

MAHENG10650/13/1/2008-TC

रिढ़ की हड्डी की चोट वाले दोस्तोंको निना फाउन्डेशन में शामिल होने का आमंत्रण

Renew the Spirit of **'LIFE'**

Lets Walk Together
for a Wonderful Tomorrow



मंजिल पथरीली है।
यहाँ मे तुफान भी मिलेंगे।
पर **NINA FOUNDATION** साथ है।
तो कामियाबी पास है।

- Support Group
- Dance Therapy
- Mumbai Marathon
- Wellness Seminars
- Employment Initiatives
- Diagnostic and Medication
- Picnics, Get-togethers
- Active Rehabilitation and Sports
- One World - Voice Of Paraplegics



To know more please contact:

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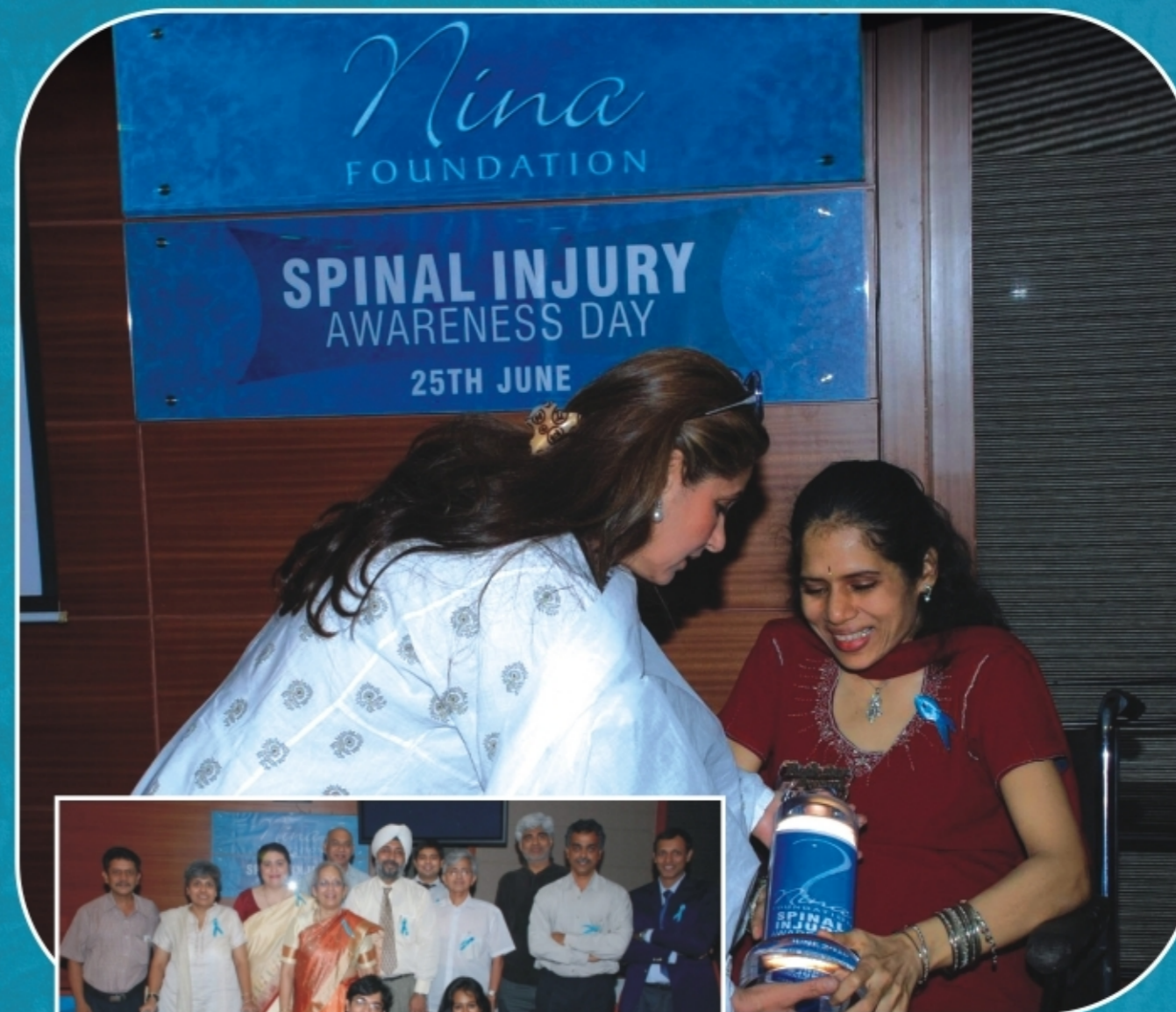


An NGO for rehabilitation of
people with Spinal Injury

Nina Foundation's Publication

ONE WORLD

October 2010



**SPINAL INJURY
AWARENESS DAY
25th June, 2010**

NINA FOUNDATION - An NGO for rehabilitation of people with Spinal Injury

The Trust's Registration Number is E- 23804 (Mumbai).

240/11, Shankar Sadan, 1st Floor, Sion (E), Mumbai - 400 022, India.

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Nina Foundation along with its Academic Partner, We School of Management hosted the second Nina Foundation Spinal Injury Day, 25th June, 2010 in Mumbai.

Nina Foundation had the privilege of hosting very prominent personalities from the fields of medicine and cinema. Dr. H. S. Chhabra, Medical Director, ISIC (Indian Spinal Injury Centre), was the Chief Guest while the ever youthful, National Award winner Ms. Dimple Kapadia was the Celebrity Guest for the evening. Dr. Chhabra was accompanied by Nekram Upadhyay, Rehabilitation Specialist, ISIC. The host for the day was Ravi IYar, who entertained the audience and kept their attention glued through the entire event by mimicking the likes of Baba Ram Dev to the Shehanshah of Bollywood Mr. Amitabh Bachchan.

The proceedings for the evening began with a formal introduction of the evening, Ms. Kapadia was felicitated by the eldest member of Nina Foundation, Shri N. D. Dharap. Ms. Kapadia expressed her wonder and absolute surprise that she was struck by the will and determination of all the SCI members of the Nina Foundation. The next to be felicitated was Prof. Dr. Uday Salunkhe, Group Director, We School of Management by Dr. Parinaz Humranwala. Dr. Salunkhe with his kind words, appreciated the mission of Nina Foundation and wished the best for all its future endeavours.

