

aaghavendiyatha paaru



aaghavendiyatha paaru was the abiding philosophy in life for the driving force behind The Ganga Trust, epitomising what a brave, forward-looking and smiling approach can accomplish.

Simply translated, *aaghavendiyatha paaru*, a Tamil phrase, means `look ahead'. You must always focus on doing what needs to be done rather than staying a hostage to the past.



THE INCLUSION JOURNEY 2017



aaghavendiyatha paaru



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VISION

Enhancing the quality of life of persons with Spinal Cord Injury in India

Spinal Cord Injury = multiple, lifelong disabilities at one stroke + no cure + Quality Rehabilitation is a must







IMPACT 33,000-plus (and counting) acts of support - financial and non-financial - for 3,100 + persons with spinal cord injury since 2010.

Kamal Kanta (right) says `Till I met Shailesh *bhai* in August 2016, I thought only death was left in my life'. Now Kamal is himself a rallying force, skills trainer and wheelchair basketball player. Shailesh Kumar (left) is engaged by The Ganga Trust as Inclusion Role Model to serve as peer mentor, skills trainer and example for persons with spinal cord injury.



This is the type of impact The Ganga Trust strives to facilitate.



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100 Lives is a program of The Ganga Trust that aspires to ensure Quality Rehabilitation and enable independent living for at least 100 persons with spinal cord injury every year.

A spinal cord injury leads to multiple disabilities at one stroke. There is no cure. The effects are life-long. Quality Rehabilitation is the only way forward. On a conservative basis, about 15,000 persons sustain spinal cord injury every year in India.

Even today less than 10% get access to Quality Rehabilitation in a timely manner. At least 85% of persons who sustain spinal cord injury hail from economically challenged background. Without support, they may just wither away unknown. This backdrop makes 100 Lives important.

On a conservative basis, Rs 60,000 will be needed to restore one life in three months of Quality Rehabilitation.

100 Lives will be the fund raising platform of The Ganga Trust for marathon events across India. The Wipro Chennai Marathon 2017 was the starting point. Runners with disability have done 4,000-plus kilometres since 2012 at this event as Running For Ability. We hope to develop 100 Lives into a life-changing initiative.



Annalakshmi from Tamil Nadu and Rajeev Prasad from Bihar ran 10 kms and 21.1 kms, unassisted, respectively to launch 100 Lives



Founder's Message



Dear Friend,

I am deeply grateful and appreciate your support for enhancing the quality of lives of persons with spinal cord injury in India. Eight years down the road, I feel vindicated by our decision to start The Ganga Trust in September 2009. For 18 years (between 1992 and 2009), I never met another person with spinal cord injury. Getting connected into the space in 2010 has been eyeopening. What is remarkable and deeply encouraging is the way persons with spinal cord injury are pushing the boundaries. This is despite the acute shortage of Quality Rehabilitation capacity and abysmal quality of assistive devices in India. Living beyond the comfort zone appears a way of life.

Please imagine the possibilities if every person with spinal cord injury gets quality, timely rehabilitation; this is what enabled me to go straight back to Indian Institute of Management, Bangalore after my injury in 1990. It is the delay in rehabilitation and / or sub-standard rehabilitation that significantly accentuates the challenges of living with spinal cord injury.

There is no cure for spinal cord injury anywhere in the world. Quality Rehabilitation is the only way forward. Even today, only less than 1,000 persons can receive Quality Rehabilitation in a year, and that is an optimistic number. Government rehabilitation centres exist in almost every state; but unless they attract and retain good therapists and physiatrists, they may struggle to offer best-in-class rehabilitation. A few hundreds receive sub-optimal rehabilitation; some do self-rehabilitation and many do not even know the way forward. And a vast proportion spends money on bad treatment or fake treatment and often ends up with additional complications.

This is why the spread of Quality Rehabilitation is the foremost need in India. We are working with local partners towards this goal. We have reflected on our work and believe that we must push for transformative initiatives. We have charted the way forward to attain macro impact in the years ahead with defined goals. The Spinal Foundation, the Pan-India Self-Help Group for Persons with Spinal Cord Injury, is providing deep networking across India. This bedrock, which will well backed by The Ganga Trust, should help reach superior services far and wide.

Our role model is the Rick Hansen Foundation (www.rickhansen.com) in Canada. By 2030, we expect to work in true empowerment, as the Rick Hansen Foundation does now rather than grapple with basics that are a given in the developed world. For now, we stay glued to getting the basics right. I am passionate about ensuring timely and quality rehabilitation to every person with spinal cord injury in India by 2030. I request you to be a part of our journey, giving liberally your time, ideas, creativity, networking and financial support for the long road ahead. The Ganga Trust will ensure execution excellence, feedback, impact assessment, integrity and transparency. Thank You

Vaidyanathan Singararaman Founder The Ganga Trust

The Ganga Trust Film

The Ganga Trust focuses on enabling persons with spinal cord injury live to their fullest and highest potential. The road ahead is long and challenging. To know why you are important in this journey, view the The Ganga Trust film at The Ganga Trust YouTube Channel.







INCLUSION IMPACT Lifestyle

- I move my wheelchair with my JAW. I now work. I go out easily.
- I was on a *charpoy* for 14 years. I am independent now.
- I was close to death due to multiple bedsores. Today I own a shop.
- 4 18 years after my injury, I got rehabilitation. I am mobile and working.
- I am India Under-23 Wheelchair Basketball Team captain & in college.
- I wish I had come earlier for healing my bedsores. I know I left it late.
- I was depressed, thinking suicide. Now I want to live as Shailesh does.
- I am enjoying my experience at ICICI Academy for Skills.
- I earn with two functional fingers. My children go to a good school.
- I am India's fastest half marathon runner on a wheelchair.
- I gather insights by visiting homes of persons with spinal cord injury.
- I stopped at Class II. I never stepped out 20-plus years. I do now.



