

















Dr. Nina Doshi's birthday is Nina Foundation Founder's Day (9th March). It was celebrated as a spiritual outing for all friends with spinal injury in Mumbai. Over 80 friends, escorts, family members, Trustees, Associates and We School students formed the contingent. We visited and prayed at Siddhivinayak Temple, Prabhadevi and Mount Mary Church, Bandra. A VVVIP

> honour was bestowed on our Group and the experience was wonderful and spiritual for all! Ferdi's mobile ramp eased the movement; Siddhivinayak trustee Shri Nitin Kadam's kind gesture and Mount Mary Father Walter's special mass on Ash Wednesday and yummy snack boxes were the crowning glory of the day.

Please Visit Picasa link for all pictures of Nina Foundation Founder's Day https://picasaweb.google.com/ketnam/NinaFounderSDay932011#



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http://twitter.com/nina\_blueribbon http://www.facebook.com/nina.blueribbon



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An NGO for rehabilitation of people with Spinal Injury





On 27th February, 2002, I was driving a car on the streets of Surat completely unaware of what happened in the Godhra city earlier in the morning – The Burning of Sabarmati Exp. Train (the repercussion of which blew the whole of Gujarat).

Suddenly, I saw few people coming towards me to stop my car. Before I could understand anything, they pierced a long knife inside my neck and moved away in search of another target. I was instantly paralyzed and was lying for hours with half body inside the car and the other half outside it. All I could see was other people running helter Skelter to save their own lives.

At present, I am 27 yrs old, having a cervical level injury at C-2, C-3, but still am able to walk with a walker only because of all the hard work and time I invested in physiotherapy instead of remorsing. After a year of my injury, I was taken to ISIC at Delhi for my rehab, have also undergone stem-cell therapy at Chennai, but did not get any benefits. Later, I joined college and finished my graduation in commerce. Finding a writer has always been more difficult for me than preparing for exams as I cannot write on my own, but still scored 78% in B.com. At present, I am pursuing M.B.A through correspondence and also look after our family business, working as general manager and a partner of the company. The mission of my life is to own a very successful company and travel all over the world.

It has been almost 10 yrs since my injury and have come a long way which would have been impossible without the support and blessings of parents and family. If I recall few of the things that have helped me a lot overcoming my disability, they are: - Association with Nina Foundation, traveling to various places and, joining business.

Nina Foundation has always guided me at all times, likehaving the right treatment at the right place, encourage to socialize being on wheelchair and many other things, but most importantly taught me that we are HUMAN BEINGS and not PATIENTS. I have always loved traveling and my visiting more than 6 countries after my injury has made all my problems look small.





Also, today, everyday, when I come back home tired after the day's work, it make me feel satisfied.

I have had so many obstacles at every stage of these 10 yrs, but I have always believed that

IF THE PATH IS BEAUTIFUL,
ASK WHERE IT LEADS TO,
BUT IF THE DESTINATION IS BEAUTIFUL,
DO NOT WORRY ABOUT THE PATH,
JUST KEEP WALKING.

Lastly, I would like to conclude with JUST SMILE AND YOU'LL FEEL HAPPY.

Mohammed M Soni, Mc/108, Eco Elegance, Church Road, Marol, Andheri (E), Mumbai - 400 059. Mob.: 99300 43002

mohammedsoni1@gmail.com



**MUMBAI MARATHON - 2011** 

For the 6th time over 50 members, volunteers, friends with spinal injury, trustees participated in the Standard Chartered Mumbai Marathon on 16th Jan 2011. Our blue brigade was highly visible as we all wheeled in a procession moving together wih our Nina Foundation placards and enjoying the outdoors. The flag off platform comprising of John Abraham, Shaan, Shilpa Shetty, Priya Dutt, Shreyas Talpade, Tina Ambani and several others cheered us at the start point. Thanks to kreate family, Adity Moorthy, Anupama Ganesh, it was a memorable beginning to the year.

Samir Kochhar, IPL Commentator donned our Nina Foundation T-shirt this year!











## **MUMBAI MARATHON - 2011**



















## **MUMBAI MARATHON - 2011**



An NGO for rehabilitation o















DR S Y BHOJRAJ, Trustee, NINA FOUNDATION completed the half marathon in 2 hours 50 mts (his personal best) as a veteran.



#### **GUZAARISH IN THE NEWS**

## Guzaarish accused of playing up disability as taboo

**Bharati Dubey** TNN

Mumbai: The pre-release buzz over filmmaker Sanjay Leela Bhansali's latest film on a magician who gets crippled after a show goes awry had so intrigued Matunga resident Ketna Mehta that she watched Guzaarish on the first day of its release. Ketna, who has been living with disability since she crashlanded while paragliding almost a decade ago, had hoped that actor Hrithik Roshan's reel-life character would emerge as a champion for the 15-lakh-odd Indians partially or fully paralysed by spinal cord injuries. But she was left disappointed.