To boost the morale of all the guests, verses from Harivanshrai Bachchan's inspiring poem 'Koshish Karne Walo ki Haar Nahi Hoti' were recited by children Sanika, Krrish and Rushil. They were presented chocolates by Dimpleji, to appreciate them; also one cannot forget the loud thunder of applause they were showered with.



KOSHISH KARNE WALON KI HAAR NAHIN HOTI
By Dr. Harivanshrai Bachchan

*Lebron se darkar nauka par nabin boti,
koshish karne walon ki haar nabin boti,*

*Nanbi cheenti jab daana lekar chalti hai,
chadhti deewaron par, sau bar phisalti hai.
Man ka vishwas ragon mein saabas bharta hai,
chadhbkar girna, girkar chadhbna na akharta hai.*

*Akhir uski mebnat bekar nabin boti,
koshish karne walon ki haar nabin boti.*

*Dubkiyan sindhu mein gotakhor lagata hai,
ja ja kar kbali haath lautkar aata hai.
Milte nabi sabaj bi moti gebre paani mein,
badhta dugna utsab isi hairani mein.*

*Mutbi uski kbali bar bar nabin boti,
Koshish karne walon ki haar nabi boti.*

*Asafhta ek chunauti hai, ise sweekar karo,
kya kami reb gayi, dekbo aur sudbar karo.
Jab tak na safal ho, neend chain ki tyago tum,
Sangbarsh ka maidan chhodkar mat bhago tum.*

*Kuch kiye bina hi jai jaikar nabin boti,
koshish karne walon ki haar nabin boti.*



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The founding pillars of Nina Foundation

Dr. S. Y. Bhojraj, the very respected spine surgeon, with Lilavati Hospital, Dr. V. C. Jacob, ace physiotherapist, and Retired HOD Sion Hospital., Dr. Himanshu Doshi, Medical Oil Rig Doctor, Ensco Shipping., Dr. Parinaz Humranwala, MD, a very reputed Homeopath, Mr. Dhaval Mehta, the CMD, of Kreate Advertising the man who keeps motivating us all. Dr. Riten Pradhan, Orthopedic Surgeon, UK and Dr. S. Sagade, a very caring Urologist from Hinduja Hospital who were not present and finally, Dr. Ketna Mehta, Editor and Associate Dean Research, We School.

A brief introduction of Dr. Nina Doshi in whose memory the Foundation is established and the vision was articulated by Dr. Parinaz Humranwala.

This was followed by the screening of the film 'Why Spinal Cord Injury Day' an initiative launched in India for the first time by Nina Foundation. This presentation gave out some mind numbing facts about spinal injury based on a breakthrough research study for Dr. Ketna Mehta's Phd in India and stressed the need for a World Class Rehab Center in Mumbai. Also as a part of the presentation, glimpses of last year's event were also shown including the wheelchair dance which had evoked an encore, and sent many of the members and guests in a nostalgic state.

Nina Foundation's Volunteer, Ms. Vidya Shenoy beautifully introduced the 2nd Rockstar Awardee 2010, Ms. Arlene D'souza. A survivor, a fighter... who has won the epic battle between life and death. Her journey could not be summed up in a



few lines. A collage of photographs right from her childhood with the song 'Rock on....' was presented. Ms. Kapadia presented Arlene the Rockstar Trophy and a purse from a benevolent donor Mr. G. K. Nene, in memory of his late wife Smt. Pramilita Nene, which stood as a mark of respect and recognition of her victory. As Arlene conveyed her heart felt gratitude, one could feel the joy in her voice, and see the happiness of her parents. Arlene Rock on!!! Always.

Hip Hoop Hurray!!! Ravi led and this is what the crowd began to roar. This was for our sports achiever Ms. Madhu Singh, who scored an amazing 5 on 6 hoops at the National Wheel Chair Games held in Mumbai in February, 2010. Nina Foundation believes in training and participating in games and sports for better health. She was awarded a gold medal by Ms. Kapadia and a purse by Dr. Chhabra (himself a basketball player and fan).

Nina Foundation has always focused on holistic rehabilitation of all its members, so to let out the creativity of its members, an unique product line has been launched by Nina Foundation. The line consists of natural and eco friendly products which are apt for gifting purposes, hand painted brass and glass lamps, earthen desk frames with the series AUM. These products were unveiled by the friends and volunteers of Nina Foundation led by Ms. Kapadia. These products were on display as well as sale at the venue, along with several other articles contributed by Madhu Singh and friends of Nina Foundation.



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Dr. Ketna Mehta introduced, the chief guest for the day, Dr. H. S. Chhabra, Spine Surgeon and Medical Director, ISIC, New Delhi, who had specially made this trip from New Delhi for the Spinal Injury Day in Mumbai.

Her introduction illuminated the audience about his personal and professional achievements.

It came as a surprise to all when young boy Sidhanth Ganesh, came up with his guitar and strummed beautifully 'Happy Birthday to you...' (It was Dr. Chhabra's birthday on 24th June 2010). Everyone enjoyed this lighter moment.

Dr. Chhabra enlightened the audience about ISIC, how it was set up, the various activities which make it a world class centre. He took up case studies to stress the importance of Spinal Injury Management and the importance of Rehabilitation Centers. His presentation included a short film about ISIC and the vision of Maj. HPS Ahluwalia which has been converted successfully. They also bring out a publication 'Joy of Living' which informs each and every aspect of tackling the various issues faced by a freshly spinal injured. Dr. Chhabra's talk and speech was so very eloquent and the audience were spell bound with the facts. It was a major realisation that Mumbai so far does not have such a rehabilitation centre for people with spinal injury. He emphasized that Mumbai and other metros must get these kind of centres to improve the quality of life as accidents are on the rise and so is population with spinal injury. He invited questions from the audience post his presentation and this interaction helped clear doubts and queries about various



areas related to rehabilitation. Dr. Chhabra and Nekram took the flight back to New Delhi the same night.