INCLUSION IMPACT Illustrative Examples (2009 - 2017)

9,300 +

Experience sharing - individual sessions

1,860 +

Persons guided at rehabilitation stage

175 +

Home visits



3,600 +

26

Experience Sharing - participants in group sessions

Restoration of acutely damaged lives

14,900 + Tele-guidance to live well with spinal cord injury, including repeat callers

180 +

Peer Mentors trained across India in best-in-class practices

330 +

270 +

Mobility aids

Enabling livelihood



	Work in 2017 - Spinal Cord Injury	6000 + Acts of Support
	Type of Work	Total
1 + 3 (Pipeline)	Rehabilitation & Experience Sharing	658
	Mobility, Livelihood, Education, Sports	178
	Networking Meets	541
	Ongoing Guidance & Knowledge Sharing	3450
	Networking & Guidance in Amputation	760
Facilitation - Quality Rehabilitation Centres	Support opportunities in other disabilities	380



INCLUSION IMPACT Thought Leadership



Dr Mary Verghese Award

Excellence in Empowering Ability



Running For Ability

Marathon Platform for Runners with Disability



India Peer Mentors Training

Informed Support System



The Spinal Foundation

Pan-India Self-Help Group

Beyond The Ramp

Beyond The Ramp is a Call for Action by persons in position of influence to enhance the lives of persons with disability. A five-point program has been presented to the Class of 1991 & 1992 at Indian Institute of Management, Bangalore (IIM – B) as a push towards a more inclusive India.



Spinal India Helpline

1800 425 1210

The Spinal Foundation Toll Free Number

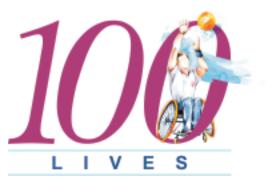
Connecting & Networking







INCLUSION IMPACT Thought Leadership



100 Lives

Fund-Raise Platform for Quality Rehabilitation



India Spinal Cord Injury Day

Pan-India Roving Peer Trainer

Role Model



Chandigarh Spinal Rehab

Spread of Rehabilitation Expertise



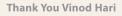
Right Wheelchair Program

Quality Mobility Solutions



Wheels At Work

Employment & Training



Spinal Cord Injury Day

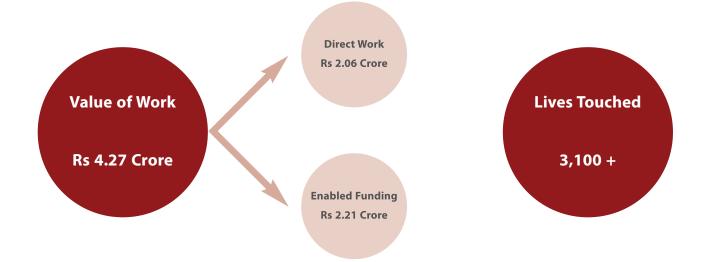
Vinod Hari, a Class of 1991 Alumnus of IIM Bangalore, has been instrumental in conceptualising and motivating the launch of 100 Lives, which is a platform to raise resources at marathon events to support rehabilitation of 100 persons with spinal cord injury every year.

Awareness Creation adopted at World Level

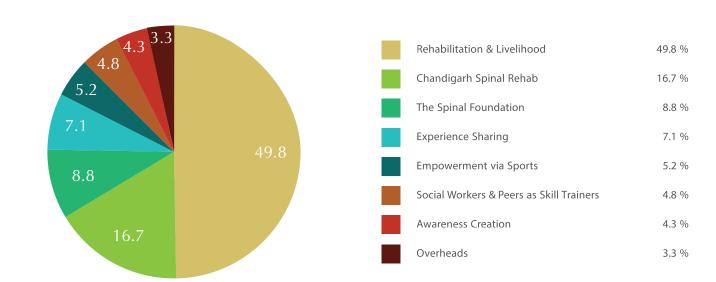




INCLUSION IMPACT Value & Flow of Work (2009-2017)



Enabling *Living Well with Spinal Cord Injury* is the focus of our work. The enabled funding has been arranged for a couple of organisations that work in the rehabilitation space. Information presented is for 2009 to March 2017 based on audited accounts.



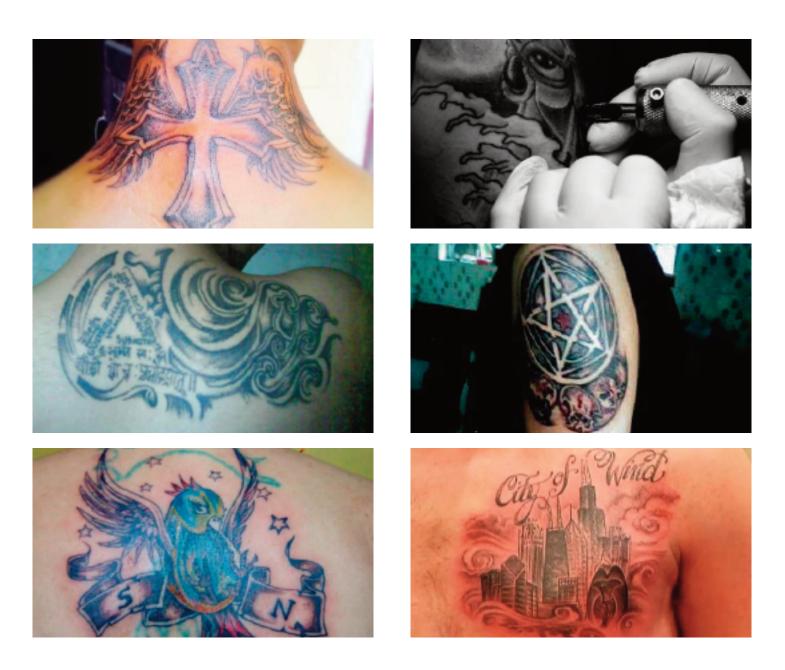
Direct Work Flow of Each Rupee

What We Do		
New Injury Guidance	Facilitation of Rehabilitation	Mobility Aids
Assistive Devices	Peer Mentors & Skill Trainers	Home Visits
Livelihood, Education & Sports Support	Experience Sharing	Awareness Creation
24 x 7 Guidance	Networking	Rehabilitation Infrastructure



Tribute Prajwal Lama

In 2017, despite intensive efforts for two-plus years, we were not able to save Prajwal Lama from Darjeeling in West Bengal, a victim of bad treatment. Prajwal was a fantastic tattoo artist. In death, he served the cause (separate story). Here we pay a pictorial tribute by presenting his select works.