"As a person with spinal injury, I would not recommend this movie to my friends in a similar situation," she says. "Disability is taboo in India. This movie with its ending propagates this very concept. Is it right to say that a disabled is better off ending his life?" she asks. Her NGO, Nina Foundation, observes every June 25 as Spinal Cord injuries Awareness Day to seek better rehabilitation services such as physiotherapy to the patients.

Ketna, who completed her doctoral thesis recently on spinal injuries and rehabilitation services, has put up her reservations with Guzaarish on the foundation's online groups. "Our NGO is attempting to create interest, involvement and inspiration amongst friends with spinal injury. Believe me, it's an uphill task. It takes years to convince people on how to overcome our daily problems and yet lead a life of happiness and dignity. Guzaarish's depressing tone nullifies that in three hours. Despite being financially independent (Ethan has written a book and has a radio show), he wants to end his life," says Ketna, who now works with Welingker Institute in Dadar. "We would like positive role models conveying inspiring messages to face that one more day of our lives."



A still from the movie Guzaarish

According to estimates available with Nina Foundation, India has over 15 lakh people with spinal cord injury; the incidence grows at 20,000 every year. Ketna feels with rehabilitation, like the kind she had, she can manage with a walker. But most patients don't have access to this. "Disabled persons don't need euthanasia or suicides in India. Poor management of bed sores. urine infections, bowel complications, osteoporosis, high cost of ventilators and medication, lack of trained attendants and caregivers and lack of world-class rehabilitation centres anyway do the job, unfailingly," she adds.

The two Rockstars whom Nina Foundation felicitated in the last two years are a testimony that people can spinal injury can lead nearnormal lives. Shivaji Park resident Balasaheb Dharap, who is 80 years old, has been confined to wheelchair for 50 years but has visited Leh and Niagara Falls among other places even while working in the state government. He attributes his success to his wife Vasumati.

Source: The Times of India, 25th November, 2010

## Right to die should not be denied: Bhansali

ilmmaker Bhansali is ready with answers as to why charisma-oozing Ethan seeks euthanasia. "A man who has lived for 14 years with paraplegia realizes that he will soon be put on dialysis, his organs are failing and he does not want to hang on to his life." But Bhansali adds that his film's take-home message is about enjoying life. "If you have seen in the film, even in the end, he brings a smile to the faces of people." "Here is a person who loses everything he had, yet he keeps fighting-this time, for his basic right: The right to die," says Bhansali. He believes this right should not be denied. TNN

## 'ગુજારિશ'ફિલ્મ સચ્ચાઈથી જોજનો દૂર છેઃ ડો. કેતના મહેતા

अवन ट्रंडाववानो માર્ગ અપનાવતા બતાવાચ છે જે અયોગ્ય છે

ભાસ્કર ન્યૂઝ. મુંબઇ

અફલાતુન બની છે. વળી, એનજીઓ કરોડરજ્જમાં આ પ્રથમ જ ફિલ્મ છે. જોકે અમુક મુદ્દાઓ સચ્ચાઈથી ધરાવનારને

અભિનય વગેરે બાબતોમાં પુનર્વસન ક્ષેત્રે કાર્યરત મેજર આવી જોજનો દૂર છે, એમ ખુદ પીઠબળ અત્યંત જરૂરી છે,

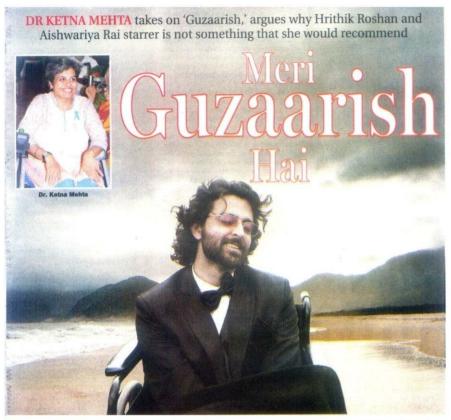
ફિલ્મમાં મુખ્ય પાત્રને 'ગુજારિશ ફિલ્મ દિગ્દર્શન, વિકલાંગતા ધરાવનારનું વિતાવતું બતાવાય છે. વળી, વિતાવી જાશે છે. તેમણે નીના અહલુવાલિયા, રાજેંદ્ર સિદ્ધ કર્યા છે, જ્યારે ફિલ્મમાં ઈજાથી ફાઉન્ડેશનનાં સ્થાપક ડો. જોહર, શ્રુતિ મોહપાત્રા, આપાત્રને જીવન ટૂંકાવવાનો આવતી વિકલાંગતા પરની કેતના મહેતાએ જણાવ્યું હતું. સુબ્રમણિયમ, અરવિંદ પ્રભુ, માર્ગ સારો છે એવું વિકલાંગતા નિશાંત ખાડે, અબદુલ્લા બતાવવામાં આવ્યું છે તે કૌટુંબિક જેવી હસ્તીઓએ સિદ્ધ કરી બરોબર નથી, એમ તેમણે દીધું છે કે આવી વિકલાંગતા જણાવ્યું હતું. કરોડરજ્જુની ઈજા સામે જ્યારે ફિલ્મમાં આ પાત્રને સાથે પણ તેઓ કુટુંબ, મિત્રો ઝઝૂમતાં અને આવી ફક્ત કેરટેકરો સાથે જીવન સાથે આનંદિત જીવન