The evening was summed up by a vote of thanks, which was given by Ms. Neenu Kewlani. All those who worked tirelessly and enthusiastically were all honoured at the hands of the trustees.

The event was concluded with a sumptuous dinner, sponsored by our own member Mr. Nishant Khade. The delicious dinner was prepared by the We School cafeteria & served in the beautiful atrium.

So many wellwishers, sponsors and supporters for our cause have made this Day possible.

Our Supporters: Dr. N. H. Athreya, Dr. Dhruv Mehta, Ms. Vidya Shenoy, Dr. Veena, Dr. Nergish Wankhadia, Shri. Himatda Advani, Mrs. Padma Patil, Nekram Upadhyaya, Gaurang & Sujal.

Hamare Sahyogi Partners: Kreate Advertising, Tribal Route, Spine Foundation, Humranwala Homeopathic Trust, Das Offshore, Rotary Club of Mumbai Sion, Access4All, Rtn. Madhu Narang of Better Services who has designed, developed and gifted the wonderful Rockstar Trophy, Youtube film: Humpty Dumpty created by Mr. Ankur Gupta of Mastermind Group, who has creatively written, animated and developed the movie as a gift for our SCI day, Mr. Suhail and Mrs. Upasana Kapadia to convince Ms. Dimple Kapadia to be our celebrity guest.





ROCKSTAR AWARDEE
MS ARLENE D'SOUZA
Against All Odds

Sometimes, hope is all you have; yet, in the end, hope is all you'll ever need!

Hope or God's grace is what lifted Arlene from the depths of despair to a life, although confined to the wheelchair, yet spiritually fulfilled and emotionally self-actualized.

The journey, literally, began on 31st December 1994. A day that began with blissful excitement but ended in heart-rending tragedy. Just married five days earlier, Arlene and her husband had boarded the Udyan Express at Mumbai, headed towards Bangalore their honeymoon destination. A love marriage, this was a cherished moment... a beautiful life beckoned. Things could not have been more blissful. But, mere kilometers from their destination, the merciless hand of destiny struck. A high-speed derailment left Arlene in a critical medical condition a serious spinal cord injury affecting the C6 and C7 vertebrae rendered her immobile.

Thus, began a long haul that took Arlene through a series of operations and surgical procedures, endless hospital stays, the bane of bedsores and an uncertain future. She was physically devastated & just when it seemed like things couldn't get worse, emotional desolation was to follow. After a few years, her husband, who was miraculously unscathed in the accident, told her he wanted to move on. She thought the accident had robbed her of everything, but now, fate was taking away the one thing that she needed most... love! It seemed the last straw. But where others would have given up, Arlene somehow found it in her to dig deep into her reserves, and extremely painful as it was, she let him go.

But hope kept her going against all odds. Slowly, effort by effort, bit by bit, she started to piece her life together with God's endless grace and the steadfast support of her family. She even found it in her heart to forgive her ex-husband.

Picking up the Pieces

At first, unable to carry out even the most basic of motor functions, Arlene gradually regained use of her right hand after a tendon transfer by Dr. Bimal Mody at Hinduja Hospital. This resulted in a fixed thumb, index & middle finger bent, so that Arlene could now clutch things, and was thus able to do her own catheterisation when she was on the bed, though she is still dependant on others for the same when she is on the wheelchair.

There would be no shortcuts to regaining control of her functions. Painstakingly, she began physiotherapy first with the help of Mrs. Josephine Fernandes, then with renowned physiotherapist Dr. V. C. Jacob, Nina Foundation trustee; finally with the help of her own father, who would take her through her physio routine every day, without fail. The regularity and discipline helped. Gradually, her strength returned and she

began to do things again she hadn't in years. Where earlier, four persons were required to shift her from the bed to the wheelchair and vice-versa, today she does it all on her own, with minimum help. She started performing tasks that most of us take for granted, like bathing on her own, helping her mother to cut vegetables, knead flour for making chapattis, scrubbing small items when her mother was ill & the maid absent (though it takes "ages") - sheer triumph for one that has gone through such deep trauma!

An active office-going girl before her accident, the prospect of being dependant gnawed at Arlene. She was determined to generate income and become as self-sufficient as she possibly could. Beyond money, it was in fact the chance to keep her mind fruitfully engaged and her time productively occupied.

Working Towards Self-Sufficiency

Sensing her mood, Arlene's brother-in-law, Leslie an IT professional with his own networking business gifted her a PC. He encouraged her to develop her typing skills all over again. It wasn't easy to begin with. In fact the bent fingers of her right hand made it impossible. Like a child learning basic tasks, Arlene had to train her left hand to type. But the ray of hope and anticipation of an opportunity to stand on her own feet (even if not in the literal sense) and earn a living drove her to keep at it. Right-handed all her life, slowly but surely she developed left-handed proficiency, and today does all her computer typing with the left hand. Till today, Leslie ensures his personnel are always on call to promptly attend to any matters of PC up-gradation and maintenance thus ensuring minimal downtime, much to the marvel and envy of her friends.

Fortune always favours the brave the first job in confinement to come her way was courtesy Dr. N. H. Athreya, Nina Foundation mentor. It entailed working at home on a PC. Thrilled at the prospect of inching even closer to normalcy, even if still in a wheelchair, Arlene grabbed the opportunity with both hands again not literally... left-hand would be more accurate!

Then came the break with Datamatics again involving a work-

from-home routine... data entry and proof checking. Being a committed and meticulous person and one who fulfilled every deadline, the volume of work consistently increased. Today, she's been doing the job for Datamatics for over 12 years, with the same diligence and enterprise. And as productive as anyone blessed with all motor functions.

Amazing Grace

God helps those who help themselves. It would have been easier to shut out the world and curse her fate. Easier to call it destiny and give up trying. Easier to simply let others do everything for her. But Arlene was determined to regain control of her life however endless and arduous that journey seemed. Overcoming dark days of despair and doubt. And pain! Painstakingly, bit by bit, piecing her life together again. Naturally, with God's endless grace.

And of course, with the steely support of her family. Especially her mother and father, who have stood by her like a rock... emotionally, mentally, physically, economically. Her brother and sisters and their families, her relatives and friends, who've always been there for anything she needs.

