



Rockstar Awardees

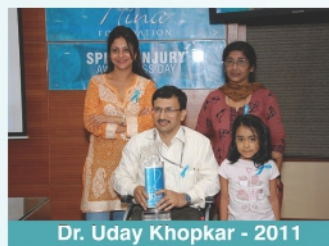
Will Star Awardee



Shri N D Dharap - 2009



Arlene D'souza - 2010



Dr. Uday Khopkar - 2011



Shri Sanjay Jagtap - 2011

Associates

Partners in Service



Dhruv



Vidya



Anu



Pranav



Aditi

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An NGO for rehabilitation of people with Spinal Injury

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ONE WORLD

August 2011

An NGO for rehabilitation of people with Spinal Injury



3rd SPINAL INJURY AWARENESS DAY 25th June, 2011

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SPEECH BY DR. KETNA MEHTA



the Mantras

that Nina Foundation believes in and inculcates in new friends with spinal injury are:

Mantra 1:

hamare mein jo shamta aur potential hai far outweighs the disability. Discover the talent within and we can sail through life cheerfully.

Mantra 2:

accept hurdles and obstacles as a vehicle to rearrange our lives. Attitudinal barriers as well as infra-structural barriers may dodge us everywhere....with a brave heart and smiling face we can overcome them.

Mantra 3:

KOSHISH aur PRAYATNA karte rahna hai. Without trying something new no discovery can be made. Attempt independent living, Activities of Daily Living, travel alone, a new vocation, bathing, standing, walking. We have to attempt all this bravely.

Nina Foundation ke 10 saal. Time indeed flies. On behalf of Nina Foundation team I not only would like to share about how we have taken flight and soared since 2001, but also pay our respects to the first few supporters who trusted Nina Foundation and gave it the power and wings to grow and fly and reach the level where we are today.

Firstly to inform all of you that spine injury badhi hi kathin hoti hai. Lifespan wahi rahta hai, magar jeevan pura upside down ho jaata hai, unka jinhe Spinal Injury hui hai aur pure parivaar ka. Mujhe yaad hai jab Dr. Jacob mere physio therapy ke liye aate the or kaafi anya patients ke life ke bare mein share karte the in 1995, ek vakya mere dimag mein baith sa gaya ' no one is interested in sci rehab- not the govt, not the hospitals, not the corporates and so on.' It is so true.

It has been our humble attempt through a series of activities and initiatives to highlight that we too exist, that we too have a mind, heart and soul and we too deserve a good quality of life.

Through our one of its kind publication ONE WORLD, through support groups, through our research papers, articles, our presentations at various conferences, our participation in outbound programmes, picnics and sports....we aim to show the positive side of spinal injury. Notice we all have a smile or grin on our faces!

In our journey of 10 years it has made us realize that Mumbai is still so primitive in sci rehab management. we periodically lose friends due to avoidable issues like UTI, pressure and bed sores, respiratory tract infection, psychological depression etc. The plight of friends with quadriplegia is worse.

World Health Organisation, Geneva, is publishing for the first time IPSCI. Nina Foundation was invited to represent and contribute to this body of knowledge. Hopefully this document will soon ensure world class rehab centres all over India, especially in Mumbai., which is the need of the hour.

At Nina Foundation we ourselves have faced several speed bumps, but the joy of achievement is much greater after overcoming them. Plus it becomes a learning for younger friends.

I would like to share some incidences.

* The first time we organized a support group meeting in 2006 at Vile Parle, suddenly the city plunged into darkness. The power supply of the entire city had tripped. Yet each and every member turned up and we conducted the meeting in the parking lot with the headlights of cars providing illumination. **It is possible!**

* I would like to share one more example. The first year of sci day on 25 June 2009 was planned on a grand scale on the welinkar rooftop. BMC and MET dept had declared it as 'max downpour day' expecting the city to be flooded. Phir bhi 80+ friends with sci and over 600 invitees made it to show solidarity for the cause. Thank God nature always succeeds in hoodwinking our MET dept!

* Recently the recipient of Nina Foundation educational scholarship telephoned from a small village in Amravati, Rajashree Patil. An excited voice 'didi mein pass ho gayi' her joy was evident over the phone. She completed her BED course and now has a job in the local school there. She could not attend classes regularly because of the distance, but she did overcome this hurdle and came out successful.

How do we know we are on the right path? Our pole star -Nina's spirit continuously guides us and gives us a sense to proceed. Limitations are but in the mind.

The IMPACT our various initiatives result in is evident from the emotions shared by our friends.

SPEECH BY DR. KETNA MEHTA

• On 9th March 2011, Nina Foundation Founder's Day we attempted something very radical and new. We planned to take our friends to Siddhivinayak temple and Mount Mary church, a contingent of we school students had this as a project under the subject Student Social Responsibility- the tears of joy expressed by Balbhim Sankpal and his words 'mujhe lagta tha mein kabhi darshan nahi kar paunga aur who bhi itne karib se' his heavy motorized wheelchair was carried down the mobile ramp and inside the sanctum sanctorum. Members from Sharan said 'chalo yahaan se Mahalaxmi temple chalthe hai'. Madhuri screamed 'today is my independence day.. for the first time I have travelled without my mother, eaten without her help' she just could not stop smiling. For the rest of us it was one more window opened to the world outside. The change in the belief that 'God hamse ruth nahi gaye hai...who toh hamari raah dekh rahe the!'