એચપીએસ સફળ કારકિર્દી વડી છે અને લક્ષ્યો

#### **GUZAARISH IN THE NEWS**



An NGO for rehabilitation of



he positives of the movie is that the film craft and direction is spectacular and flawless, the actors are more than convincing and this is the first movie on a spinal injured, a quadriplegic, in Indian cinema. The images are real and flawless—the accident, topple from the bed, helplessness at the leaking roof, feeling the fresh air outdoors and many other such images. A film is both a potent tool for transforming mindsets and can sometimes also don the role of weapons of mass destruction. We need the best in the industry to project and showcase more responsible cinema.

As a person with spinal injury and as the founder of our NGO, Nina Foundation I would not recommend this movie to my friends with spinal injury. I will elaborate this rationale:

- 1. It's a non-Indian take. The biggest motivating factor for a traumatic spinal injured is his ring of family. The entire family rallies around and forms a ring of support both physical and emotional. The independent living concept shown in the movie with Ethan living with only caretakers and caregivers is remote. More than one member of the family takes charge and enables one to sail through life happily.
- 2. We have glowing examples of Indian quadriplegics living with this life transforming disability for more than 14 years (the number in the movie). Maj HP S Ahluwalia, Rajendra Johar, Sruti Mohapatra, Subramaniam, Arvind Prabhoo, Nishant Khade, Abdulla and I can go on. They have families, friends and successful careers and goals and are leading successful lives.

- 3. Disability is a 'untouchable' 'invisible' taboo concept in India. The movie with its ending propagates this very concept. That a human being and his wishes are above the law? A disabled is better off ending his life? Obstacles and problems should taint our view about life? Spinal injury is too big a problem to live with?
- 4. Our NGO is attempting to create interest, involvement and inspiration amongst friends with spinal injury. Believe me it's an uphill task. It takes hours and years to convince how to overcome our daily problems and yet lead a life of happiness and dignity. 'Guzaarish's' depressing tone nullifies that in three hours. Despite being financially independent (Ethan has written a book, has a radio show), he wants to end his life.
- 5. India is the capital of people with spinal injury, over 15 lakhs and we add 20,000 every year. Most are 'invisible', as they are tucked away at home struggling to manage each day. How many can afford a 10-lakh sip and puff wheelchair or tilt table in our country. The reason for being depressed is that there are no rehabilitation centres offering holistic services to face life. The rehabilitation at physical, psychological,

social, vocational, recreational and spiritual levels prepare us to conduct our lives and also achieve a lot personally, professionally and in sports (there is wheelchair tennis, basketball, quad rugby, swimming, etc).

- 6. Along with the helplessness of rain falling on Ethan's face there could have been more instances of enjoying the 'fly on the nose' moments. Spinal injury is a 'real' tough issue. Its not easy either living with paraplegia or quadriplegia. Yet it is hope, which makes us rewrite medical books, push our limits, surprise our doctors and therapists. All the stakeholders' work towards giving spunk back to our spines and this is a huge healthcare force. They too are disappointed by the treatment of the subject and ending of the movie.
- 7. And finally, Mr. Bhansali, we don't need euthanasia or suicides to end our lives in India. Poor management of bed sores, urine infections, bowel complications, osteoporosis, high cost of ventilators and medication, lack of trained attendants and caregivers and lack of world class rehabilitation centres anyway do the job, unfailingly. Even today in Bollywood land, Mumbai, we don't have a world class spinal injury rehabilitation centre.

Charity is very easy, sponsoring a few spinal injured is simpler but getting involved with interest and inspiring our friends with spinal injury is the need of the hour. Imagine our children and young friends with spinal injury watching the movie with their devoted parents and families. The fact is that the very talented Mr. Bhansali makes convincing movies on different aspects of disability; we would like positive role models conveying inspiring messages to face that one more day of our lives!



(Dr. Ketna Mehta has received the NCPEDP Shell Helen Keller Award in 2002, NASEOH Award in 2005 and is the Founder Trustee, Nina Foundation, a Mumbai based NGO for spinal cord injury rehabilitation)



#### SPORTS NEWS



## Hurdles kept disabled away from CWG spectacle

"The games was not at all barrier free. The website of the Delhi CWG 2010 had only half a page of information on facilities provided for disabled spectators visiting the various venues, whereas the website for the Melbourne Games, held four years ago, had pages and pages of precise information," lamented Javed Abidi, NCPEDP.