WHO CARES

In the months before Prajwal Lama eventually reached Christian Medical College, Vellore, we were fortunate to connect with WHO Cares, an outstanding volunteering group that does extensive grassrooots work in West Bengal and Sikkim. In life or death, WHO CARES is a bastion of support. We need more WHO CARES.





Roadmap Transformative Impact

Eight years of learning, networking and grassroots understanding have helped The Ganga Trust gain insights for the road ahead. By 2030, we hope to ensure that every person with spinal cord injury in India gets timely, quality rehabilitation and leads a meaningful life. The Ganga Trust firmly believes that **Quality Rehabilitation** must become top priority in India to raise the quality of life about 10% of our population who are disabled. We will continue to push for making India an attractive place for rehabilitation professionals to work with best-in-class compensation. Else, we believe we would deal only at the margins. As part of this vision, the roadmap for The Ganga Trust for next three years has the following markers.

Centre for Rehabilitation Excellence This is the most aspirational and ambitious project on our radar - a rehabilitation facility to serve as the benchmark for training in independent living for persons with spinal cord injury and other acute disabilities.

Spread of rehabilitation expertise We will work with local partners with good credentials to enhance rehabilitation capacity in India. After Chandigarh in 2016, Puri (Odisha), Raxaul (Bihar) and Chennai (Tamil Nadu) are the next possible stops.

Back Up India This will be a structured grassroots program underpinned by the enriching experience of Shailesh Kumar and two other peers in roving roles and reaching out to persons with spinal cord injury. We are targeting expansion of this program to a team of 20.

Expanded footprint of networking meets As a part of Back Up India, a key project will encourage the select team to hold meets of persons with spinal cord injury in their hometown and one nearby place at least twice every year.

Rehab Plus Model Rehabilitation centres offering acute stage training can go only to a point in empowering the individual. Peer training centres, which are also more affordable, can provide holistic training that enables active living.

Right Wheelchair Program 95% users in India sit on bad wheelchairs that actually damage their health. We will work with partners, including IIT Madras and CSR programs, to change the landscape for mobility devices in India.

The Spinal Foundation The most important project for The Ganga Trust so far has been facilitation and funding of The Spinal Foundation. We will continue to invest in making the Pan-India Self-Help Group a robust organisation.

Best Minds Workshop As part of a systematic plan to understand the needs and map out strategy, a Best Minds Workshop will get together about 20 persons with spinal cord injury with vision to brainstorm and make a plan.

Rehabilitation Knowledge Base A well-structured evidence-based rehabilitation program will be made available in multiple formats and languages. This will also have a 24 x 7 Guidance by rehabilitation professionals built in.

Wheels At Work To translate the wide-ranging expertise available in the ranks of persons with spinal cord injury into livelihood opportunities, Wheels At Work will create employment, residential and from home. It will kick off in early 2018.

The Ganga Trust Schools Program This will be a structured connect with schools and colleges to sensitise children on injury prevention, consequences of spinal cord injury and disability.

Spinal India Storyboard This will be a systematic program of developing storyboard of persons with spinal cord injury from across India. Spinal India Storyboard will serve as a motivation and guidance platform.

We cherish a collaborative approach with like-minded organisations in varied spaces, as that is the only path to accomplish Vision 2030.

Justin Vijay Jesudas

Shailesh Kumar

Vaidyanathan Singararaman

The Ganga Trust

The Ganga Trust is a registered public charitable trust. It is registered under Section 12AA of the Income Tax Act. Contribution to The Ganga Trust qualifies for deduction under Section 80G of the Income-Tax Act, 1961 vide DIT (E) No.2 (934) / 09-10 dated 03-03-2011. The PAN of The Ganga Trust is AABTT8436G.





Independence leap, courtesy his JAW









Ajeya Raj, who is completely paralysed neck down, no longer needs a person to push his wheelchair from one place to another. He even navigates the Delhi Metro on his own. He travels on the roads of Chandigarh on his own and handles traffic smartly.

A wheelchair that moves by jaw control is the latest addition to the landscape of Chandigarh. Yes, for Ajeya Raj, there was an unexpected change in mobility in 2017. His independence soared as a result.

He came to Chandigarh Spinal Rehab to learn mouth painting. What the therapy team managed was a life-changing initiative for Ajeya. He slowly but surely mastered moving the wheelchair by using his jaw.

The traditional motorised wheelchair moves by operation of the joystick with the hand. As he has no hand movement, an out-of-the-box approach was the only way out.

This was not an expensive solution. The customised joystick was locally made at a cost less than Rs 3,000. This is just a reinforcement of what can be accomplished by high-quality therapy team.

Ajeya has always exhibited courage and moved ahead since his spinal cord injury in 2006 in a bike accident. He completed his graduation and now manages social media, public relations and a community kitchen at Chandigarh Spinal Rehab.

Message If you are willing to move forward, there is no limit.

We are happy to be a part of this enriching journey.

Home Visits



Being completely paralysed neck-down mostly ensures a person rarely moves out of home. That is not true with Ajeya Raj. He makes it a point to visit persons with spinal cord injury in remote villages in Jharkhand. The very fact that he comes home is enough to get them for rehabilitation and a second chance at life.



This SHOP is Special



He started off on a *charpoy*, a nuts-and-bolts shop of the kind that one can find in massive numbers across India.

It was opened in October 2017 in a small village in Siwan district in Bihar.

What makes this shop started by Deepak Sharma special?

- Livelihood is possible even in a remote part of India, if you have the perseverance. Deepak's shop sends that message to every person with disability. You need to take initiative.
- You can recover from the jaws of death and make it in life. Yes, Deepak Sharma was on the brink. His doctor on seeing his massive bedsores in 2015 had remarked 'He has no sacrum'.
- Even Deepak Sharma had not believed he would sit and sit safe; bedsores had ravaged him so badly, and he had access only to bad treatment till late 2015. His is a journey of the triumph of hope.