Some in Arlene's emotional state would have resorted to anti-depressants. Actually Arlene did too except they were anti-depressants of a different kind... her nephew and nieces! Little as they were, back then, they instinctively comprehended the gravity of the situation. They realized she could no longer perform simple everyday tasks. They literally became her hands and legs. Her little helpers who, to this day, despite having grown up into worldly-wise teenagers, continue to be her dearest emotional supports.

Support has poured in from all sources. Arlene stays on the first floor, in a building that has no elevator. Her parents are senior citizens, while her siblings reside far away. So it was her neighbours who came to her aid helping to carry her up and down whenever she required.

For one in Arlene's condition, the support system is critical. To ride through the emotional roller coaster that each day would initially bring. Every act big or small by the supporting cast was important to help her make physical prowess and just as importantly replenish her mental and emotional strength. Arlene insists the degree of one's recovery is directly proportional to the intensity of this support system. She's grateful, she's been blessed with an outpouring.

Miracles Still Happen

It's been over 15 years since that fateful last day of 1994. One that ripped all hope from Arlene's life. Yet, in an inexplicable way, one that has given her a new and enlightening perspective to what life is all about. To appreciate the little things that most of us take for granted. To cherish even the most mundane of tasks. To value the priceless bonds of family and friendship. Underlining the axiom that life itself is a gift, and never a guarantee.

For those that saw her soon after her accident, the Arlene of

today is a miracle, carrying out most of her personal tasks independently. Arlene herself insists what pulled her through is her trust in God, the support of her family, friends and relatives, will-power and a determination to confront the most overwhelming odds.

Life's tragedies inevitably leave its victims bitter and cynical. Not Arlene. Even rank strangers who have interacted with her are amazed by her calm, cool, collected, unruffled & cheerful demeanour. She keeps in touch with others in similar situations via the phone & internet, sharing problems, inspirational stories & tips on how to overcome common difficulties. People find it a real pleasure to hold a conversation with her. Yet, most cannot reconcile the fact that one who has gone through such an unimaginable life story is so genuinely sweet, without even a trace of bitterness.

This trial by fire has brought her closer to God. She is living example of the fact that when God closes a door, he always opens a window. God has been with her every step of the way. He was there in the very empathetic and capable doctors Dr. Hegde who operated on her spine at Manipal Hospital Bangalore, soon after the accident; Dr. Mody who performed the rotation flap (for her bedsores) and tendon transfer procedures at Hinduja Hospital, Mumbai, Dr. Bhojraj and Dr. Sagade, who till this very day are ever so helpful Angels of mercy, indeed!

For Arlene, God has manifested Himself most in a beautiful friendship that has blossomed over precisely these 15 tumultuous years. Destiny had it that at the same time that she was being treated at Hinduja Hospital, so was a girl named Ketna. A deep bond of friendship developed and today Ketna is more than Arlene's dearest friend a role model and an inspiration.

Through her ordeal and subsequent triumph, Arlene says she discovered one of life's most consoling truisms: That even when things seem at their lowest and most desolate, God never abandons us.

Never give up hope. Because, sometimes, hope is all you will ever have!



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Members Making News

- Nitin Goyal is now, Head of Treasury, India for NSN - Nokia Siemens Network, Gurgaon. Wow...way to grow, we are proud of you!



- Nehal Thakker has been busy v v busy. She has been meeting actors Ranbir Kapoor, Priyanka Chopra and Suniel Shetty. Way to go gal! She also visited Singapore and Malaysia with her family.



- Shri Anjan Reddy Vanella, Andhra Pradesh was the Runner-up in the 'Beyond the Workplace' Category of the Energising Lives Contest by BPCL. Do continue 'energising lives' in all your endeavours.

- Bhavna Chhedha is doing a Diploma in Jainology alongwith her mother at Somaiya college, Mumbai. Jai Jinendra.

- Anup Chandran is studying banking and finance from NMIMS, Mumbai while continuing working with Stanchart Bank.

- Cliff Borges visited Ireland with his family and lived it up. He continues an active worklife managing his travel agency and camps for school children.

- Arlene our rockstar awardee was down with Malaria, UTI and Typhoid. With God's grace she is hale and hearty and back in action. God bless.

- Bijal Gada has taken up a new job as a CA, Mahavir Group of companies which offers flexi timing so that she can continue with her singing assignments.

- Sunita Sancheti had a successful spinal surgery and is back from hospital. She is the recipient of the NCPEDP Mphasis Universal Design Award for her contribution in making Mumbai accessible and disabled friendly. Way to go, we are proud of you.

- Nishant Khade checked out how Goa looks in the rains with his family and had a soaking holiday.

- Tushar and Saili Parab have started a tiffin service for fellow firemen with yummy Maharashtrian food.



- Shivani Gupta was the keynote speaker for a 5-day workshop on Universal Design by Ekansh in Pune.

- Nisha Gupta is a qualified Tattoo artist and you may contact her for an appointment in Mumbai: 96994 98211 or 022 2494 5322.

- Sanika and Kriesh featured in a video musical album by a young singer Sahir... 'I believe'. Congrats!

- Harshad Shinde has set up his own interior designing firm and goes without saying he would be following universal design principals for a barrier free environment. You may contact him on harshadshinde@yahoo.com

- Neenu Kewlani is now President of Mumbai Toastmasters Club. Congrats!

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





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We thank you for walking with us.
Please fill in your details below:

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in words

Cheque No.:

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Kindly prepare a Cheque (payable in Mumbai)/DD in favour of
'Nina Foundation'

Please send this form with your cheque/dd to:

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240/11, Shankar Sadan, 1st Floor,
Sion (E), Mumbai - 400 022.
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Public Trust Regn. No. E-23804 (Mumbai)
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Log on: ninafoundation.org

How can you get involved with NINA FOUNDATION?