"How and why should disabled people from across Delhi, NCR, Gurgaon go all the way to Tolstoy marg, make their way up to the first floor to buy tickets," asked Arun Sondhi, a wheelchair former olympian athlete who promotes disabled sports.



## Technology An Equality Enabler

Technology is providing the person with disabilities with a better life through telecommuting, mobile telephone, video conferencing, skype, high speed internet, wifi enabled spaces and software for specific problems.

With globalisation, there are no boundaries between the Western world and India. Its only the awareness about the existence of these products and the high price which is a detrimental aspect. One has to meet a quadriplegic or paraplegic from around the world and realise the difference in the quality of life amongst us and them. They are made aware of, trained and involved with the technology right at the time of their rehabilitation. Acess to technology can liberate us!



## **Budget Recommendations**

**Recommendations for The Budget** 

- **Higher interest rates** on Fixed Deposits for people with disabilities and parents. (Maybe at par with the rates offered to senior citizens).
- Acess Tax: all those public spaces who yet do not have basic facilities for wheelchairs would be liable to pay a tax and the money then can be utilised by the local municipality to create this infrastructure. Imagine all educational institutions like schools, colleges as well as public places like banks, post offices, office complexes, parks et al with ramps, elevators and other barrier free accessible features.
- Our young bright minds have a high Innovation Quotient. Our IlTians have developed prototypes of Ascender, Stair lift, blow switch as well as there is tremendous potential to indigenize and develop eco friendly diapers, catheters, calipers and wheelchairs (bamboo). The government must give tax holidays and sops to commercialise these much-needed necessities for the masses.

We look forward to these recommendations implemented soon!



### **About Nina Foundation**



NINA FOUNDATION is a nine year old NGO established in the memory of Dr. Nina Doshi for rehabilitation of people with spinal cord injury.

#### VISION:

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

#### MISSION:

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

There are over 3 lakh people with spinal cord injury in India, which makes it the second largest population with this disability in the world.

Spinal cord injury is a permanent disability which transforms the person's life and rehabilitation is the key to facing life with dignity.

Our Foundation has been encouraging the members enabling them to excel in their respective fields.

NCPEDP Shell Helen Keller Award in 2002

NASEOH Award in 2005

Limca Book of World Records 2008 edition

Inclusion in the book Chicken Soup for the Indian Spiritual Soul 2009

#### **Activities include**

One World - Voice of Paraplegics. A bi-monthly **newsletter**. The first of its kind in India. Work therapy enables people with spinal cord injury, to express their abilities, gives them financial independence and thus self confidence a sense of respect in their family and community.

Support Group facilitates sharing of experiences and have a cathartic effect.

**Donate** wheelchairs, walkers, crutches, calipers other aids and appliances as well as medicines and expenses for regular urodynamics, sonography, x-rays and pathology tests.

Making India and Mumbai, barrier free & accessible for people with disability.

> The first **Helpline** for spinal injury in India. Sponsor trophies for paraplegic sports.

'06, '07, '08, '09,'10 – for **Mumbai Marathon** over 50 members with spinal cord injury wheeled for Nina Foundation.

Participation in disability seminars and workshops.

Author and present research papers / articles on the status of the disability sector in India.

Organize picnics, get-togethers and outbound programmes for the community with family members.

> Create powerful advertisements, calendars. presentations and films about abilities of the differently abled and inclusion.

> > **Dance** Therapy Active Rehabilitation and sports. **Wellness Seminars**

#### Activities planned for the future for making every person with spinal cord injury self reliant and independent

**Employment** initiatives including work place solutions and technology **Education** initiatives for children with spinal cord injury

Efficacy survey on stem cell treatment

Wellness Seminars and Workshops on Spinal Cord Injury

Access and Sports Solutions

**Diagnostic** and **medication** expenses for underprivileged people with Spinal Cord Injury Publication Book on 'Spinal Cord Injury achievers from India' Holistic Rehabilitation services

Educational Lectures & Demo series





## Obstacles Faced by People with Spinal Injury in India NINA FOUNDATION'S PERSPECTIVE

# SCIs in lower income group face the existential problems of health, access and employment.

#### They face problems in:

- Getting access to good quality healthcare services and expert knowledge necessary to survive the severe health problems of Spinal Cord Injury.
- · Accessible public transport so they can travel for employment, access to hospitals and socializing.
- · Schools and colleges which accept people with disabilities.
- Avenues of employment so they can survive, afford healthcare, support their families and live with dignity.
- The process of getting disability certificate is also cumbersome and difficult.