Deepak has received outstanding support from his peers, Gajendra Negi and Shailesh Kumar. His mother has been a pillar of support. Local knowledge and perseverance helps create livelihood options. This is the type of rehabilitation we are always happy to support.



Charpoy Alone for 14 Years



Facebook opened the window of hope. A name that had 'spinal injury' as part of it, but badly spelt, was enough to raise an alert.

A quick chat was followed by a phone call. The story of Arul Mahesh (name has been changed to ensure anonymity at the request of the person), a young man, captures the state of persons with spinal cord injury in India.

Most of them are confined to a bed, a house, unaware of rehabilitation and often subjected to bad treatment. All that Arul Mahesh knew for 14 years was a tattered charpoy and the support of his mother who had no clue of what to do. She took good care.

He was on the *charpoy* in the room. On the rare occasion he came out of the home, his *charpoy* was carried out. He did not have a wheelchair. He is now happily rehabilitated and become fully independent. Arul Mahesh is exploring livelihood options at his village.

What stands out is the fact that he survived 14 years despite a weakening body due to secondary complications imposed by lack of proper and timely training. It points to at least one source of good support; in his case, it was his mother.

Ferreting out the many such as Arul Mahesh is as much of a challenge as getting to know the newly injured in a timely manner.

Message India Spinal Cord Injury Registry is a must to keep track.

We will be with Arul Mahesh, as he looks at life beyond the charpoy.

A First by Annalakshmi



At The Wipro Chennai Marathon 2017, Annalakshmi became the first lady in India to do 10 kilometres without assistance. Unlike earlier years, when she took assistance and finished with fatigue, this time she was all energy at the finish. This is reflective of the determination shown by her for 12-plus years now.



The PRAJWAL LAMA Message



NEVER again: 'Rehabilitation first, bedsore management later'

Young Prajwal Lama, a wondrous tattoo artist who had a design studio in Darjeeling before his spinal cord injury about three years ago, passed away due to the damage inflicted on him twice over by a `doctor of repute'.

The illogical and foolhardy emphasis on rehabilitation ahead of bedsore management, the first of which happened in the early months after his injury, and was again repeated a year later, effectively left Prajwal with a life-threatening condition.

We had never imagined Prajwal would not have that design studio again. And our Founder, Vaidy, had never ever imagined that he would be bidding goodbye forever to him at the Chennai Egmore Railway station one day in 2017.

Let nobody else fall a victim to improper priorities in rehabilitation. Let the proven Best Practice of 'Absolutely no sitting and no sittingbased activity / training till the bedsore heals' be followed uniformly by hospitals and rehabilitation centres in India.

Going through his WhatsApp chat history with Prajwal, Vaidy was struck by his repeated wish to 'do something for persons with spinal cord injuries in Darjeeling.' He clearly did not want a repeat of his experience.

Prajwal managed to pull on only thanks to his girl friend, a group of dedicated volunteers and a bed in a Darjeeling hospital. His parents had abandoned him soon after his injury.

Hats off to Team WHO CARES, a volunteering group, that did its very best to give Prajwal every possible chance. Thanks to Prajwal, we now work with WHO Cares to build awareness on injury prevention, spinal cord injury and rehabilitation in West Bengal and Sikkim.







Salute Sabin Syangbo

Even as Prajwal Lama languished without family support, there was no shortage of volunteers to care for him. Sabin Syangbo travelled with him to Vellore and had to handle his death at the Howrah Railway station. It was touching to see the way Syabin took care of Prajwal Lama. Deep respect for his work.





Active LIFE after 19 Years



Quality Rehabilitation restores Active LIFE,18 years after a spinal cord injury Paramjeet is paralysed neck down. She could not sit erect even for a few minutes. Six months of Quality Rehabilitation enabled her to sit. She moves independently using a motorised wheelchair and has started teaching.

A simple girl from a village of Hoshiarpur, Punjab, Paramjeet Kaur (Param) is now 50. Daughter of a farmer, Param was married at an early age. Her husband hailed from Mumbai.

With dreams in her eyes and the excitement to be in the `City of Dreams', Param's happiness knew no limits. Soon, a few harsh realities of her husband left her shattered and led to separation. With the wounds of her divorce and two young boys to take care of, she shifted to Pune and took to tailoring.

With tears in her eyes, Param recounts the events of the fateful day of 1998. She was on her way to Mumbai to get stitching material. The Maruti van in which she was travelling had an an accident injuring her spinal cord. Param opened her eyes to a life in which all her movements below her neck had ceased. A never ending search for treatment began. Not finding any solution after consulting various doctors, Param accepted her destiny and stayed at home, lying on the bed like a log.

Due to neglect, the body had developed contracture and life had become an endless routine of changing wet and soiled sheets, as she had no bowel and bladder control. Luck smiled at her almost after eighteen years, when she met Nicky Pavan Kaur, the founder of Chandigarh Spinal Rehab, and was brought there in July 2016. Param's treatment and rehab at Chandigarh Spinal Rehab has brought back hope in her eyes.

Param smiles and tells, "For 18 years, I had not seen anything except the ceiling of my house. Now, with therapy, I can sit on the wheelchair and enjoy nature's treats. I have also travelled by car and been a part of a few rallies. I can also manage my bowel and bladder, sit straight, brush my teeth, eat with a specially designed spoon and propel my motorised wheelchair. I know, my struggle is long, but with care and support, life will be exciting and worth living."

Exemplary Support, Worthy of Emulation

For Chandigarh Spinal Rehab, ICICI Bank set an example in creating a support system to take care of compensation for a high-quality therapy team for two years as of now. This is funding of essential soft skills. We deeply appreciate the understanding shown on the importance of therapists in Quality Rehabilitation.





Support for the children



Edward Sigamani uses his two functioning fingers to make a living by doing mobile recharge and bill payments from his bed. He was left without rehabilitation due to poverty. A chance meeting with the Social Worker of the Dr Mary Verghese Institute of Rehabilitation, and an excellent set of committed supporters helped lift his life.

