative, local solutions.

#### DESIGN IDEAS FOR PREVENTION OF SCI ROAD TRAFFIC ACCIDENTS

Road Traffic Accidents are a major cause for spinal cord injury in India.



- al Develop Crash proof vehicles, cars, bikes, buses, tempos, rickshaws, rural vehicles, etc.
- b] Design safety features inside the vehicles such that occupants are completely protected and unharmed.
- c] Design road surfaces with such materials that do not form pot holes and huge craters and there is no skidding.
- d] Design burst proof vehicle tyres which are also a cause for road accidents.





e] Design predictive alarm & brakes inside the vehicle if any object like a tree, animal or other vehicles or pedestrians come within one feet of your vehicle.

f] Automatic speed limit during nights and also perceptive sensors if the driver closes her or his eyes for more than five minutes. Many drivers tend to sleep on the wheel which cause irreversible accidents.

g] Many of our villages are still without regular electricity, rural roads generally don't have any street lighting and there are huge stretches of farmlands many accidents happen because of driving in the dark. Design Vehicles like intelligent buildings which automatically illuminates during nights when more light is required making the surroundings brighter.

h] In India there are several people who do not have a valid driving license for light motor vehicles, heavy motor vehicles or two wheelers, etc. Vehicles to be designed such that as soon as the driver is behind the wheel and switches on the ignition it searches for a valid digital driving license match in the database and only when found the vehicle starts.

i] There is increase in the consumption of alcohol and other substances across stratas of society and gender in India despite a law and breath analyzing tests by the traffic police. Such incidences do occur of drunk driving causing RTA. Design built-in sensors in vehicles to smell breath & not start. A recorded admonition that the driver is not 100% alert to drive plays repeatedly, as well a loud siren goes off from the vehicle.

#### DESIGN IDEAS FOR PREVENTION OF SPINAL CORD INJURY - FALLS



Another leading cause of spinal cord injury in India is fall from heights like construction sites, balconies, terraces & roofs (Barsaati), trees, pyramid formations during festivals like Janmashtami (Govinda), adventure sports, diving in shallow water bodies, falling off overcrowded trains, buses, or alighting while the public transport is in motion. Interiors of homes, restaurants, hotels, airports, malls & retail shops have granite, marble and generally very smooth slippery surfaces. Especially washroom tiles with a combination of soap & water cause falls (most are fracture cases which heal over time but this also causes head & spine injuries.)

a] Design a Bomber suit or similar clothing for such occupations where safety harness and rules are ignored. This suit would protect the head and spine. Design a behavioural change campaign such that people actually heed this before embarking on risky activities.

b] To avoid falls on smooth surfaces especially bathrooms, design such tiles especially for wet surfaces. Washroom tiles to have a natural absorption of on all flowing water and the same is recycled for flushing, gardening, etc. This would prevent the common reason for falling inside and outside washrooms.

c] Sleeping on the terrace of rural homes typically called Barsaatis is a common practice in India. Waking up in the night to go to the washroom without lights and still sleepy, many roll down the terrace & fall to grave spinal cord injuries. Design such materials for edges and parapets of terraces which self-illuminate warning red colours or beep on approaching the wrong exit.

d] To safely fall from stairs, balcony, ladder, heights, design special clothing which opens like parachutes or wings and one to glide down safely.