• The Mumbai Marathon in Jan 2006. Our friend Subramaniam was called not less than 5 times to convince him to join in the morning for the race. That all will go right. (Mind you a great responsibility on our part!). He agreed and no sooner then the 2.5 kms run was over he was all smiles with his wife Mahalaxmi puffing behind him and he said 'Ketna why is the marathon only once a year. We are ready for the next.'

And we can go on narrating scores of such incidences. The IMPACT is definitely there... some tangible and visible, a few others intangible (as yet).

We have witnessed personalities transformed, confidence resurrected and life goals formalized. We have made strong friendships, shared parental love, established enduring relationships. The thread binding us together is that of understanding... 'we know what it means to have a devastating spinal injury.'

Believe us we are all ROCKSTARS. We are proud to live with sci with less than 40-50% of our physical abilities functioning yet we continue with our professional, personal, family and social lives and also care for our sci community. Without complaining. We all deserve an applause.

We take this opportunity to thank each and every individual who has inspired us in our journey so far. We look forward to our relationship growing stronger, the trust deeper and scope of work bigger. Nina Foundation hopes to continue to enjoy your support in all our future endeavours.

Now we pay our deep and heartfelt respects to the first few supporters who trusted the fledgling Nina Foundation and give it the power and wings to grow and fly.

25 June 2000 we suddenly lost our elder sister NINA. We were showered with love, care and attention from relatives, colleagues and friends. What was happening parents no more, major accident and now this. Amongst all one family friend stood out. Rtn. and PP Himat da Advani. He visited us a few weeks later and gave us special blessings, spent time with us and communicated his philosophy of life. He himself had gone through similar pain. Somehow those blessings instilled a glimmer of hope in our hearts and made us positive again. This was the beginning of hope and possibility for the idea of NF to take root. Today we take the opportunity to publicly thank Shri Himat da Advani...Dhaval please escort him and we invite our senior member Dharapkaka to kindly felicitate Himatda with shawl, coconut and a Nina Foundation handmade lamp.

Feb 2001 we started with the first issue of One World. We sent a copy

to our mentor and management guru, Dr. N. H. Athreya. In his characteristic green pen and hand written note he said 'congrats...my suggestion for you is to start a foundation to spread the good work.' And thus was born NINA FOUNDATION. For giving us the idea to set up an institution which is 10 yrs old we bow before you and feel privileged to have you as our guide, always. May I request Usha to escort Dr. Athreya on stage and Nina's school teacher Prochee Writer to honour Dr. Athreya.

Now we have two wonderful souls who have sewa bhav in them. First may I call Bunty oorf Raghbir Singh. My friend Divya's driver, but has taken Nina and self on several trips safely during the initial rehab period. Dr. Jacob joined us for a trip to PRC Pune, he has been with us for the Marathon, darshan visit and many community projects.

For a true Bhagwan ka dhoot without any expectations, we thank you for all that you have done and are doing. You gave us courage to take on more responsibility.

We request Shifaaliji to felicitate Bunty.

Our next special honour is for Mr. Santosh Kedare, who was with us as our driver cum escort since 2001. He took me and my colleagues to various conferences, workshops, sat and put labels on our One World issues, visited the post office and pasted stamps on the 600 covers religiously and with devotion. Would reach medicines and supplies like diapers to needy patients and came with me for hospital visits. Tujhe hey sewa bhav saathi, Nina Foundation is happy to felicitate you. Shefaaliji please honour Santosh.

Mukund Pai. Kreate has been an integral part of our journey. We use their office, creative, office boys etc., for all our activities. Their creative director has designed my book Nano Thoughts on management each page is specially designed and proceeds go to Nina Foundation. The impactful film... "lets walk together", all the PPT's for conference, workshops etc. including our logos and branding is by him. For an international conference I actually had delegates asking me for a copy of the ppt as they were impressed. All this has gone a long way in establishing the credibility and brand Nina Foundation.

Mukund thank you for doing all from your heart. Request Prof. Dr. Uday Salunkhe to honour him.

Gyanesh Parab, also from Kreate. One world designing, back drops, banners, website, collaterals for sci dayquickly and without any fuss. Speed and quality thy name is Gyan. Shukriya for matching our speed of thought. Our Chief Guest Dr. Athani to honour him please.

We are 10 years now, but we will continue having the childlike qualities which has propelled us thus far. We believe in living in the now, present moment. We are sure the guiding pole star of Nina's soul will motivate us and direct our actions with greater speed and force to spread hope, joy, fun and laughter all around.

The greatest thing in this world is not where we stand, but in what direction we are moving.

Lets walk together for a wonderful tomorrow...
[Speech by Dr. Ms. Ketna Mehta, Founder Trustee, Nina Foundation]

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Renew the Spirit of 'LIFE'
Lets Walk Together for a Wonderful Tomorrow



SPINAL INJURY AWARENESS DAY
25th June
2011



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Renew the Spirit of **'LIFE'**
Lets Walk Together for a Wonderful Tomorrow

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SPINAL INJURY AWARENESS DAY
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An NGO for rehabilitation of people with Spinal Injury

SPINAL INJURY AWARENESS DAY
25th June
2011



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This year, on June 25, 2011 - the Spinal Injury Awareness Day was celebrated by Nina Foundation with more gusto and fervor with over 200 people socially aware of SCI in attendance. Rain or no rain, SCI members from Cheshire Home, Sharan, Paraplegic Foundation also joined in with our own members to have a jolly, good time.