We have been part of his journey in becoming financially independent.

Children of persons who are paralysed neck down and come from economically challenged background tend to struggle more. This is the most vulnerable group for which The Ganga Trust wishes to have support systems in place.

Towards this goal, Immanuel and Jenitamary, children of Edward and Parveen, get complete support for their schooling. We plan to make this a special project that will be rolled out in the next two years.



A stunning transformation



When Parthasarathi had his rehabilitation a few years ago, it appeared he would never sit comfortably. His legs were straight and stiff, and he used to be precariously perched on the wheelchair. Slowly the tide turned, and once he could sit, there was no stopping this young lad.

In three years, he has developed well in sports – marathons and wheelchair basketball. His skills have developed so much in wheelchair basketball that, in early 2017, he led the first India Under-23 Wheelchair Basketball Team to go to an international championship.

He has also made it to the elite group selected for the men's national level camp. The good aspect of Parthasarathi is that he has not been focussed just on sports. He has joined his graduation and works constantly on developing his communication skills.

We stay committed to his supporting his excellence in sports.



India Spinal Cord Injury Registry

If we are to avoid the traumatic tales of Prajwal Lama, Arul Mahesh and Paramjeet Kaur, the most important need is the establishment of an India Spinal Cord Injury Registry. This must be mandated by the government to ensure every spinal cord injury is promptly reported and captured for follow-up and guidance.





At home with a talented dancer

It was a home visit that will forever stay in my mind. It may be tough to think of a more inaccessible environment. On the outskirts of Kolkata, amid piles of dirt, water and rubble, it was a colony of homes with a pathway ridden with every imaginable hurdle.

My wheelchair had to be carried and then wheeled in a slanted position to navigate the terrain leading to the home of an outrageously talented dancer, Akash Sardar, who is paralysed neck down; he had modest hand movements while undergoing rehabilitation at Dr Mary Verghese Institute of Rehabilitation.

Before his injury, Akash, now 17, was a dancer and choreographer with dreams of making it big. He withered for a few months once he went back home. Then he started training a friend from his wheelchair.

Soon he was dancing on his wheelchair. He has been part of a few TV shows and is getting recognition.

What was interesting was that his effort at dancing and systematic practice in front of a mirror appears to have enhanced his strength, fitness and hand movements. Young Akash may be sending out a message to rehabilitation professionals on the value of dancing in recovering, at least partly, lost hand and finger function.

Akash hopes to make the most of his skills at dance. He will complete his schooling by 2019. Dancers Got Talent is a major group at the world level. We hope to link him - S Vaidyanathan, Founder, The Ganga Trust.



Naresh, Class II, but at work now



We came to know about Naresh Sundararaman from a network partner in Dubai. As we planned a home visit, trepidation on what shape we would find him in was foremost in our mind. It had been almost 25 years since he quit school after Class II.

Brittle Bone Disease, a rare condition, that causes fractures galore due to falls affects Naresh. The fear of fall and fractures is what ended Naresh's schooling. A supportive family has helped him not just survive, but also develop computer skills, photoshop and a basic ability to develop his own banners.

He proudly showed his self-made Facebook cover image. By reading newspapers and watching cricket on TV, Naresh picked up a modicum of communication skills and stayed in touch. His fear of falls is intact. His physical growth has been stunted. A good wheelchair was suggested and he has started going out at last.

At The Wipro Chennai Marathon 2017, he took part for the first time and pushed his wheelchair for 6 of the 10 kms. His dad got him over the Finish banner. For his parents, it was a vindication of the excellent support provided to Naresh for long years without an idea of what to do to get him forward.

His computer skills have enabled the creation of work from home. He handles support services for The Ganga Trust as the first in our Wheels At Work project. It is going to take much training to develop his skills in the context of work. We are determined to do our best to empower him.

Wilderness to Marriage



Sivakumar was stuck inside his home for 12 years before he received Quality Rehabilitation. He has moved on wonderfully in life. His marriage was an occasion of great joy, as we have travelled with him in his battles for a few years. This turn of events is also a rich reward for the persistence of his mother.



Impact Inclusion Role Model



Shailesh Kumar has been engaged as a roving Pan-India Inclusion Role Model for persons with spinal cord injury. Shailesh is based out of Chandigarh Spinal Rehab where his presence as part of the therapy team has led to significant impact on persons undergoing rehabilitation.

Shailesh has worked extremely hard on not just his fitness and strength, but also developing expertise in Living Well with Spinal Cord Injury. Hailing from a small village near Gaya in Bihar, Shailesh's work touches the lives of at least 1,000 persons (and counting) with spinal cord injury in various ways. Thanks to his travels across India, Shailesh brings rich insights from the grassroots level and empowers lives. He is at hand to guide those who are stuck in remote parts of India and not knowing how to deal with the challenges of living with spinal cord injury.

The impact that Shailesh has had on people with spinal cord injuries is immeasurable. He is the life of any sporting event or networking meeting of persons with spinal cord injury. He is a bundle of energy, who can maintain the same intensity from 4.30 AM to 11.00 PM or more. Shailesh gives extensive time to persons with spinal cord injury in meetings, via tele-calls, WhatsApp and Facebook. In 2017, at least five persons with spinal cord injury get guidance from him on a daily basis, and this is an increasing number.

A View on the IMPACT of Shailesh



"Shailesh is an inspiration to every person having a spinal cord injury regardless of his or her injury level. He is always available for advice or help anytime and he will never say no to anyone who needs his help. Most persons having spinal cord injury would think twice, and probably hesitate to travel as much as he does to spread awareness and share his experience. Shailesh is a person with a very positive approach. One special memory I have with him is when we all wanted to go for a movie in Chandigarh. Unfortunately at the last moment, the cab drivers refused to take us to the theatre and it was a very hot afternoon. The theatre was about four kms away. Shailesh with his enthusiasm convinced all of us to go there on our wheelchairs. He said "Sab chalenge aur jo nahi chalega mein usko utha kar le jaunga". On the roads, it appeared as if he was in charge of traffic control. When Shailesh is around, he is like a Dada, and then we also become Sher, thinking if he can do this, we can also try" - Paramjeet Kumar who received her first Quality Rehabilitation 18 years after her injury.