#### DESIGN IDEAS FOR PREVENTION OF SPINAL CORD INJURIES - MEDICAL FIELD



- a] A vaccine to be developed and taken as an infant such that spinal cord injury can be prevented.
- b] A protective sheath for the spine like how an umbrella or raincoat protects us from rains for those activities which generally cause spinal cord injury.
- c] Possibility of
- Spine transplant?
   Spinal-cord transplant?
- Nerve transplant?
- d] Like there is artificial heart patented by an Indian scientist, Dr. J. Yakhmi, let's explore possibilities for:
- Artificial spinal-cord
- Artificial nerves
- Artificial bladder sphincter
- Artificial bowel sphincter
- Artificial skin for bed sores
- Artificial fingers for quadriplegics
- Artificial arms and artificial legs for mobility.
- e] Design a Bypass technique of surgery to restore major functions caused due to spinal cord injury.
- f] Medical Design solutions to restore bladder, bowel, fertility, bed sores, brittle bones, muscle
- g] Superior plastic surgery for use of hands, fingers in quadriplegics and to have trunk strength for getting up on our own, balance and walking in paraplegics.
- h] Innovations in new drugs, injections, surgeries, implants and therapy to restore & revive the nerve functions.
- i] Explore multiple & better uses of cord blood stored during child birth. It may have the magic

to restore nerve axons.

- j] Further research in Alternative Medicines especially Homoeopathy which can reinforce our immune system.
- k] Explore newer Applications of Neem & Turmeric in healing & repairing the spinal cord.
- IJ In the Hollywood movie Elysium (a space habitat) which is technologically highly sophisticated, has Med-Bays that repairs all bruises, injuries, cure all diseases, and regenerate body parts. Why not this fiction be turned into a reality for spinal cord injury repair.
- m] Like cord blood bank store the placentas at birth and use this periodically to inject till the age of 12 years such that spinal cord injury damage is averted.
- n] Design and develop new vitamins and minerals, calcium necessary for a fortified spine with a combination of purple coloured food as supplementary diet.
- o] Just like Folic acid is proven supplement in pregnant ladies which prevent spina bifida research for natural food and nutrition to prevent spinal cord injury.



#### YOGA, CHAKRAS, MANTRAS FOR HEALING

p] Yoga asanas & breathing techniques especially the Power of Kundalini which can internally heal the spinal cord and nerve functioning.

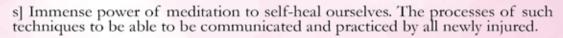






q] Power of Aum and other Mantras to be further researched and explored. I know of an old uncle who cannot speak due to a paralytic stroke but when aunty sings Bhajans (devotional songs) he joins her and can articulate all the words clearly!!

 Research and explore the healing properties of hotsprings, volcanic ash, other minerals in nature.





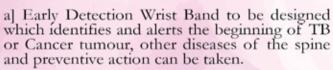
function.

t] In the world acclaimed Indian Text Bhagwad Gita, Lord Krishna speaks of the seven yogic centres of life energy within the human body, roughly aligned with the spinal cord. Somehow I believe the answer to the age old mystery of the spinal cord maybe in our Indian scriptures. Design research design around this concept.

ul Mudras and pressure points to control respiration, sweating, spasms, conjectures, phantom pain, autonomic dysreflexia, bladder and bowel incontinence.

v] Explore the Power of the subconscious mind further as the root of all miracles is here.

#### **DESIGN IDEAS FOR** SPINAL CORD INJURY - TECHNOLOGY



b] A controllable switch like a ring finger for bladder and bowel sphincter

c Design wings which can be freely available in the market such that people can attach these to themselves allowing them to fly and land safely knowing certain activities are risky.

d Design technology for avoiding bed sores and create a new layer of healthy skin.

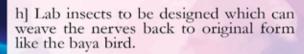
el Design technology for restoring sensation of pain, hot, cold temperatures, sensation of pinch, pressure. This will avoid several complications like burning of toes/legs due to electric blankets or room heaters (in cold places) which heat the metal of the wheelchair and the person gets burnt due to lack of sensation. We also had a friend who while seated in the front seat of a cab in Mumbai the hot engine during the long commute caused major burns on his legs.

f Crystal ball Predictive Analytics. Dangerous accident prone roads and spots alerts the driver and passengers.

g] An external portable spinal cord machine supporting all functions much like an oxygen

cylinder used for patients with breathing

issues.



i] Design Loving Robots trained as caregivers/attendants for quadriplegics & paraplegics. Helpful in all daily activities like put on calipers, change clothes, bladder, bowel care, bathing, transfers, driving and assisting in work at home as well as the office.

il The Dalai Lama states that compassion & love work as curative medicines. Design surgeons 'Love Gloves' such that while operating on the spine post injury emits love signals for the nerve axons to heal.

k] Eco-friendly sustainable, self cleaning diapers, underpads, catheters and other medical supplies to reduce our carbon footprint.