The evening was beautifully compered in multi languages by Vidya Shenoy who naturally elicited impromptu humour and on the other side, a very warm response from the



guests. The evening focused on an attitude of "enjoy life to the fullest and have a laugh and live life with miles of smiles in spite of challenges one meets even in day-to-day life". And, this was amply backed up with an afternoon of fun-games and for all those who wanted a 'peek preview' of their future, also a tarot card reader. To top this all, also an evening of entertainment and music by band, Coshish, whilst enjoying a sumptuous Chinese dinner!

Our special invitees included **Mrs. Shifaali Shah**, Celebrity Guest of the evening, **Prof. Dr. Uday Salunkhe**, Group Director, We School -India's fastest growing B-School- who addressed our family. Chief Guest **Dr. B. D. Athani**, Additional Director General of Health Services and Director, All India Institute of Physical Rehabilitation, Mumbai and popular film journalist and author of 'Bachchanalia', **Ms. Bhawana Somaaya**, as Guest of Honour. **Mrs. Prochee**, Writer, KG Teacher of Dr. Nina Mehta Doshi as a Special Guest. The 'miles of smiles and laughter' was amply provided by catalyst, **Vikram Sathaye**, well-known stand up comedian famous through numerous shows on TV Sports Channels as also corporate events.

Once again, We School Management with the kind courtesy extended to Nina Foundation by **Prof. Dr. Uday Salunkhe**, Group Director, We School, this event was held in the

HIGHLIGHTS OF THE EVENT

Announcement of GREAT news: Newly formed organization, Rehab Alumni Network (RAN), Chennai, has approbated adoption of Nina Foundation practice, that of celebrating a Spinal Injury Awareness day on June 25th from this year. How encouraging! So, why not cheer? Three cheers for Nina Foundation....Hip hip hurray! Hip hip hurray! Hip hip hurray!

The INTRODUCTION of the WILLSTAR Award (2011) this year, it was awarded to Mr. Sanjay Jagtap, Mumbai. He received this Award from Guest of Honour, Ms. Bhawana Somaaya.

The 3rd Rockstar Award of 2011- who "Infinitely Inspires", was presented to Dr. Uday Khopkar, MD in Dermatology and Head of Dept. at KEM Hospital, Mumbai by Celebrity Guest, Ms. Shifaali Shah.

Besides felicitation of our Special Invitees, due acknowledgement and honour was given to Nina Foundation Supporters viz., Rotarian Himmatda, guiding force, Dr. H. N. Athreya, Bunty, Santosh Kedare, Mukund Pai & Gyanesh Parab, our We School Photographer, Jaisukh Parmar, Volunteers and Support staff of the Facilities, Security, Housekeeping, Canteen and Lift Services departments and Pooja Khedekar, Research Assistant, all of We School as also students of the MGM School of Physiotherapy.

Lots of laughter, thanks to Vikram Sathaye, the laugh-riot machine who brought cricketers, singers and politicians all under one roof of the Nina Foundation! There was not a single person in the audience with a straight face as he performed for the evening.

Brainstorm Room of the We School, one of the few wheelchair accessible B School in India. Trustees of Nina Foundation present included **Dr. S. Y. Bhojraj, Dr. V. C. Jacob, Dr. Parinaz Humranwala, Dhaval Mehta and Dr. Ketna Mehta**, who addressed the audience with "A Decade - 10 years of the Nina Foundation." Registration counters and a display-cum sale of products made by our members were also exhibited.

This year too, we heartily appreciated our members, meaning our Angels in the form of Sunita Sancheti, Bhavna Chheda, Madhu Singh, Neenu Kewlani, Nishant Khade, Arvind Prabhuo, as also Pranav and Aditi. Also, special mention of Kreate Advertising for all publicity and creative work, Tribal Route for sponsoring gifts for guests, Spine Foundation, Humranwala Homeopathy Trust, Das Offshore, Access for all, Rtn.

Madhu Narang of Better Services who sponsored the trophies for both, Rockstar and Willstar Awards, Nehal and Alok of Ace Entertainment for games, Sagar Tejura of Ayrton Agencies for sponsoring gifts for games, Neenu Kewlani for providing water, Nishant Khade for sponsoring afternoon snacks and dinner, **Dr. Dhruv Mehta** in garrisoning student volunteers from students of the MGM School of Physiotherapy.

Nina Foundation is strongly committed to its mission of rehabilitation of people with Spinal Cord Injury (SCI) and has instituted awards, viz., Rockstar Award and Willstar Award to recognise those individuals who infinitely inspire us, who we can and do look up to and, who have with exemplary courage, faced and won the battles in life in spite of having SCI. By presenting these Awards, Nina Foundation "renews the spirit of life". It is proud that these

achievers also encourage others to reach the top in whatever vocations they choose. Not to forget that they are both chosen without bias, i.e. irrespective of geographic, religious, linguistic or ethnic differences. (Compered by Vidya Shenoy, Associate, Nina Foundation)



Good evening and congratulations to Nina Foundation for completing 10 years. We School's credo is to support an education of the youth which gears them to have a business mind and a emotional connect. Serving the community to have a social impact has been a CSR thrust at We School, we have a subject student social responsibility which emphasizes strong social alliances. We School is proud to be a partner in service for Nina Foundation and especially the Spinal Injury Day. We intend to take our healthcare programme too to wider shores creating a robust human resource and management system. We wish you all good health and a strong spirit always.