### SCIs in higher income group face problems of quality of living:

- Major problems in getting driving license and also to renew it.
- Car manufacturers don't provide driving helper attachments.
- Lot of people don't have access to good quality healthcare services, physiotherapy, occupational therapy, etc. because there simply isn't any available.
- Good quality wheelchairs are also not easy to get at reasonable cost. Not a single brand of excellent sturdy wheelchairs for less than Rs. 25,000.
- Avenues of sports tennis, swimming etc. is lacking.

#### The other obstacles faced in India are:

- Lack of health statistics for spinal injury by Government.
- · Lack of interest in the concept of rehabilitation.
- The credo 'do it right the first time' missing. Bed Sores, Pressure Sores, UTI, Osteoporosis very common.
- Alternate therapies Madiwala, Massage, Maalish, Black Magic, Karma, Scrubbing with a Scotch Brite, Acupressure, Acupuncture, Pyramid Therapy, Magnet Therapy etc. proliferate shifting the focus.
- Lack of passion and complete knowledge by young physiotherapists.
- Lack of motivation to continue with schooling, office, daily home activities in kitchen etc.
- Proliferation of fraudulent Stem Cell clinics.
- · Built environment is not conducive.
- Lack of qualified and affordable ward boys, attendants, both male and female.
- Lack of availability of assistive technology, simple splints, aids for quadris almost negligible, no
  occupation therapy intervention.

#### **BOOKS**



An NGO for rehabilitation o



### **ONE LITTLE FINGER** - by MALINI CHIB

One Little Finger is the autobiography of Malini Chib—a woman who defied all odds to emerge victorious in spite of a crippling disability and an indifferent society; who dragged herself out of the limits of her condition. This is the story of Malini's search for independence and identity, and her zeal to live a full, meaningful life despite lifelong disability. Malini has Cerebral Palsy, a neurological condition similar to adult stroke, which makes body movement and speech extremely difficult. However, the cognitive functions of brain can often remain unimpaired, as in the case of Malini. She recounts her experiences from childhood to adulthood, her struggles with motor skills and speech, managing day-to-day activities, and the apathy and indifference of people towards her and others who are disabled. She educates herself, learns to type with her little finger and speak through the Lightwriter. Finally, she works through unfavourable social systems and attitudes to get a career as an event manager. As life becomes a tear and a smile for her, Malini tells us the story of her heroic battle against adversity, prejudice, stigmas, stereotypes, of her will to succeed and her search for an identity in a contrary world. And in the process of self-realization, she becomes a beacon of hope for everyone.

ISBN - 9788132106326

Publisher: SAGE Publications India Pvt. Ltd.

Pages: 228 Price: ₹350

## Stem Cell Therapy In Neurological Disorders

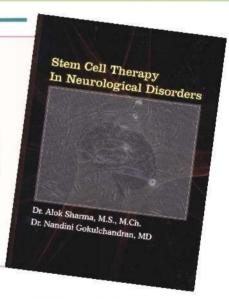
- Dr. Alok Sharma, M.S, M.Ch and Dr. Nandini Gokulchandran, MD

The book has been created for those medical practitioners, who are keen to start using stem cell therapy for their patients with incurable neurological disorders, to understand some of the fundamental principles as well as practical aspects that are involved in this line of therapy as well as get informed about all the current clinical data from all over the world that is already published.

ISBN - 81-86876-06-5

Publisher: NeuroGen Brain and Spine Insitute

Pages: 270 Price: ₹ 1500





## Dhyas aani Pravaas - Smt. Sulabha Warde

Smt. Sulabha Warde, Founder, Trustee, President Emeritus and author of "Dhyas aani Pravaas" a book penned by her on Paraplegics

Pages: 186 Price: ₹ 100.00

Publisher - Granthali Prakashan

Available at: Paraplegic Foundation at Sion

Right now available only in Marathi. English & Hindi will be published soon.



#### MEMBERS MAKING NEWS



Sat Naam Wahe Guru! Ketna did the Golden Temple (Amritsar) parikrama on her walker on 1st Nov. 2010 alongwith Anu, Kulbir and Arnav

The film club of India International Centre organised the screening of a 54 minute documentary, "Still Standing", on the founder-coordinator of Family of Disabled, Mr. Rajinder Johar in New Delhi on 6th Nov. 2010.



Neenu Kewlani is now Assistant Divisional Governor (edu & training) Div D. Dist 82 Toastmaster International. She also was the compere for the We care film festival in Mumbai on 17th Jan and impressed the likes of Govind Nihlani, Amol Gupte and Prahlad Kakkar.

Nishant Khade made his maiden voyage to Bangkok in the 'seasoned' company of Arvind Prabhoo and enjoyed. Cheers!

Anjan Reddy Vennela and his NPDO team met Hon'ble President of India Shri Pratibha Patil in Hyderabad on 27th Dec. 2010.



Sunita Sancheti had a femur fracture and was operated in Mumbai. We pray for her speedy recovery.