India's Fastest Half Marathon Runner on a wheelchair

At the Kotak Wheelchair Marathon 2017, Shailesh Kumar continued his remarkable progress in the Half Marathon. In nine months, he cut his best time from 2 hours 20 minutes to 1 hour 45 minutes 50 seconds. This is the fastest Half Marathon in India by a runner using a wheelchair.





Chandigarh Spinal Rehab Breaking Frontiers

Knowledge sharing, linkages with high-quality rehabilitation professionals, observation visits, networking across stakeholders, active role in governance, funding linkage and most importantly, empowerment of a high-quality therapy team are areas of support by The Ganga Trust since 2014.



Dive For Joy – scuba diving & swimming camp



Vocational Training – embroidery workshop



IIT Madras - expertise sharing



Udan - paramotoring event



Mouth Painting Training Workshop



Awareness Programs

World Spinal Cord Injury Day - September 5

The concept of World Spinal Cord Injury Day was pushed aggressively by The Spinal Foundation from August 2014. The idea gathered momentum. From 2016, September 5 is marked as World Spinal Cord Injury Day. Injury prevention and awareness is the main focus. The Ganga Trust is a key partner in India.



Kotak Wheelchair Marathon

Initiatives

Ankur Dhama, India's first Paralympic Blind Runner, gracing and finishing first in 10 kms, was the highlight of Kotak Wheelchair Marathon 2017, the second edition of India's only marathon organised by persons with disability.

Kotak Wheelchair Marathon is an inclusive event meant for one and all to run and featured a Half Marathon, 10 kms and 5 kms run.

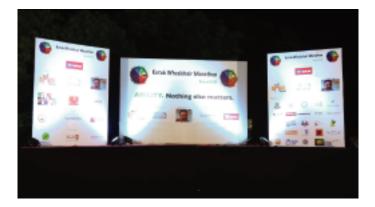
The event attracted about 1300 registrations. Race Day participation was about 850 runners, with absenteeism being slightly higher than normal due to the long weekend.

The surplus from the event will be used to provide good quality wheelchairs – manual or motorised – to persons with spinal cord injury across India.

Sushant Kumar Suna from Jharkhand, a prosthetic leg user, ran his first Half Marathon (21.1 kms). Kamal Kanta (Odisha) and Rajeev Prasad (Bihar) also did their first half marathons. For the first time in India, a unique exhibition of artwork by persons with disability was an integral part of Race Day in a marathon.

There were about 250 persons with disability who took part. Even if several of them took assistance, they also got the chance to see fellow disabled runners doing long distances without assistance.

Kotak Wheelchair Marathon will develop into a long-term franchise that will drive inclusion, quality assistive devices and empowered lives.



- Development of The Spinal Foundation, founded on May 26, 2014, as a robust platform stays a top priority for The Ganga Trust.
- Spinal India Helpline 1800 425 1210 for The Spinal Foundation received about 100 calls last year.
- Sponsorship of role of Head Programs of The Spinal Foundation has helped develop the organisation and glean grassroots insights.
- The Spinal Foundation was part of a three-month Social Cohort at N S Raghavan Centre for Entrepreneurial Learning at IIM Bangalore.
- Crowd funding campaign raised funds needed to buy a World-Class Racing Wheelchair for Shailesh Kumar and learning by therapists.
- Expertise sharing, pilot trials and networking were organised for quality mobility solutions under development at IIT Madras.
- kNOw Bedsore, a project by Paul Joshua, Alumnus of CMC, Vellore and NID, Ahmedabad, was selected by India Inclusion Foundation.
- Johan Dhinakaran, Inclusion Leader of The Ganga Trust, championed kNOw Bedsore and participated in the India Inclusion Fellowship.
- Wheelchair distribution camps at Nav Jivan Hospital, Satbarwa and Broadwell Mission Hospital, Fatehpur were partly supported.
- Participation of Ankur Dhama, the first fully blind runner to take part in the Paralympics, at Kotak Wheelchair Marathon was facilitated.
- Support was given to the sports team of St Louis Institute For The Deaf & the Blind, Chennai. The football team won the Nationals.
- Awareness programs on injury prevention and spinal cord injury were conducted by The Ganga Trust team at various places in India.
- *Wheels At Work* will offer employment for persons with spinal cord injury. Naresh Sundararaman is our first at Wheels At Work.
- Dr Mary Verghese Award recognises Excellence in Empowering Ability, and has a stellar roaster since its launch in late 2011.
- Extensive support provided for a wheelchair basketball camp in Odisha and the state team to take part in National Championship.

Viral Impact - Justin Vijay Jesudas

Kotak Wheelchair Marathon is the brainchild of Justin Vijay Jesudas. And a video made by Suryan FM on Justin for the 2017 event went viral. It has close to two million views and has been shared 4500-plus times. If you wish to know how active life can be with spinal cord injury, just Google RJ Ranjith & Justin Jesudas.





Giving Back Class of 1992 IIM, Bangalore Gratitude & Thank You







It has been a blessing and privilege for The Ganga Trust to have backing from the alumni of Indian Institute of Management, Bangalore (IIM - B)

Year 2017 was the 25th Year Reunion of the Class of 1992, the batch with whom S Vaidyanathan, Founder of The Ganga Trust, completed his MBA program at IIM - B. The Giving Back program of the Class of 1992 has given a solid platform for The Ganga Trust to do significant impact-making work.

In addition to The Ganga Trust, the Class of 1992 has also funded two projects at IIM-B. The Giving Back Program led to the largest collection so far in the history of reunions at Indian Institutes of Management.

The Ganga Trust has proposed three projects for Class of 1992 Giving Back:

Right Wheelchair Program - Bad wheelchairs that damage health dominate the market in India. In a bid to change the landscape, Right Wheelchair Program has been launched. This will provide quality wheelchairs to 400 persons with spinal cord injury, and more if backed by sponsorship.