- Sponsor our member with spinal cord injury by contributing ₹ 9,900/- pm.
- Sponsor our member with spinal cord injury by donating to our corpus fund. ₹ 25,000/-
- Banner advertisements in our website www.ninafoundation.org ₹ 10,000/-
- Full page b/w ad in our publication: One World, Voice of Paraplegics. ₹ 3,000/-
- Provide sponsorships for home modification and work place solution to make our member with spinal cord injury independent ₹ 5,000/- to ₹ 50,000/-
- Provide employment opportunities to our members email us: ninafoundation@gmail.com
- Sponsor educational expenses of children with spinal cord injury ₹ 5,000/- p.m
- Sponsor transportation expenses for our members for hospital visits etc. ₹ 3,000/- p.m
- Donation for wheelchairs, aids, calipers, appliances, crutches etc ₹ 10,000/- p.a
- Volunteer for our picnics, out bounds, sports, tourism activities. email us: ninafoundation@gmail.com

TRUSTEES

Dr. Riten Pradhan | Dr. S. Y. Bhojraj
Dr. V. C. Jacob | Dr. Sharad N. Sagade
Dr. Parinaz Humranwala | Dr. Himanshu Doshi
Mr. Dhaval Mehta | Dr. Ketna L Mehta



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INVITING
friends with spinal cord injury to
JOIN NINA FOUNDATION

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'HUM HONGE KAMYAB'



An incident in **Madhuri Bhide's** life on 18th March, 2010 in Mumbai.

"It was around 12 pm on 18th March, when I was sitting on the wheelchair in the hall and my mother went to neighbourhood. While leaving she just shut the door gently. But the lower bolt of the door automatically slid over which actually locked the house from inside.

So even though mom had keys with her, she could not open it. Someone had to open that bolt from inside otherwise the door wouldn't have opened. I was alone in the house and locked from inside. By the time, all the neighbours started telling mom that she should call someone to help, ask someone to climb 2 floors up, enter into house n open the door. Because they thought there's no way i can reach or even open the bolt.

Meanwhile I asked my mom to wait some time outside and started moving towards the door. It took me around 10 minutes to reach there, making way from obstacles-chair, sofa in between. At one point i was almost stuck in the narrow width passage, neither able to go forward nor backward. But somehow making some adjustments to left-right side, I reached the door.

Next hurdle was opening the bolt. The bolt was so tight that my one arm was not enough to pull it. I again shifted my chair to right n used left arm to support and right arm to pull. Finally I opened the bolt in the 5-6th attempt. It was already 12.25 pm then. I saw 7-8 of my neighbourhood aunties had gathered around and were actually stunned to see me at the door opening the bolt. They were constantly asking me how did i get there clearing all obstacles in between. This was very much unexpected to everyone including me n my mom too.

It was a big thing for me as I have never maneuvered my chair before and never ever thought that I could do this even in my dream."

Madhuri Bhide is aged 29 years, BE Computer from Mumbai. She met with an accident in 2003 and has Spinal cord injury at C5 level. She has good and strong movement in right and left shoulders, both elbows has average/weaker movement. She has no mobility in fingers.

She can transfer from bed to chair and vice versa with help of shift board. She can eat with spoon, brush, type, operate computer mouse, keys, write with pen, turn pages of book, operate remote control, can wear shirt/t-shirt/kurta and clothes of upper body only. Can go prone and supine on her own. Can turn to sides and get up with very little assistance.

She takes private tuitions and does online work from home.

She stays alone with her mom on the 2nd floor of an old building without an elevator. On 18th March, 2010 she was home alone when this incident happened.

Congratulate Madhuri for her feat!

E-mail id: rani@yahoo.com

Feedback

Dear Rtn. Sister Ketna,

It was indeed an honour and privilege to be with you for sometime on that special day of the Annual event of the Nina Foundation for which your sincere devotion was visible. The admiration of the visitors around you and on the smiling expectant confident faces on the mobile chairs, said it all.

Your MC was good. I liked the mobile Asana which was something I have not seen before. The recitation by the children emphasising that koshish can only lead to success was revealing of their talent. Dimple was beautiful; short and sweet as always. The many screens, anecdotes and so many small things made me a very happy person, for all this brought joy to my heart that you have successfully reached a high degree of excellence.

Thank you for inviting me.

The physically challenged were so cheerful, forgetting their problem and so very inspiring to others. Hats off to them.

I wish you well, pray that you achieve many more pinnacles of successive successes and bring glory to the institution, to the cause and to our country.

May you bring more comfort to the lives of the physically challenged. May you continue to bring smiles to them every hour of every day and may you lead them along the path to happiness with contentment, accepting and handling themselves in the best manner possible.

Do let me know if I can be of any assistance at any time. I assure you it will be done till the time with me is no more.

Thanking you once again for the invitation.

Yours sincerely and truly,
[MADHU NARANG] a friend and Chairman of Better Services.
madhunarang@yahoo.com

HI KETNA DIDI!

I want to say thanks from myself n my family for 25th June SCI get-together n the lovely dinner served to us.

it was a gr8 evening n we really enjoyed meeting all there.

everything was very good.

thanks once again.

regards,
tejas parmar
tejas_parmar@yahoo.com

YOUTUBE MOVIE

Humpty Dumpty sat on a wall
Humpty Dumpty had a small fall
All the king's horses & all the king's men
Could not put Humpty Dumpty together again.

That was yesterday...

Everything in our life is fine
So long as we have a healthy spine
A gift from the Almighty divine
In a nutshell - our Life Line

Today there is hope for Spinal Injury
Celebrate Spinal Injury Awareness Day June 25, 2010
Visit www.ninafoundation.org for more info

HUMPTY DUMPTY BY ANKUR GUPTA ,MASTERMIND
<http://www.youtube.com/watch?v=WJ-9j1BHh4>
www.mindmanagement.in

YouTube Search Browse Upload

Humpty Dumpty By Ankur Gupta, Mastermind



Obstacles Faced By People with Spinal Injury In India:

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 socialising.
- Schools and colleges which accept people with disabilities.
- And most of all they need 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 licence 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 ₹ 25,000.
- Avenues of sports - tennis, swimming etc. is lacking.