....Prof. Dr. Uday Salunkhe, Group Director, We School.



Rockstar
Award



Our 3rd Rockstar Awardee for the year 2011, Dr. Uday Khopkar, then, a young 21-year old doctor who enjoyed travelling, trekking, photography and computers, loved the mountains, budding with fun, accepted the offer of accompanying IIT-ian's Trek

Himalaya 1984' as a doctor in their Team. In spite of contrary advice given to them by others, they dared and met the challenge of scaling new heights to reach a peak close to their camp. For which, they had excitedly set out for the peak close to theirs at 4.30 early next morning and touched the summit after 5 hours. After a sense of achievement and some rest, as the weather was showing signs of deteriorating, they started the downhill trek. Unknown to both, the friend erroneously chose the steeper path that was under layered with loose rocks. Though this friend escaped injury, Uday fell 100 feet below, rendering him unconscious. It was dark by the time other teammates came and over the next 48 hours, was taken by a makeshift stretcher through 8-hour shifts to the base camp, about 7000 feet below where a bus transported him to Dehradun. Eight days later, he was operated at Bombay Hospital.

In this crisis, his parents through their hard work supported him silently and ceaselessly as also a genuine circle of friends, that included doctors who were his colleagues, helped him cope this stress as he was admitted in the same hospital he was working in. The Nair Hospital Departments of Physiotherapy and Occupational Therapy teams were responsible for his successful rehabilitation. His senior colleagues and also the social worker helped in arranging an auto-rickshaw that could be driven to improve his mobility and, which was also conducive for attending rehab sessions and caliper-making visits at the All India Institute at

Haji Ali.

1991 changed the course of events in his academic life as he was selected for the World Congress scholarship, New York, to represent India. Dr. Ackerman, a Dermato-Pathologist of renown accepted his application for a Fellowship. During this scholarship, daily

transport and boarding was gratis hosted by people who he had just met! This term taught him the art of living, to accept defeat and failure, the yes-es and the no-esone faces in the battle of life with equal poise.

M. D. in Dermatology came as default since emergencies in this department are few. Work-related travel started with local meetings and 1992 saw him attending national conferences. He says, "Special gratitude to my boss at Nair Hospital, Dr. Wadhwa, and also other senior and junior colleagues who were instrumental in encouraging and helping me during travel. It was only because of the sustained, positive influence of my colleagues in the fraternity and friends that my disability never ever stood in my way".

With academia, professional areas settled into comfortably, as per social norms, his family wanted this confident and successful doctor to settle down and get married. It was through media and common relatives that Sunita's parents, now, who are now his in-laws, came to know of this accomplished dermatologist. So, he had found his soul mate in Sunita! He happily lost his independence forever and they mutually decided to tie the knot on 15th August 2001. They are now blessed with a daughter, Dnyanada, who was born on 21st April, 2006. A complete, content family!

At 48 years now, inspite of level of injury: T12-L1 Lower motor neuron type complete injury. Zero power. Hypotonic, he is a realised being! Teaching, giving lectures, attending the hospital and clinics, meetings, conferences, visiting family or outings on weekends form the routine of this young, ambitious doctor's life. Challenging destiny to move on courageously, his ambition now is to be a vehicle for better understanding of skin diseases peculiar to India.

(To view the Rockstar Video, please visit our website: www.ninafoundation.org)

This year, Nina foundation introduced a new award, the Will Star Award 2011. This award has been instituted for the one who, in his journey of courage, has shown grit and determination to overcome obstacles and rise high, to reach the stars, in spite of challenges faced by him. He has the spirit, the spirit that Nina Foundation stands for....that indomitable 'spirit of life 'and' to walk together for a wonderful tomorrow' with a head held high! A life that is truly filled with renewed hope, positivity and achievement!

The winner Shri. Sanjay Jagtap, Mumbai who thought the following:

**Khud par karo bharosa to bhagwaan milta hai
Saath ho iccha, shakti to har samaan milta hai
Apne iraadon ko apne boolund kar itna
Dilme in lagan ho, to aasmaan milta hai.**

truly achieved what he set his eyes on and hence, well deserves this Award, which has " Journey of Courage" inscribed on it.

Born in 1968 in Yewlewadi, Sangli, Sanjay Laxman Jagtap came from a simple family which included his father who earned his livelihood by farming, his 2 older sisters, Vimal Uthale and Kamal Khot, married and also at Sangli. Armed with a SSC certificate, he came to Mumbai in 1984 and stayed at Fort to work as an Office Assistant in a painting company where he worked for 6 years.

The year 1995 saw him in a road accident at ChunaBhatti caused by an oil-spill. The 3-wheeler he was riding along with a friend skid on the road damaging his spine completely resulting in Level of injury D11 D12, L1-L3. He was taken to Sion Hospital where he underwent surgery, during which plates were fixed in his spine. After 3 months of hospitalization, he was discharged from there and shifted for a month to Paraplegic Foundation on the suggestion of Prema, a social worker.

Our Dr. Jacob's physiotherapy, that of disciplined exercise for 2 hours, twice a day, for a period of 6 months from March to October 1995, Jagtap was able to walk with the help of a crutches. In 1996, he set up a vada-paav and chai stall near Akashwaani, Sachivalaya with a capital of ₹ 20,000 which came from his uncle, in which he was assisted by a Team of 10 workers. This stall operated till 2004.