## DESIGN IDEAS FOR INFRASTRUCTURE, LAWS & ENVIRONMENT FOR AN IMPROVED QUALITY OF LIFE FOR FRIENDS WITH SPINAL CORD INJURY



- a] Design Experience Zones in all hospitals, physiotherapy & rehabilitation centres pan India for spinal cord injury. Lack of awareness & information causes limitations in living a full life.
- b] Design universal floor mobility devices for urban homes & rural mud houses.
- c] Design CSR (Corporate Social Responsibility) Funding to actually make a difference in this much needed healthcare rehabilitation segment. SCI rehabilitation centres, Activities of Daily Living Modules, safe, customised assistive aids & technology as well as modifications of homes, accessible vehicles and sports centres for recreation.
- d] Design a policy & process and make foldable scoop stretchers ubiquitous at police stations, traffic islands, railway platforms, taxi & rickshaw stands, hospitals, ambulances, schools, colleges, housing societies sport centres, etc. This simple low cost stretcher can save someone from a grievous spinal cord injury.
- e] Design Indian laws to add spinal cord injury as a separate distinct disability in RPWD Act, such that appropriate policy, processes and funding is duly allocated.
- f] Design an SCI Registry to collect real time data on incidence & prevalence pan India.
- g] Design training modules of 'Golden Hour' technique and conduct sessions for school children, drivers, adventure sports trainers, literate & otherwise, everyone just like CPR modules. This would save several lives.
- h] Design all academic curriculum across disciplines to include awareness about all aspects of spinal cord injury.
- i] My wish list from Indian Railway Authorities for our friends with disabilities using wheelchairs to go beyond the belated announcement that some outstation trains may soon have a coach dedicated for use of disabled passengers and women, and incorporate the following too:
- Emergency button inside the coach which connects to the Engine driver.
- Intercom Phone in working condition.
- Wheelchair accessible hygienic & clean washroom including a rexine bench for diaper change.
- Incinerator to dispose diapers and sanitary pads.
- Wide doors and a ramp for convenient entry and exit into the coach.
- Wheelchair chains for safety while train is in motion.
- A female and male police to guide, support and protect the disabled passengers as well as help with luggage inside as we need to encourage independent travel.
- A water cooler inside for long journeys and regular canteen service.
- A 3 digit special Helpline number as it may happen that there is only 1 disabled woman in the coach and others are male.

Let's truly make Indian Railways a safe, reasonable and inclusive mode of transport.







## DESIGN IDEAS FOR INFRASTRUCTURE, LAWS & ENVIRONMENT FOR AN IMPROVED QUALITY OF LIFE FOR FRIENDS WITH SPINAL CORD INJURY



j] I always look at win-win inclusive management solutions for regular problems faced by us, people on wheelchairs in India. (Believe me its never a smooth ride!)

Service Providers like Cabs, Uber, airlines, hotels, restaurants, etc. can have a box on their App/Websites which while booking we can tick 'Wheelchair User'. Accordingly such a cab with a trained driver is allotted and thus both the user as well as the driver have a happy journey together.

As a passenger we are paying EQUAL FARE and the onus of converging their technology, training of drivers with type of vehicle is squarely on the service provider. People with disabilities have Equal Rights for living a full life as per our laws and any denial of this basic Right is a violation.

k] Change Indian adoption and other laws until such time that spinal cord injury gets its due importance with the awareness, rehabilitation facilities, centres and trained qualified teams. Persons with spinal cord injury can be adopted by international NGOs, organisations, families, Institutions and companies with massive CSR budgets in such countries like Canada, USA, Europe, UK, Australia where state-of-the-art superlative facilities exist and non affording newly spinal cord injured can experience a good quality of life.