THE OTHER OBSTACLES FACED IN INDIA ARE:

- LACK OF INTEREST IN THE CONCEPT OF REHABILITATION.
- THE CREDO 'DO IT RIGHT THE FIRST TIME' MISSING. BED SORES, PRESSURE SORES, UTI, OSTEOPOROSIS.
- ALTERNATE THERAPIES- MADIWALA, MASSAGE, MAALISH, BLACK MAGIC, KARMA, SCRUBBING WITH A SCOTCH BRITE, ACUPRESSURE, ACUPUNCTURE, PYRAMID THERAPY, MAGNET THERAPY ETC.
- LACK OF PASSION AND COMPLETE KNOWLEDGE BY YOUNG PHYSIOTHERAPISTS.
- LACK OF MOTIVATION TO CONTINUE WITH SCHOOLING, OFFICE, DAILY HOME ACTIVITIES IN KITCHEN ETC.
- BUILT ENVIRONMENT IS NOT CONDUCTIVE.
- 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 OCCUPATION THERAPY INTERVENTION.
- STIGMA FOR LACK OF BOWEL AND BLADDER INCONTINENCE. FAMILY SHUNS AND DO NOT INVITE THEM TO THEIR HOMES & RELIGIOUS FUNCTIONS.
- INDEPENDENT LIVING CONCEPT STILL A DREAM.
- MODEL REHAB CENTRES WITH COMPREHENSIVE FACILITIES MISSING.
- INSURANCE SCHEMES FOR VARIOUS AIDS / APPLIANCES ETC., LACKING.

Announcements

VISIT YOUTUBE
FOR OUR NINA FOUNDATION VIDEOS

- Rockstars
- humpty dumpty
- sci day dance
- family dance
- rockstar awardee 2009
- rockstar awardee 2010

NINA FOUNDATION EDUCATIONAL SCHOLARSHIPS

Young children in India aged 4-25 years can avail of school, college or vocational course educational scholarships.
Please send your bio data with letter from your school / institute with details of fees and course.

Please send to:

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240/11 Shankar Sadan, Sion [E], Mumbai 400 022.
Tel: 022-2407 1952, ketnam@gmail.com
www.ninafoundation.org

INVENTIONS AND RESEARCH



REX BIONICS (Robotic Legs)

Rex - a user's perspective

"Rex gives me the independence and ability to move freely about the world without barriers. These are wonderful first steps towards true equality for all people with disabilities."

When I was given the opportunity to test the "Walking Robot", Rex, I was sceptical to say the least. As a long term wheelchair user and a professional in the disability industry I have met many people with weird and wonderful inventions, ideas and cure-alls. However, at my first introduction to Rex Bionics I was immediately impressed with the logical approach taken to the problem of personal mobility for a wheelchair user in an inaccessible world.

Could I really stand with a simple push of a button that said "STAND"? Could I really walk; even up stairs? A strange mix of emotions came over me as I was strapped into this, now intriguing, machine. When I was first told to stand I hesitated, how could this be possible and so simple as the press of a button after I had spent 30 years sitting in a chair?

To describe the feelings that surrounded that moment is almost impossible. I was overwhelmed with so many emotions, despite the tears escaping I felt powerful and in control: at the press of a button I could independently perform the simplest human activity that had alluded and intrigued me for 30 years.

I felt a strong sense of being part of something greater than myself. My mind raced as I thought of the implications; freedom and independence for not only myself but millions of people affected by disability world-wide. We have come so far, even in my lifetime, towards the goal of making the world more accessible, but the simple truth is that the world will never be totally wheelchair friendly.

After each experience, I am anxious to get back into Rex again. My body seems to be grateful for a walking session with Rex; I sleep better and my circulation also seems to improve.

Rex gives me the independence and ability to move freely about the world without barriers. These, I believe, are wonderful first steps towards true equality for all people with disabilities.

Rachel Peterson
Disability Consultant, Rex user, tester and mother.

Experts Remove Bio-brake, Regenerate Spinal Cord

For the first time, scientists have regenerated spinal cord nerves by removing a "biological brake" on their growth – a breakthrough that raises hope for thousands of patients left paralysed by back and neck injuries.



Researchers at the Reeve-Irvine Research Centre in the US, focused on a protein that turns off the growth of nerve fibres in adults, using mice as test subjects. By genetically deleting the enzyme, they were able to switch the ability of the nerves to regenerate back on.

The scientists are now investigating whether the technique can restore movement to mice crippled by spinal cord injuries, the Daily Mail reported. Study leader Oswald Steward, from the University of California at Irvine, said: "Until now, such robust nerve regeneration has been impossible in the spinal cord. Paralysis and loss of function from spinal cord injury has been considered untreatable, but our discovery points the way towards a potential therapy to induce regeneration of nerve connections following spinal cord injury in people."

Steward is director of the Reeve-Irvine Research Centre, named after Christopher Reeve, the former 'Superman' star, who was paralysed neck down in a riding accident. It is dedicated to investigating treatments for spinal injury.

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NEWS

SURAT gets a high tech physio rehab clinic for members with spinal injury. Clinic area is 1700 sq. ft. and is equipped with all those equipments to serve paraplegics at best level.

You may contact: Shital Lathiya, Physiotherapist:
dr.shital_8@yahoo.co.in

NAGPUR Dr. Manoj Singrakhia Spine Surgeon has set up a 15 bedded Spine Centre in Nagpur. Tel- 91-09320580013
singrakhia@hotmail.com, www.spinecurencare.com



INNOVATION STANFORD BIO DESIGN

Every year, sometime during the June-September monsoon season, a bunch of engineers and designers, fresh from a stimulating six months at Stanford University in California, step into one of India's most chaotic medical establishments -- the All India Institute of Medical Sciences (AIIMS). Over the next year, after hundreds of visits to wards, operation theatres, lecture halls, accident sites and consulting rooms, these aspirant medical craftsmen progress from shock, amazement and understanding to gain insight into India's rather complex health-care needs.

"During the first year, the state of the wards and the general inefficiency with which people were handled as new patients was overwhelming. I couldn't help thinking that there had to be a better way to manage them," said Amit Sharma, among the first entrepreneurs to have trained on the Stanford Biodesign Program in India.