His mission to promote the cause for disabled made him go on a hunger strike supported by 25 other members of the National Confederation for the Development of the Disabled. Their demand was to be allocated at least 200 sq. ft. of place for their members to start business and also to re-instate the



system of special BEST passes which had been discontinued. From 2005-2009, he spent more time for his Members, by actively spreading awareness of facilities and Rights given by the Govt. to the Disabled. This mission successfully covered 30/35 districts in Maharashtra.

In 2006, he attended the International Conference for the Disabled - Asia and Pacific held in Bangkok in June 2010. This Conference discussed the implementation of the Rights of People with Disabilities. He also works as a Secretary to a National Confederation for the Development of the Disabled that provides assistance to those disabled members who want to start their own enterprise. As of date, it has about 200 members and, we, at Nina Foundation are sure that with Jagtap and Mr. Suhas Kale, the founder of the Organisation, the sky is also NOT the limit. He now would also like to set up a Self Employment Centre in each district of Maharashtra to promote this cause.

Since Jan 2010, he worked as BEAT MARSHALL with BMC for maintaining cleanliness in the city and promoted as Supervisor for the Mumbai Region with 25 staff under him. He had been given the power to fine offenders a sum of anything between ₹ 8000 to ₹ 20000. He now stays unemployed as the Govt. is planning to revise the Cleanup Marshall Act, now under scrutiny and scheduled to be reintroduced in Dec 2011. We sincerely hope that he is back on his 'Beat' soon.

We, at NINA FOUNDATION, are all very, very proud of you and stand up and salute our hero, Shri Sanjay Jagtap!

(To view the Will Star video, please visit our website: www.ninafoundation.org)





SPINAL CORD INJURY REHABILITATION: RE-UNITING THE SCI PATIENT BACK INTO SOCIETY, NOT JUST RE-UNITING THE FRACTURE - A PILOT STUDY

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3. Association of People with Disabilities, Bangalore, India.
4. St. John's Medical College, Bangalore, India.



STOP!

LOOK!

THINK!

BACKGROUND

Controversy has cloaked the acute management of spinal cord injury (SCI) for millennia. In the last two decades treatment options have been transformed beyond recognition. However, some things haven't changed, especially in India. For the vast majority of Indians who suffer traumatic SCI, options such as neuro-protection and regeneration are either not (because they reach the centre after the so-called window of opportunity).

Therefore, in the Indian context, the only remaining polar options are surgery or postural reduction. We have chosen to follow the footsteps of

- 1) H L FRANKEL - In his seminal paper of 1969 - which is quoted even today - showed that postural reduction was effective in closed SCI in a study of 682 patients.
- 2) CHARLES H. TATOR - analysed all treatment trials in human SCI over the last 50 years, and concluded that surgical decompression was of unproven effectiveness or ineffectiveness

We have chosen to accept them, their beliefs and their findings. Accordingly, we propose that most traumatic SCIs in the developing world be managed by postural reduction.

THINK IT OVER

Should my aim be restoration of the vertebral body height, or restoration of the victim's personal earning capacity?

IN MEMORY of all SCI Patients who were Fixed, Screwed, Plated & Died

PEOPLE WHOM WE BELIEVE BELIEVE IN WHAT WE BELIEVE

- Dr. Mary Verghese • Dr. Suranjan Bhattacharji
- Dr. Charles H. Tator • Mr. H. L. Frankel
- Dr. Wagih El Masry • Mr. Brian Carlin
- Dr. Sruti Mohapatra And many many more!

EPITAPH

*Superman wasn't saved, was he ?
Why then say, Soolaiman can be ?
Superman & his wife had their billions
Soolaiman's widow only had bills...
to pay.*

*Bills she couldn't pay in cash
So she had to pay in kind
She & her daughters, 17, 12 & 10
Forever & ever. Ah! men.
But... what the heck!
Stop!*

*Look !!
See!!!
The vertebral height had been restored !!!!
- Kurian Zachariah*

RESOURCES

** While you may find all the resources for surgical instrumentation of the spine, you will however have a struggle to find the necessary resources to take care of the real needs of the patient!*

WAGIH EL MASRY
President
International Spinal Cord Society
(2008-2010)

RESULTS

- The monthly income of the patients varied from Rs. 800/- to Rs. 13,200/-
- The duration of hospitalization varied from 30 days to 2 years
- 70% of patients had undergone surgery
- Average cost per patient for surgical management was Rs. 316,000/- and that of non-surgical management was Rs. 201,000/-
- 80% of patients paid for their own treatment
- The majority of families borrowed money to pay for their treatment
- 73% of patients lost their job after their spinal cord injury
- 83% of the patients reported feelings of inadequacy

OBJECTIVES

1. To create awareness of the private costs (economic, social, and psychological) that are incurred by a SCI patient in the developing world.
2. To establish the need for these costs to form an independent variable in deciding which acute intervention option is the most appropriate.

METHODS

30 SCI patients from 3 centres in Bangalore were randomly selected and analysed based on their socio-economic demographics, hospitalization details, costs incurred, funding sources, and neurological recovery.

The data for the private costs was collected on:

- (i) Medical costs - expenditure incurred by the patients,
- (ii) Non-medical costs (travel, food, accomodation),
- (iii) Opportunity cost i.e. earnings foregone during the period, and
- (iv) Psycho-social costs.