Impact: 400 Lives

Therapy Hall Support – We are working with Thee Trust led by Dr Abhishek Sanyal, a young physiatrist passionate about rehabilitation, for a rehabilitation facility near Bhubaneshwar in Odisha. 25% of the funds will be used to fund a no-frills but functionally effective therapy hall.

Impact: 540 Lives over a five-year period

Rehabilitation Knowledge Base: This will be a Rehabilitation Platform that will offer guidance for post-injury rehabilitation training and also ongoing 24 x 7 healthcare guidance, as the effects of spinal cord injury are lifelong. Training resources will be delivered in multiple languages and formats.

Impact: Several-hundred lives a year

The funding needs outlined for the three projects at about Rs 1.6 crore have been covered by pledges by the IIM - B Class of 1992.

In addition, several members of the Class of 1992 have offered to support the vision of The Ganga Trust in non-financial ways. A few of them are already playing a major role in refining the work of The Ganga Trust.

This support is a landmark for The Ganga Trust. We are deeply grateful for the support through the Giving Back program of the IIM - B Class of 1992.

The Jaskaran Singh Impact at IIM, Bangalore & Beyond

2016 was an enriching journey as Jaskaran Singh, paralysed neck down, became the most physically challenged person to secure admission to an IIM. Now at IIM Bangalore, Jaskaran's example has led to three more persons with spinal cord injury making to the top three IIMs in 2017.





Sexual Harassment Needed Safe Therapy Code

Embarking on the work of The Ganga Trust in the space of spinal cord injury in 2009, we never imagined that we would have to get involved in dealing with sexual harassment in the course of therapy of persons grappling with life-altering conditions and multiple disabilities.

It is impossible to even think that a person dealing with a recent injury that has led to multiple disabilities at one stroke can be subjected to sexual harassment. Yet it is, sadly, reality.

It was traumatic to sit and listen to a highly-educated girl from the East of India narrate the abuses she suffered at the hands of a therapist. For 20 minutes, a group of 10 of us sat there dumbstruck listening to the girl who could not hold back tears.

You people forget about rehabilitation. First ensure that we are not subjected to sexual harassment during or in the garb of therapy. Finally, I just walked out despite my acute disabilities. The peroid of three months was a waste. It only added additional trauma in my mind'.

She was a knowledgeable girl who was able to, after a while, figure out what was going on. There are several who do not do so. That is not a surprise.

In another instance, we came across a senior therapist with a track record of patient abuse for about eight years. Several therapists and students of therapy – male and female – who have worked with him have also noted his shenanigans. Patients & relatives have also complained to other therapists.

In this case, abuse appeared to be at two levels:

- It feels crass to even write this out, but selecting `good-looking' patients appeared to be the first stage.
- Subjecting them to needless touches, movements and words during therapy was the second stage.

These are just two of the several instances that came to our notice while dealing with the case.

We have consulted with senior and knowledgeable women with spinal cord injury and medical professionals. Their uniform view: `We must take a tough stance and put an end to such practices that add to trauma and make rehabilitation meaningless'. The Ganga Trust, in partnership with The Spinal Foundation, will bring out a Best-Practices Guide for Therapists & Patients in 2018 to prevent sexual abuse.

A large proportion of therapists work in a sensitive manner. We respect and are grateful for their work. But depraved therapists must be stamped out.



`The Dangers of Wilful Blindness'

"What I've found going around the world and talking to whistleblowers is, actually, they're very loyal and quite often very conservative people. They're hugely dedicated to the institutions that they work for, and the reason that they speak up, the reason they insist on seeing, is because they care so much about the institution and want to keep it healthy.

And the other thing that people often say about whistleblowers is, "Well, there's no point, because you see what happens to them. They are crushed. Nobody would want to go through something like that." And yet, when I talk to whistleblowers, the recurrent tone that I hear is pride".

Margaret Heffernan, a Management Thinker and Author of `Wilful Blindness' in a TED Talk in 2015

Code of Physiotherapy New Zealand - A Marker for India

Quote The physiotherapist to patient relationship is not one of equality. In seeking assistance, guidance and treatment, the patient is vulnerable. Sexual exploitation of the patient is an abuse of power. Sexual contact of any kind with patients / clients is unacceptable. *Unquote*





Pushing Pledges Seeking Enhanced Footprint of Impact



Dear Friend,

At The Ganga Trust, we continued to push ahead with our focus on rehabilitation in 2017. In the eight years of work, we have touched 3,100 + persons with spinal cord injury across India and have put at work Rs 4.27 crore cumulatively.

From a one-man shop in 2009, we now have an outstanding team of 10, including four in a purely voluntary capacity. A core team of volunteers augments the Inclusion Team. The expanded Inclusion Team has and will enable us to reach more lives with quality rehabilitation initiatives, support and experience sharing sessions.

We continue to spend a significant proportion of the amount raised towards rehabilitation and related areas. We are happy to note that nearly one-sixth was defrayed towards Chandigarh Spinal Rehab, which has become a welcome high-quality addition to the rehabilitation landscape in India in just 18 months.

As a purely volunteer-driven organisation till May 2016, we have maintained overheads at 3.3% of total value of work till July 2017. As we build a team to drive our work, our target would be to be operate at a 90 : 10 structure over the long term; we may exceed the 10% cap in the next couple of years, as we upfront the needs of team building.

We have invested the corpus donation and funds pending deployment in accordance with the guidelines framed by the Investment Committee. We are doing the spadework to deploy the pledges made by the Class of 1991 and Class of 1992 of IIM, Bangalore in specific projects.

As outlined in our Founder's Message by Vaidyanathan Singararaman (Vaidy) and Roadmap for Transformative Impact, our aspiration is to expand the scale at which we operate in an accelerated manner. We need a significant scale up in fund raising in the next three years under special pledges, 100 Lives and the broad banner of The Ganga Trust.



Bhushan Gopalani beat back the lost years after a spinal cord injury and a delayed rehabilitation to forge ahead in pursuing his academic dreams. He landed an admission at Indian Institute of Management, Kolkata. The Ganga Trust is happy to be a part of his long journey. We thank IIM - C for making accommodations for Bhushan's special needs.