I] Taxation laws to exclude people with spinal cord injuries from all taxes-income tax, corporate tax, GST, etc. Because their family has to pay extra for non existence of seamless facilities. Also there is loss of earning during rehabilitation. This needs a serious thought to prevent them from hitting poverty levels.

m] People on wheelchairs with spinal cord injury despite paying equal fare to any airline whether in economy or business class are unable to access the tiny washroom. Agonising stories of sitting through the 'cold, freezing, high air conditioning' flight duration without being able to catheterize or transfer from the aisle wheelchair (that is if it exists onboard) causes urinary tract infections, leakages, the indignity of wetting their diapers, clothes and seats. Not everyone can afford a first class seat which comes with privacy and a personal bed or washroom. Airlines have to think through their policies and allow such passengers to either use the first class cabins for self-catheterisation & changing diapers or redesign their aircrafts for special bays like transferable long couches with screens. Till such time these modifications are effected such passengers must be given appropriate concessions for not being able to use the washrooms.

n] I believe the architects, interior designers, Urban planners and the respective institutions & faculty must include in their curriculum the legal requirement for wheelchair access. They must firstly have the knowledge and communicate (just like energy conservation, recycling, etc.) to their respective clients and build in disabled friendly features in their blue prints & plans. During my research which is published in a peer reviewed journal (www.ninafoundation.org) we have discovered that it does not cost a penny more to make new establishments disabled friendly.





## DESIGN IDEAS FOR INFRASTRUCTURE, LAWS & ENVIRONMENT FOR AN IMPROVED QUALITY OF LIFE FOR FRIENDS WITH SPINAL CORD INJURY

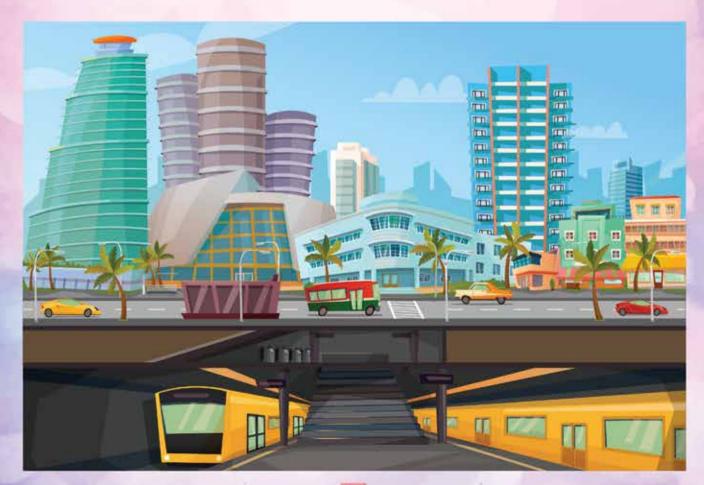
of The local governing authority like Municipalities must send a Notice and warning to each and every public place for retrofitting and making existing places accessible.

Proactively they can give general guidelines along with the notice to make it informative and play a role of nurturers.

p] The state municipalities can have a dedicated department for sharing disabled friendly guidelines and hand-hold the existing establishments to incorporate precise changes recommending materials, gradient, location, etc. It can begin with their own offices and employ people on wheelchairs for this role!

q] Due to lack of comprehensive rehabilitation in activities of daily living several women with spinal cord injury face indignity while travelling. Based on my research it is necessary to have 'nappy change rooms for infants used by parents' (Chennai domestic airport has a perfect room and long size of couch without arms for easy transfers from wheelchairs) which can ease the bladder discomfort. Similarly all train, bus, airline platforms as well as petrol stations and public washrooms on road expressways to design such facilities. Please realise we too are humans with a bladder.

r] Recreational clubs, parks, playgrounds & sports facilities are also very much needed for regular sunlight, fitness, fun and work life balance.