Sharma and his colleague worked on a device that was triggered by the desire to improve hygiene and preserve the patient's dignity, a factor that gets short shrift in a health system desperately trying to cope with huge numbers of people. Fecal incontinence is one of those conditions that overworked nursing staff may not be able to deal with in time. The device they developed works like a urinary catheter to collect a patient's stool via specialised bags and can be systematically, painlessly, quickly and most importantly hygienically disposed.

Unlike medical scientists and academic researchers looking for the next big drug molecule that can offer cures for India's diabetic or cardiovascular disease epidemics, the entrepreneurs at AIIMS are travelling a less glamorous and far more circuitous route to technological glory.

"Rather than products, we are looking at creating an ecosystem," said M. K. Bhan, secretary, Department of Biotechnology, and one of the key visionaries of the programme. By that, he means creating a "Silicon Valley-like" atmosphere in which individual inventors make products that venture capitalists will want to invest in, followed by private equity firms. The innovators are thus encouraged -- financially and intellectually -- to move on to more complex products like implants and, thereby, trigger a high-quality, self-sustaining Indian medical devices industry.

According to a report by BioSpectrum India, an industry journal, India's medical devices industry is estimated at \$2.5 billion (Rs 11,500 crore) and is expected to cross \$4 billion by 2012, growing at more than 15 per cent annually. While most of the volume comes from non-implantable devices (classified as Class I medical devices), much of the revenue comes from lower-volume Class II and Class III devices, many of which are implantables such as stents and pacemakers.



While India's numerous engineering colleges have been offering biomedical engineering courses for over a decade, the Stanford Biodesign Program a collaborative enterprise involving the Department of Biotechnology, AIIMS, Indian Institute of Technology-Delhi, and Stanford University is unique in the kind of talent mix it attracts.

Since 2007, when the India programme began, four candidates are selected every year to spend six months at Stanford, where they are taught that innovation isn't just about so-called eureka moments or flights of whimsy.

"We learn that innovation is a well-structured process. We are taught to break down health-care needs, zero in on which are most pressing, can be reasonably solved, and can be translated into a viable product," said Darshan Nayak, another fellow at the programme.

A doctor from Mumbai, Nayak had eschewed medical practice for a startup and had developed a device to quickly check haemoglobin levels without pin pricks and long-drawn blood tests. After the Stanford programme, he says he's much better informed of the regulatory and intellectual property laws regarding medical devices in the US and India. He's cagey about the specific devices that he's developed, saying it's "too early to discuss them." He and Pulin Raje, his inventor colleague, are focused on trauma care.

"We've spent lot of time outside AIIMS too, being in ambulances and observing how patients were handled and transported to accident sites.

Often, this handling was so bad that the patients were worse off by the time they reach(ed) the hospital," he said.

The innovations he's working on include devices to help prevent patients from deteriorating in such a situation and which can be modified to suit various kinds of accidents.

"We have a definite plan on how to bring products to the market. It's different from being in an academic environment where you work on a concept, prepare a power point presentation and then go on to something else," said Raje, who graduated in design from the Indian Institute of Science, Bangalore.

Being able to develop a viable business plan and encourage doctors to be entrepreneurs and inventors is one of the key motives of the programme.

Whether a product actually fails or succeeds is secondary, said Balram Bhargava, senior cardiologist at AIIMS, and a key architect and executive director of the Stanford programme.

Bhargava recounts his own attempts at developing a stent during the late 90s. "By the time the stent was somewhat ready, the design was outdated."

The realisation that the right ecosystem had to be fostered to encourage faster product development and a car ride with Paul Yock, who headed the Stanford Biodesign Program, laid the seed for the India venture.

Programme interns are already working on their own ideas. One group, Sharma said, is trying to solve a commonplace,

universal problem of how to transfer patients among beds without having doctors and nurses having to physically haul them around.

"They are working on a bed spread, made of a different kind of material, that can be easily handled by one person," said Sharma.

Apart from the ability to spin off their own companies, the programme participants see participation as an opportunity to sharpen skills learnt in design school, apart from doing something that can benefit society.

That's partly what persuaded Pushkar Ingale and Nitin Sisodia to say goodbye to designing cars and bike parts at Maruti Suzuki India Ltd. and Bajaj Auto Ltd. "I felt that this was an opportunity to do social good," said Sisodia, a graduate from the National Institute of Design, Ahmedabad. "If I can work on something that can touch a lot of people simultaneously, it's worth going after."

(jacob.k@livemint.com • Source: HT livemint)

Home Remedy

Balbhim Sankpal (Injury level C4, C5)
of Mumbai has developed the hand splints himself.



*I work on Computer from bed
with required set-up*

*Windows operating system using special Accessibility Services
I use computer with suitable Accessibility settings for
controlling the mouse pointer for using numerical keys
on the keyboard and adapted typing orthosis.*

*After few years of physical therapy,
I gained minimal physical function.*

Goal: Return to work.



Seminar Series - A Report



EDUCATIONAL SEMINAR SERIES - 1

9th March 2010, Somaiya Medical College, Mumbai

Over 80 students of Physiotherapy final year and staff members participated in this informative seminar comprising of presentation, films and talk. The team from Nina Foundation led by Dr. Ketna Mehta comprised of: Dr. Dhruv Mehta, Dr. Ameya Argekar, Sunita, Hardik and Bhavna. The practical and critical issues of physiotherapy with special emphasis on spinal injury were highlighted.



EDUCATIONAL SEMINAR SERIES - 2

24th Sept. 2010, Dr. D. Y. Patil Medical College, Navi Mumbai

About 120 students of Physiotherapy and all the staff members participated in this Seminar. A special presentation and films tailor made to sensitize the students informing them about practical aspects of spinal injury was made. This supplemented their theoretical knowledge and highlighted the major role played by physiotherapists in the rehabilitation of members with spinal injury. The team from Nina Foundation led by Dr. Ketna Mehta comprised of: Dr. Dhruv Mehta, Bhavna Chhedha and Mohammed Soni.