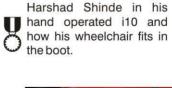
Nehal thakker was hospitalized too for a short while but is back in action!

Oliver D'souza performed wheelchair acrobatics with Imran at Intelinet, TISS, HR, MSSI and impressed 1 n





Dr. Padma Patil, a strong lady with sci, from Amravati, was honoured by 'Tapovan' an institution celebrating 'Pahat Nav Varshachi' where chairman Motilal Rathi honoured her on the recommendation of Govind Kasat. Badhai Ho. She also has set up her medical clinic in her small room in a chawl and started her practice in her village.





#### WHEELCHAIR DANCE BY NINA FOUNDATION

AT ASSICON, MUMBAI ON 27TH JAN 2011. THE TRIDENT, NARIMAN POINT



An NGO for rehabilitation of neonle with Sninal Injury



Nina Foundation had an opportunity to put up a wheelchair dance performance at the prestigious spine conference as part of the cultural evening on the first day at ASSICON.

12 of our members alongwith 14 volunteers, children, friends and Welingkar Institute's enthusiasitic and competent students put up a grand show. The show was choreographed by Subodh Aarekar and his team comprising of Jeetendra, Hemant and Robin. Dipesh coached Nandlal for the wheelies.

The performance began with our young member Krish as Ganpati on a wheelchair with Disha Sancheti performing to Ganesh stuti in kathak style. This was followed by a Michael Jackson act by duo Dev and Harsh Mehta. They moved to the beats of 'Heal the World' and 'Billie Jean.". Then the wheelchair members comprising of Ketna, Neenu, Madhu, Hardik, Bhavna, Nandlal, Madhuri, Sanika, Oliver, Gopika and Nisha took the stage with Vidya, Aditi, Pranav, Pooja Khedekar, Pooja Bhojraj, Monica Gadhecha, Nishit Surana, Priyanka Amar, Jashmili Dhulla, Aditi Moorthy, Vidya Shenoy, Pranav Bathimathb, Hindavi P Aware & Nikhil Gala.

#### Students in Logistics -

Divyansh Nigam, Vishal Singh, Ajay Tiwari, Mayank Pushpam & Kumar Gandharva Mishra Joy.



The standing ovation at the end of our performance was a culmination of all the meticulous hard work put in by all the team members.

One week before the performance, Sunita, our key performer, discovered a fracture on her thigh. Her good wishes and Hardik's acceptance to our appeal to join saved us. Also we had one more Sancheti - Disha who flawlessly performed kathak to Ganesh stuti. Harsh and Dev with their MJ act communicated everyone's responsibility to 'Heal our world'!

Nandlal's sudden convulsion an hour before us taking the stage was unsettling for all who were witness to this episode. Sunita's brother Shailesh and Dr Abhay Nene's timely call for Dr Shalini Saxena had him back on his wheelchair ready to groove. And How!!

Oliver's wheelies and acrobatics had the team and audience roaring. Watch out for this young man and his antics!

The audio at Trident failed thrice, yet the tenacity and spirit of our team was so defatigable that we overcame these 'minor' hurdles. Hardik's spirited lead in singing charged the team and the audience.

Subhodh's 'out of the box' thinking to go ahead with the 'Bharat song' as he connected his mobile to the music system and we concluded to a rousing standing ovation.

Together we motivated even the spine surgeons for all the hard work they do to fix our spines and for once they knew that we have got our spunk back!!

The weschool student team was a dream team. Each and everyone not only were dedicated but also got involved and bonded with all our members.

There were classes, project submissions and exams - yet they multitasked superbly. Priyanka and Pooja Khedekar also doubled up as trainers when the choreographers were missing and guided us beautifully. NF volunteer Aditi Moorthy was an inspiration for all in her dance form.

Of course our youngest member VIDYA SHENOY stole the limelight by putting us to shame with her energy and youthfulness.

We are all richer today in our hearts with the knowledge that we have shared

ourselves for a true cause.

Thanks to Prof Dr. Uday Salunkhe for always believing in Nina Foundation and making our campus available for practice. Thanks to Dr Bhojraj for recommending NF to perform at the prestigious ASSICON, and the entire NF team for believing in us.

Dr Abhay Nene for all the support.



Watch all the snaps & videos on www.ninafoundation.org



### SCIENTIFIC NEWS STEM CELL TREATMENT

## **First Patient Treated** With Embryonic Stem Cells

**Paralyzed Atlanta Patient Gets** Stem Cells Injected Into Spine - by Daniel J. DeNoon, Web MD Health News Reviewed by Laura J. Martin, MD

Oct. 11, 2010 - The first person treated with embryonic stem cells is an Atlanta patient paralyzed by a recent spine injury.

The Geron Corp. GRNOPC1 stem cells come from embryos left over after in vitro fertilization and donated by the parents. The FDA approved the study in early 2009.