#### CONCLUSION

The above design ideas are doable, fantastic and some may sound crazy, outlandish or funny too! But the fact of the matter is there is a tremendous need for positive development across disciplines to improve the quality of life of friends with spinal cord injury in India. This is an open invitation and ideas for Thought Leaders, innovators, designers, children, creative citizens, technologists, corporate leaders, management students, architects, urban designers, healthcare professionals, spiritual practitioners and

compassionate human beings who can make a difference.

I look forward to your opinions, action ideas & views and I believe each one of us has the power to be a changemaker.

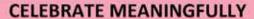
This citation which I quote below by Rob Siltanen was given to me by young Rotractors post my talk on spinal cord injury impact sums it all:

"Here's to the crazy ones. The misfits. The rebels. The troublemakers. The round pegs in the square holes. The ones who see things differently. They're not fond of rules And they have no respect for the status quo. You can quote them, disagree with them, glorify or vilify them. About the only thing you can't do is ignore them. Because they change things. They push the human race forward. And while some may see them as the crazy ones, we see genius. Because the people who are crazy enough to think they can change the world, are the ones who do."

Dr. Ketna L. Mehta, PhD.
Founder Trustee & Editor - One World, Nina Foundation.
Hon. Guest Editor (Dec. 2019),
Design For All Institute Of India, (www.designforall.in)
Theme: "Quality of life of living with spinal cord injury in India-Rehabilitation Design Challenges & Solutions."
Email: ketnam@gmail.com
ninafoundation@gmail.com | www.ninafoundation.org











FRIENDS WITH SPINAL CORD INJURY. A PERMANENT DISABILITY CAUSED DUE TO ROAD ACCIDENTS, FALLS, SPORTS, TB & CANCER OF THE SPINE.

Donations in Honour of

would like to make a donation to Nina Foundation for

/- in remembrance of Birthday / Anniversaries / Festivals (Name)

Disclaimer: Nina Foundation reserves the right to use this amount for the most prepared of their patients.

The following are the current requirements of Nina Foundation per patient. Every contribution you make, transforms the life of our friend with Spinal Injury:

₹ 1,000/-Hope Kit

Nutrition ₹ 2,000/- Per Month

₹ 3,000/-Diagnostics

Nursing Expenses ₹ 5,000/- Per Month

Calipers ₹ 8,000/-Transportation ₹ 10,000/-Wheelchairs ₹ 12,000/-

₹ 24,000/- Per Month Caregivers

₹ 1,00,000/-Surgery Your Choice

#### PAYMENT OPTIONS

1. Cheque in favour of 'Nina Foundation' to be sent by courier to our address

2. Bank to Bank Transfer

IFSC Code: CORP0000601 A/c No.: 060100101003601

Name of Account: Nina Foundation, Corporation Bank,

Matunga Branch, Mumbai.

. Edited and Published by: Prof. Dr. (Ms.) Ketna L. Mehta, PhD.

· Editorial Team: Ms. Bhawana Manral | Ms. Bhavna Chheda

· Concept and Designed by: kreate&young, 240/11, Shankar Sadan, 1" Floor, Opp. Mata Lachmi Hospital, Near Tamil Sangham Hall, Above Punjab & Maharashtra Bank, Sion (E),

Mumbai - 400 022. INDIA. E-mail: mail@kreateandyoung.com

Please address all letters to: The Editor, NINA FOLINDATION.

240/11, Shankar Sadan, Opp. Mata Lachmi Hospital, Sion (E), Mumbai - 400 022, INDIA. Tel.: +91 22 2409 4319 / +91 22 2407 1952 E-mail: ninafoundation@gmail.com, ketnam@gmail.com

HELPLINE: +91 97696 80820 WEBSITE: www.ninafoundation.org



RELIVE. REJOICE

#### SHUKRIYA FOR WALKING TOGETHER



ONE WORLD















3. SWIFT Code: CORPINBB 060100101003601