Sachin Pilot - Minister of State in the Ministry of Communication and Technology
14 August, 2010



Sunita Sancheti, Nina Foundation, Mumbai

Ferdinand J. Rodricks, Ferroequip, Mumbai

NINA FOUNDATION'S, FORTHCOMING PROGRAMMES:

- 29th, 30th, 31st Oct, 2010 : ISCOS, New Delhi
- Oct, Nov & Dec 2010 : Poster campaign in all hospitals of Mumbai
- Nov. 2010 : Training for Caregivers and Attendants
- Dec. 2010 : Wheelchair Basketball Camp
- 3rd Dec, 2010 : Get together: International Day of the Disabled
- 16th Jan, 2011 : Mumbai Marathon
- 27th to 31st Jan, 2011 : ASSICON Spinal Injury Conference
- 9th March, 2011 : Founder's Day
- 25th June, 2011 : Spinal Injury Day



Stem Cell fraud in UK –Doctor Struck off by GMC.

Source: BBC.CO.UK, 29th Sept 2010

The doctor who preyed on the vulnerable

A doctor who carried out controversial stem cell treatments has been struck off by the General Medical Council. Newsnight science editor Susan Watts, whose investigation sparked the case, reports on the impact on patients.

Most of the families we met had paid about £10,000 - sometimes more. Many were friends and family of multiple sclerosis (MS) patients.

Conventional medicine had helped as far as it could. They'd read about other sufferers who had apparently got out of their wheelchairs and walked, regained movement or flexibility - or just a little spark of their old personality.

So they gave up their pension money, re-mortgaged homes or organised fundraisers in their local community, because Dr Robert Trossel and his stem cells were their last hope of finding a cure.

'Exploitative of patients'

But instead of offering hope, the General Medical Council (GMC) found the Dutch-trained doctor had actually treated patients with stem cells not designed for human use and that he had breached many of the essential tenets of "good medical practice"

They also said he had exaggerated the benefits of the treatment, and overstated his success rate in treating patients with MS, and concluded that his treatment was "exploitative of a vulnerable patient" and "an abuse of his position as a doctor".

As a result, Dr Trossel, whose stem cell practice was strictly limited by the GMC in 2007 and also has a conviction for breaching the law on stem cell treatments in Belgium, has now received the ultimate sanction - the loss of his UK medical licence.

The GMC began looking into Dr Trossel's case after a Newsnight investigation broadcast in 2006.

It just disgusts me that he did what he did, and took advantage of vulnerable people

Our report had a significant impact on Andrew Sandford, whose wife Debbie was diagnosed with MS in 2001. She has the most severe form, and requires 24-hour care. Mr Sandford had read about internet-based Advanced Cell Therapeutics (ACT), which was recommended by glowing testimonials, some in the New Pathways magazine for MS sufferers. He then handed over £12,500.

What he, and scores of others like him, hadn't appreciated was that stem cell science is still largely at the research stage and most treatments are still unproven.

Because it's illegal to carry out stem cell injections in the UK, ACT booked Mrs Sandford into Dr Trossel's clinic in Rotterdam. But, just days before they were due to fly, a relative happened to watch Newsnight's investigation.

US connection

In our original film we revealed that ACT was run by a couple based in South Africa, wanted by the FBI for stem cell fraud while operating under the guise of another web-based company called Biomark. Their extradition proceedings have resumed this week in South Africa.

He has abused his position of trust, preyed on people that only live on the hope that one day a cure will come

Andrew Sandford
Husband of MS patient

The film also showed that the stem cells ACT had sent to Dr Trossel

were from a company called AllCells in the US, and intended only for research purposes - not for human use. After confirming that the stem cells Dr Trossel had intended to inject into Mrs Sandford were indeed the AllCells research material, Mr and Mrs Sandford decided not to go ahead with the treatment.

Four years later, Mr Sandford recalls being shocked when he found out what was going on. "My feelings have not changed," he says. "He has abused his position of trust, preyed on people that only live on the hope that one day a cure will come. He disgusts me. His only concern about well being was how much money he could make." Another of those who hoped Dr Trossel would be able to help was Steve Murphy. The 42-year-old from Manchester, who was diagnosed with MS in 2000, also saw Newsnight's report in 2006. Mr Murphy had fallen ill straight after his Rotterdam injections and was hospitalised, though no firm link has been established between the two. It emerged during the GMC hearing that not only had Dr Trossel injected Mr Murphy with stem cells from ACT, but also with what he called RNA, to "guide" the stem cells to where they were needed.

This material is known as Regeneresen cell therapy and contained bovine brain and spinal cord material. It appears to be an approach not recognised by mainstream stem cell science. The GMC panel concluded that in Mr Murphy's case - and for three of the other patients they heard from - Dr Trossel failed to obtain proper consent because he didn't tell them what was in this injection.

'Trusted him'

Mr Murphy admits to being angry with himself for being taken in by ACT, but he is also angry with Dr Trossel. "In his testimony, Dr Trossel admitted using these substances but claimed it was 'worth a try' to inject MS sufferers with them," he says. "The GMC didn't agree, and brought this case.

He exploited them [patients] and that's unacceptable

Simon Gillespie
Multiple Sclerosis Society

"The result is a Dr Trossel without a medical licence and I think that was worth a try - not only from my point of view, but for all who may have trusted his apparent medical legitimacy."

The GMC hearing also heard from MS sufferer Karen Galley, from Essex. She too had been injected with the Regeneresen material.

"I feel angry, let down... and I hate him," she says. "It just disgusts me that he did what he did, and took advantage of vulnerable people. The word 'doctor' I can't associate with him. It's an insult to the medical profession."

In his defence, Dr Trossel told the hearing that following the Newsnight investigation he severed his links with ACT, and that the batch of stem cells Newsnight filmed was a defective supply from ACT. But he did admit he was supplying stem cells to patients from his own source too, though would not identify it to us. Simon Gillespie, chief executive of the Multiple Sclerosis Society, warns patients against pursuing treatments via faceless companies on the internet, and condemns Dr Trossel's actions. "He broke that fundamental bond of trust and confidence that anyone has the right to expect in any doctor who's treating them. We think that's totally reprehensible," he says. "Many people with MS are desperate to improve their condition and in this respect they can

be very vulnerable to people exploiting them. He exploited them and that's unacceptable." Now that Dr Trossel no longer has a licence, his former patients say they are beginning a new fight to get their money back.

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