The clinical trial is a first step toward an eventual cure for paralysis, says study leader Richard Fessler, MD, PhD, professor of neurological surgery at Northwestern University Feinberg School of Medicine and a surgeon at Northwestern Memorial Hospital.

"We would love to see paralysis cured. Will that happen with this study? Of course not. We would be thrilled to see

take 10-25 years."

enroll 10 patients in its first stage. Patients with complete grade A thoracic spinal cord injuries will be treated seven to 14 days after their injury. Such patients cannot move or feel their lower bodies and usually lose bladder and bowel control. Physical therapy has only limited benefits.

#### **Embryonic Stem Cells Mature Before Injection**

Before being given to patients, the embryonic cells are matured into "precursor cells" destined to become oligodendrocytes. These are the cells that make up the myelin sheaths that protect nerves in the spinal cord.

It's hoped that the GRNOPC1 cells will restore spinal function by replacing lost myelin and by giving off chemical signals that promote new nerve growth.

The cells are injected directly into the site of the spinal injury using a syringe positioning device that attaches to the frame of the operating room table.

Patients in the study must undergo short-term immunesuppressing therapy to ensure that their bodies do not reject the new cells.

The Atlanta patient, and nine more patients to be enrolled in the first phase of the clinical trial, get only small doses of the GRNOPC1 cells. It's the human equivalent of the smallest dose to show benefit in animal studies. If the treatment proves safe, the next phase of the study will use up to tenfold larger doses of the cells.

Key questions are whether the stem cells will spur growth of tumors called teratomas, whether the cells will be rejected by the immune system, and whether there will be unintended consequences such as nerve pain.

In preclinical studies, animals with severe spinal injuries regained the ability to walk after treatment with OPC1 cells. The animals did not develop teratomas, reject the cells, or suffer nerve pain.

In addition to showing clinical improvement, treated animals' damaged nerves became coated with new myelin and there was new nerve growth in the vicinity of the injected cells.

Whether humans will respond as well as animals remains an open question. Study patients will be followed closely, and must agree to check-up visits for 15 years.

So far, the only active clinical trial centers are at Northwestern University in Chicago and the Shepherd Spinal Center in Atlanta.

> Fessler notes that this study is not the first time he's explored using embryonic

tissues to repair spinal injuries. In the late 1990s, when he was at the University of Florida, Fessler and colleagues explored the use of fetal spinal tissue to treat paralysis.

Overall, this treatment showed little effect. But individual patients had substantial improvement -- and Fessler says that crucial knowledge gained in that

study planted the seeds of the stem-cell trial that began today.

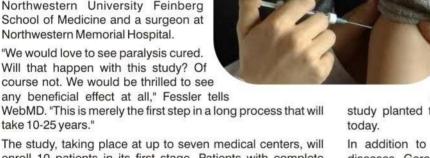
In addition to the GRNOPC1 cells for nervous system diseases, Geron is also making six other cell types from embryonic stem cells:

- · Heart muscle cells for treatment of heart failure and heart attack
- · Pancreatic islet cells for the treatment of diabetes
- · Cartilage cells for the treatment of osteoarthritis
- · Liver cells for drug testing
- · Antigen-presenting cells for immunotherapy of cancer and infectious diseases
- · Bone cells for the treatment of osteoporosis and bone fracture

#### NINA FOUNDATION FEEDBACK - DR RITEN PRADHAN, TRUSTEE

Finally a reliable, scientific study has started, I am very optimistic. On hindsight, what an ignorant decision by George Bush, to have blocked such vital research in US for 12 years, and that's because he had religious beliefs, fetal/ embryonic life rights and did more harm to humanity and

The logic about conversion to precursor cells is fantastic and the method is far too superior to just injecting the hotchpotch marrow aspirates, which some people have been doing for reasons best known to them.



## ISCoS 2010 Report by Dr H S Chhabra, ISIC, New Delhi

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Combined 49th International Spinal Cord Society (ISCoS), 10th Spinal Cord Society (SCS) & 9th Asian Spinal Cord Network (ASCoN) Annual Scientific Meeting was held at Hotel Le Meridien, New Delhi from 29th to 31st October.

There were 18 workshops in all -3 pre conference, 13 parallel and 2 post conference. In addition there were 13 sessions. The Post-Conference Workshop on "Comprehensive Management of SCI" constituted of a combined workshop for all team members on day 1 followed by discipline specific workshop for doctors, nurses, physiotherapists, occupational therapists and assistive technologists as well as psychologists, social workers and peer counselors.

There were 671 participants from 44 countries. 460 were registered for the main conference, 434 delegates and 28 accompanying persons. There were 40 exhibitors during the conference. The pre-conference workshop was attended by 59 Delegates. 233 delegates participated in the post-conference Workshop. There were 88 international faculties and 63 India faculties to share their expertise at the conference.