CONCLUSION

Patient treatment needs to be individualised & holistic. The decision making should take into consideration both the costs as well as the benefits of each treatment option.

DO KEEP IN TOUCH!

Dr. Kurian Zachariah's Poster Presented at ISCOS October, 2010, New Delhi
E-mail: kurian.shoba@gmail.com • Mob.: 094483 86028

Link
<http://pmr-sjmch.tripod.com>
pmrd.sjmch@gmail.com
www.apd-india.com

My family trip to Europe – An unforgettable experience

– By Bhavna Chheda.

This year we planned a family trip to Europe. It was a 16 days trip covering London, Edinburgh, Paris, Switzerland and Italy.

We took the famous red bus to historic sites in London. St. Paul's Cathedral, Madam Tussad's Wax Museum, the famous Buckingham palace and the guard changing parade, British Museum, White Hall, Tower of London houses the Crown Jewels including the "Kohinoor", the Big Ben, Bloody Tower, the Houses of Parliament, Trafalgar Square. The London Eye offers one of the best views of the city. We saw the unforgettable London Bridge across the Thames River.

Getting around London in a wheelchair was fairly easy because there were no bumpy roads. I also traveled in trains, taxis and buses which were wheelchair accessible. Most of the taxis had a wheelchair ramp that the driver can extend from the side of the car to the sidewalk. I must say that people in London are more than willing to assist and were accommodating when necessary.



The highlight of the trip was the Windsor Castle, one of the largest and oldest castles in the world, is one of the official residences of Her Majesty The Queen.

We then headed to Paris and explored photogenic monuments Arc de Triomphe, Eiffel Tower, Petit Palais, Dome Les Invalides, Palais Royal and countless others and its architectural beauty is superb. We went to the Louvre, where we saw the famous "Mona Lisa".

We also went to Disney Land and Walt Disney Studios in Paris. It was great fun watching shows of different cartoon characters. A lot of the rides are wheelchair friendly and I had lots of fun.

We did a one day tour to Versailles-The Chateau de Versailles.



The next destination on our itinerary was Switzerland. We went to Interlaken and Lucerne. One of the main attractions of Interlaken was Jungfrau, which is at an altitude of 4,158 m or 13,642 ft. I was amazed at the scenic splendour from The Cog Wheel train, which climbs up to a height of 11,333 feet to reach Jungfraujoch, the highest railway station in the world. The Cog Wheel train is one of the best, most incredible train journeys in the world. When we reached the summit there was snow all around! It was one of the most memorable days of my life.

In Lucerne, we went to Mt. Titlis on the famous Rotair, which is the world's first revolving cable car, on which we got an incredibly panoramic view of the surrounding glaciers, mountains and scenery.

We also went to Mount Pilatus in a train which is the steepest railway in the world.

Switzerland is like heaven and I am really looking forward to visiting this beautiful country again. Also it is incredible that all these places where so easily accessible that I had no difficulty reaching anywhere whether it was the mountain peak or a river cruise.

The last destination of our trip was Italy. We went to Florence and Rome.

We saw the Santa Maria Novella Church, Piazza del Duomo, Piazza Della Signoria and Palazzio Vecchio in Florence.

Then we went to Vatican City, which is also the smallest country in the world. We visited the magnificent St. Peters Basilica, the Vatican Museums and the Sistine Chapel.

We took a hop-on hop-off bus in Rome. We saw the famous Roman Colosseum, Rome's greatest architectural wonder. We then saw the Piazza Venezia, Piazza Navona, Trevi Fountain. Rome is no doubt one the most beautiful cities in the world full of beautiful art and architecture.





The best and safest method for men to manage incontinence outdoors is to use "self-adhesive external male cath". This cath sticks on with a safe adhesive – it's safe for skin, safe for organ, and it's rare for it to slip off. The difficulty is, that it costs Rs 60 – 80 per piece, and can be used only once. So if you do CIC just once a day, you can wear it for the rest of 22 hours. Bladder accidents become very rare with this product. Rs 60 a day seems very expensive, but Rs 1800 per month doesn't seem so expensive considering the huge difference it makes to our lives.

BLADDER MANAGEMENT

- For women, the various methods are 4-hourly CIC combined with controlled fluid intake, diapers, supra-pubic cath.
- The reasons of UTI vary from people to people.
- It happens in some because of defective methodology of CIC which introduces infection inside.
- Sometimes infections happen despite all precautions, because we can't get sterile, we can only get clean in our CIC.
- With me, I have seen that indigestion causes UTI. Strange, and no doctors believes it, but it's true. And somehow it ties-in with the discovery in us that taking "Alka Seltzer" anta-acid (like Eno in India) reduces UTI in people.
- You have to study your body rhythms to figure out what works for you. And this goes for every part of your health. If something has gone wrong, reflect deeply on the past 24-48 hours to determine what was different that could have caused the issue
- Drink plenty of water, always. I like the phrase Dr. Sinha sent – The solution to pollution is dilution
- A list member found decaff green tea as very effective. Others use cranberry juice or lemon juice. For some people none of these work.