# WHO'S MAIDEN INITIATIVE ON SPINAL INJURY IPSCI [INTERNATIONAL PERSPECTIVES ON SPINAL CORD INJURY] workshop, October 31st, 2010 2010 ISCoS, ASCoN and SCS meeting, New Delhi

Led by Ms Allana Officer, Coordinator Disability and Rehabilitation (DAR), Department of Violence and Injury Prevention and Disability, World Health Organization, Geneva, Switzerland. Dr Jerome Bickenbach, IPSCI Editor in Chief; Group Leader, Department of Health Science and Health Policy, University of Lucerne and Swiss Paraplegic Research (SPF), Switzerland. Prof Fin Biering-Sorensen, Head of department, Clinic for Spinal Cord Injuries, The Neuro Science Centre, Rigshospitalet, Copenhagen University Hospital, Denmark; ISCoS President. Ms Sue Lukersmith, WHO DAR consultant, Sydney, Australia. Mr Per von Groote IPSCI Assistant Editor; Project Scientist, Department of Health Science and Health Policy, University of Lucerne and Swiss Paraplegic Research (SPF), Switzerland

Nina Foundation was invited to be one of the select 20 participants represented by Dr. Ketna Mehta along with several others from around the globe.

#### **Background**

The 2010 annual joint ISCoS scientific conference in New Delhi brought together people from clinical care, health policy, research and the broader SCI community -- including people living with a SCI -- from around the world, and in particular from the developed and the developing parts of Asia. A group of SCI researchers, clinicians, policy makers, advocates and people from the broader SCI community were asked to discuss IPSCI's relevance, provide feedback on its content and to gather and further develop ideas for using IPSCI by means of existing organizations and newly formed alliances.

- To obtain feedback on each chapter of IPSCI, especially on its scientific and cultural relevance;
- To get feedback and ideas on how IPSCI can be used in different contexts -- clinical, research, policy;
- · To explore dissemination and knowledge transfer ideas;
- To identify people of organizations that might be called upon for dissemination and knowledge transfer activities.



#### **Consumer Group Workshop**

(Right to Left) Panel Chairman:
Jane Horsewell, the European Spinal Cord Injury Federation
Professor Fin Biering-Sorensen, President, ISCoS,
Dr. Ketna Mehta, Nina Foundation, Mumbai, India
Professor Dajue Wang (on behalf of Mr. Wen) China
Professor Apichana Kovindha, ASCoN Thailand

## The interesting workshops and sessions were as under:

- Consumer Group Workshop "Considering the benefit of a Global SCI Consumer Organization"
- It will happen again: disaster preparation response for spinal cord injuries.
- · Prevention of SCI Fall
- Prevention and Management of Neurological Complications during Spine Surgery.
- Ethical and Scientific Challenges in the Translation of Discoveries to Human Treatments for Spinal Cord Injury and Related Neurological Disorders
- · Cost Effective management of Spinal Cord Injury.
- Post conference workshop "Comprehensive management of SCI"

#### FEEDBACK:

It was a memorable conference, deeply enriching, knowing about the comprehensive management of persons with spinal cord injury in all areas of medical science, what are the current advances, eminent doctors, therapists, counsellors, persons with spinal cord injuries, assistive technology experts from India, Asia and all over the world shared their expertise, the commitment and the zeal with which persons are so dedicatedly involved was so empowering.

- Dr Dhruv Mehta,
 Associate, Nina Foundation and Physiotherapist.





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### NINA FOUNDATION TEAM





Neenu Kewlani



Sunita Sancheti



Hardik Dholabai



**Arvind Prabhoo** 



Partners in Service



**Nitin Goyal** 

**Nishant Khade** 



Bhavna Chedha



Madhu Singh Associates



**Mohammed Soni** 





Dhruv



Vidya



Anu



**Pranav** 



Aditi



Arlene D'souza - 2010



Dr Riten R Pradhan M.S.Orth. FRCS(Ed), FRCS Tr. & Orth., Orthopedic Surgeon, UK



Dr S Y Bhojraj MS, FCPS (ORTHO), D (ORTHO) Consultant Spine Surgeon



Dr Sharad N Sagade MS (General Surgery) MCH (Urology) Consultant Urologist



Dr V C Jacob BSc, D.P.T., MIAP, Physiotherapist.

DHMS, M.D,



Dr Himanshu Doshi MBBS, Ensco Shipping



Dr Parinaz Humranwala

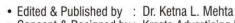
Consultant Homoeopath



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Dr Ketna L Mehta MMM, FIMC, PhD Editor and Associate Dean, Research, We School of Management



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The Foundation is registered with the Charities Commissioner's office, Government of Maharashtra, India. Donations are exempt under Sec 80G of Income Tax.



An NGO for rehabilitation of people with Spinal Injury

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