You can learn more about these from the various links at:

http://www.google.co.in/#hl=en&source=hp&q=self+adhesive+external+male+cath&oq=self+adhesive+external+male+cath&aq=f&aq1=&aq1=undefined&gs_sm=e&gs_upl=1063157501032127101151151013441198510.2.4.218&bav=on.2.or.r_gc_r_pw.&fp=9c00825008819c2c&biw=1280&bih=589

Source: Nitin Goyal - Founder & Moderator, sci-india@yahoogroups.com

CAR FOR SALE



Maruti Versa which is Wheel Chair Supported

Cost: ₹ 190000

Contact Person: Melvin Tharail

Location: Pune (Car Registered in Mumbai)

Contact No: 90049 16355 or 98925 50896

Contact Address: A/804, Shubhashree Residency

Ph-2, Akurdi Chowk, Old Mumbai Pune Highway, Pune

Contact Time: 9:00 am to 10:00 am (Mon - Sun)

Modifications Done:

- 1) Sideways entry.
- 2) Height of the door Increased on One side for entrance.
- 3) Height of the roof increased, a 5.1" can stand in the Versa, also the aero dynamism is changed as per the Height.
- 4) There is ramp with which one can placed inside Versa with Wheelchair.
- 5) There is holder in side the Versa with which wheelchair can be held tight.
- 6) Total seats including driver is 5 (excluding the wheelchair person).

Model: VERSA DX2 8STR BS III

Colour: White

Odometer: 51757

Condition: Excellent

Twin AC: Power Windows

Average: In City 11. Highway 13



SUGGESTIONS BY NINA FOUNDATION AMENDMENTS TO PWD ACT 1995 INPUTS FOR DRAFT LAW

BY DR. KETNA L. MEHTA, TRUSTEE, NINA FOUNDATION

1. A comprehensive Health Registry for spinal injury to be set up for updated and latest statistics and data to evolve accurate and relevant policies.
2. Banks to give a higher rate of interest to all persons with disabilities with a valid disability certificate and their parents as bonafide guardians. (similar or higher to senior citizens interest rates)
3. Any new accommodation like flats, apartments, rooms booked by a person with disability/parent, the builder to do customized home modification without any extra cost. For eg, kitchen, washrooms, brailled switches, flooring etc. If not complied with then a concession in the rate of purchase to personally get these suitable modifications done by the pwd.
4. Any PIL or complaint received about non compliance, a lumpsum penalty to be levied which is to be settled by the local court within 2 months.
5. All schools, institutions of education like college, university, coaching classes, public places like post offices, banks, public utility offices, government centres like ration offices, MTNL offices etc which has no access for pwd to conduct their tasks independently will attract a penalty of a lumpsum amount which has to be paid to the complainant within 2 months by the specific defaulter.
6. Access audit NGO's to follow universal design guidelines and to be accredited by the ministry of social welfare and justice. These audit reports to be complied within 2 months of the audit.
7. Curriculum in all graduate courses of educational institutions like medicine, architecture, physiotherapy, occupation therapy, social sciences etc to include a specific course in DISABILITY STUDIES to create an all-round sensitization and authentic knowledge about etiquettes, prognosis and treatment etc.
8. A disability cess to be levied to corporate tax payers only for 5 years to create a corpus for making India a model disabled friendly nation.
9. Companies can allocate the 2% CSR expense made mandatory to a specific disability of their choice and have CSR programmes articulated.
10. Technology to aid the capture of DISABILITY certificate data at district, state and national level for specific implementation programmes.
11. Role of Disability commissioner to be measurable and specified for making them more responsible.
12. Insurance companies to launch Rehabilitation Insurance for reimbursement of medical and non-medical expenses incurred for long term or life long rehabilitation especially in conditions like spinal injury,

DOs AND DON'Ts By Dr. Mary Verghese

Constant vigilance! watchword of the paraplegic.

Day after day, week after week, year after year, for as long as one should live, the patient, exacting ritual:

- Examining the body thoroughly for reddened areas
- Using a hand mirror for back, hips, heels, and elbows
- Bathing daily with warm water and soap
- Then rubbing lightly over paralyzed parts
- Applying powder when the skin was dry
- Using foam rubber pads to keep pressure off any part that showed signs of redness
- Making sure that no part was subjected to pressure for more than an hour
- Keeping the skin dry
- Treating every slightest abrasion as if it were a mortal wound.

Monotonous, time consuming routines, but for the paraplegic, a matter of life or death!
(Source: Take My Hands)

Courtesy: vaidynath@gmail.com, The Rehab Newsletter



Announcement

WHOLESALE DIAPERS AVAILABLE IN MUMBAI

Please Contact: Ambika Trading Co.

Room No. 14, Shamji Karamshi Wadi, Kirol Road,
Ghatkopar (West), Mumbai 400 086.

E-mail: sanketsamani@yahoo.com

Tel. No: (022) 6955 4676 Mob.: 93235 07848

MEMBERS MAKING NEWS



Shree Ganesh Greeting Cards!
Shri. Sambhaji Jadhav, our friend with spinal injury from Cheshire Home, Mumbai designs such beautiful greeting cards. Do support his creativity by placing your orders. Mob.: 098674 95792



Rajeshree Patil after completing her B Ed. successfully from her village in district Amravati now has a job as a teacher in a school. Hearty Congratulations!



Dinkle Shah successfully scored 78.8% marks in SSC and has now taken admission in college. She has also started making chocolates as a hobby and business.



Adil Ansari participated in a group wheel chair dance on 9th July 2011, choreographed by Arts in Motion.



Alka Nigam was down with malaria and has now bounced back and looking after her mother solo who is unwell.



Dayanand Bhadwankar 29 year old, was featured recently in the press including Mid-Day for his spinal injury during Janmashtami festival on 24th August 2008. He is bouncing back having learnt computer operations and is seeking a job.



EDUCATIONAL SCHOLARSHIPS BY NINA FOUNDATION

Since last year, Nina Foundation has provided Educational scholarship to four students from the Helpers of the Handicapped, Kolhapur. All the students have a spinal injury and stay at the "Gharonda" hostel at Shanti Nagar, Kolhapur.



Pavan Tavandkar
Studying in: 12th standard (Commerce)



Bhagyashri Ramesh Mazire
Studying in: 10th standard



Nishant Nivas Sutar
Studying in: 10th standard



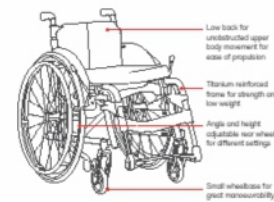
Vanita Vijay Aparadh
Studying in: S.Y.B.Com



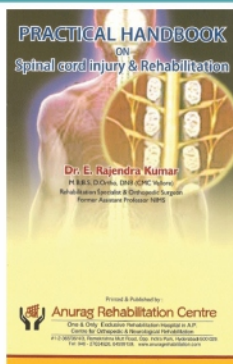
Oliver D'souza in the Otto Bock Mobility Solutions Brochure!!!

"And you think only bikers can do a wheelie?!"

Active Wheelchairs from Otto Bock



Books



For Details Contact:
Dr. E. Rajendra Kumar
Anurag Rehabilitation Centre
#1-2-365/36/4/3, Ramakrishna Mutt Road,
Opp. Indira Park, Hyderabad - 500 029
Ph : +91-040-2763 4920, 6610 6558, 6459 9159
- Courtesy Dr. Dhruv Mehta



Nano Thoughts on Management

by Dr. Ketna L. Mehta
Price ₹ 250
Cheques in favour of Nina Foundation.
(All proceeds from the sales go to the Foundation and rehabilitation of people with spinal cord injury.)

NINA FOUNDATION Donates Wheelchairs to Paraplegic Foundation Members



Alka Nigam



Hiraman Bhoir



Mohammed Aneesh



Narendra Saroj



Sunanda Jawale

About Nina Foundation

NINA FOUNDATION is a eight 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 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, xrays 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 – 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

Nina Foundation's Charter

What can WE all do for improving the quality of life of People with Spinal Injury?

Education Institutions

- 1 Accessible premises & access to assistive technology for students, staff and faculty with disabilities.
- 2 The education department/ authorities to be aware off all the policies, facilities, concessions & best practices to be able to inform parents/gurardians at the time of admissions.
3. Prominent signages about facilities for people with disabilities.
- 4 Training the security and staff of school, colleges and universities about proper etiquettes of dealing with persons with disabilities.
5. Disability Resource Centre like the kind which exists in universities in USA to be made mandatory in Indian education institutions
6. All architectural colleges, interior design and design institutes to include in their curriculum universal design study
7. A wheelchair in the premises for use by visitors with disabilities.
8. Accreditation authorities to emphasise diversity in classrooms and make it mandatory.

Media

- 1 To include regular columns on disability related issues which could be informative, motivating and positive as well. (to go beyond the ritual of mentioning this only on the world disability day)
- 2 Udating the readers about new policies,rules, any such good practices for People with disabilities.
3. To follow appropriate nomenclature to address disability in all languages.
4. To critique improper portrayal of disability in films, serials, plays, stories etc.
5. To project educated people with disabilities for their domain expertise and invite them for their informed opinions on business, budget or any other subject.

Corporates

- 1 To make their premises disabled friendly
- 2 To sensitize the employees and management about people with disability
- 3 To give equal opportunity to disabled
4. To share case studies of employing people with disabilities.
5. To jointly set up vocational training centres with government.

Government

- 1 Implementation and enforcement of existing Acts, Laws and Policies.
- 2 Take strict measures where the policy or law is violated
- 3 To conduct free camps regularly about corrective treatment or therapies.
- 4 To issue instructions to all the concerned departments (RTO, hospitals, etc) about the policies and facilities to be given to people with disability.
- 5 To have a grievance cell and helpline for people with disability .
6. Finance ministry to offer higher Fixed Deposit rates.
7. All public transport to be disabled friendly including railway platforms, bustops and curb cuts.
8. Easy availability of disability and concession certificates with proper information on the procedures on their websites.
9. to collaborate with NGOs and Private institutions to spread awareness about different disabilities.
10. State disability commissioners to become proactive and meet up with various disability groups.
11. Medical curriculum to include updated and complete module on spinal injuries and the impact of the central nervous system.
12. periodic training programmes and educational lectures to the staff of the casualty department of hospital and trauma centres on 'preventing spinal injuries'
13. Ample recreational, leisure and sports facilities for pwsci.

Healthcare professionals

- 1 Updating themselves with new treatment and therapies available.
- 2 Updates on new aids, appliances and technology available to communicate to people with spinal injuries.
- 3 To equip themselves with internationally accepted correct and complete rehabilitation approach
4. information manual and booklets on spinal injury impact and rehabilitation to be made available to all newly injured.
5. A standard operating procedure for the entire rehabilitation team to give uniform guidance to the newly injured. For eg urologists, physiotherapists and occupation therapists.

Citizens

1. Each one of us has the potential to encourage
2. To be compassionate rather than patronizing
3. Develop inclusive thinking in all that we plan and do.