The overall leadership for the Inclusion Initiatives continues to be under Vaidy, while Justin Vijay Jesudas and Shailesh Kumar have significantly enhanced their contributions to strengthen Vaidy's hands.

Over the past 18 months, we also noted with shock and concern the prevalence of Sexual Harassment in the field of therapy for persons with disabilities. We have taken a firm stand, raised our voice and seek your support to root it out in rehabilitation across India.

We sincerely thank you for your support in 2017. As we prepare to look at a larger footprint of work, we seek your support and pledges in the years ahead. We also place on record our appreciation and gratitude to 100-plus volunteers who play a vital role in our work.

We wish you a Merry, More Inclusive 2018!

Soresh

Suresh Krishnamurthy Managing Trustee The Ganga Trust

Thank You Anumeha, Our First Employee

We were privileged to have Anumeha Srivastava as the first employee of The Ganga Trust. She worked with us for about 11 months. She is pursuing her MBA program at Indian School Business. We are acting on her feedback - `amazing energy & ideas, resourceful, but structured approach and robust processes are must'.





The Governing Board



Elango Thambiah Alumnus, IIM Bangalore Founder, The Ganga Trust



Suresh Krishnamurthy Finance Professional Managing Trustee



Vaidyanathan Singararaman Alumnus, IIM Bangalore Founder, The Ganga Trust



Nath Balakrishnan Alumnus, S P Jain, Mumbai Founder, The Ganga Trust



Amrutha Rajagopalan Alumnus, NID Ahmedabad Trustee



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Vidya Subramanian Asian College of Journalism Trustee





Dr Suranjan Bhattacharji Gandhian & Physiatrist Rehabilitation Leader



Dr Guru Nagarajan Community Work Expert Social Worker



Parakkal Unnikrishnan Carnatic Musician Goodwill Ambassador



Rasheeda Bhagat Rotary News & The Hindu Writer & Media Specialist



Sunil Gautam Founder, Pitchfork Partners Branding & Marketing



W S Ravishankar Banyan Tree Advisors Start-up Specialist



Ramakrishnan Subramanian Founder, Sports Mechanics Analytics, India Cricket Team



Inclusion Team



Justin Vijay Jesudas Leadership, thinking & ideation, resources networking, project planning, awareness



Leadership, networking, experience sharing, ideation & planning, oversight



Shailesh Kumar

Therapy coordination, Pan-India roving peer mentor, wheelchair skills trainer, networking



Johan Dhinakaran

Projects - planning & coordination, peer organisations networking, CSR preparedness



Kannadasan

The Spinal Foundation, networking, outreach, rehabilitation facilitation, awareness



Ganesan Nagarajan Local language project coordination, 100 Lives, Spinal India Storyboard



Dastagir Mohammed Fasihuddin

Amputee networking, inclusive marathons, donor management, back-end coordination



Kotak Wheelchair Marathon, 100 Lives, event management, outreach, social media



Meera Srinivasan Banking, management of spending, record keeping, documentation



Inclusion Team - Support

Ashish Giri Occupational Therapy & Outreach

Karthickeyan Gopal Artwork & Page Making

Naresh Sundararaman Support Services

Prahalad Bhatt Legal Advisor

Sunil Raj Physical Therapy

Venkataramani Accounting Advisor Ganesh Murugan Support Services

Nandini Mohan Rao Editorial Support

Paul Athisayaraj Joshua Design

Sarveshwara Narayanan K R Design

Vasanth Sampath Banking & Access Custodian

> Vijay Prasad Compliance

Investment Committee

Ashwini Agarwal Class of 1992, IIM – Bangalore Wealth Management

> W S Ravishankar Class of 1993, IIM – Bangalore The Advisory Board- The Ganga Trust

Sanjay Santhanam Class of 1991, IIM, Bangalore Financial Advisor

> Suresh Krishnamurthy Director, CRISIL Managing Trustee, The Ganga Trust

Executive Committee

Imran Khan Student, Jamnalal Bajaj Institute of Management Studies Peer Mentor

> Justin Vijay Jesudas Associate Director, Cognizant International Paralympic Swimmer

Alumnus, S P Jain, Mumbai Founder, The Ganga Trust

Nath Balakrishnan

Vaidyanathan Singararaman Class of 1992, IIM Bangalore Founder, The Ganga Trust

Pillar of Support for Amputees

We are proud to have Dastagir Mohammed Fasihuddin in The Ganga Trust Inclusion Team. His work at The Ganga Trust is only a minor part of his story. Dastagir is the backbone for networking and integration of persons with amputation across India. His networking has built a 1400-plus self-help group.



We believe in Networking & Collaboration

Corporate

Accel Partners Aditya Birla Fashion & Retail **CL Educate** Delight Foods Eventjini Fuel A Dream FundsIndia Grand by GRT **HK Strategies** ICICI Bank IIMPOWER Kotak Group Letz Change Marathon Needs NeoMotion **Pitchfork Partners** Quantum Leap RAGE Scripbox Seed Design Studio E Sundaram Finance Group Sustainable Square Vindhya E Infotech WABAG

Rehabilitation

APD, Bangalore Broadwell Mission Hospital, Fatehpur Chandigarh Spinal Rehab Duncan Hospital, Raxaul Kauvery Hospital Nav Jivan Hospital, Satbarwa REHAB Facility in Tamil Nadu St John's National Academy Swami Vivekananda NIRTAR

Partners & Institutions Class of 1991, IIM Bangalore Class of 1992, IIM Bangalore IIM B Alumni Association IIM Bangalore IIT Madras

Awareness Partners Kamal Haasan Know Your Star Suryan FM The Better India The Hindu Group

Olcott Memorial School



Gratitude & Thank You

Social Sector Organisations Ability Foundation Chandigarh Spinal Rehab Chennai Runners **CRISIL Foundation** Dr Mary Verghese Award Foundation **Dream Runners** Enable India **ESCIP** Trust India **HeART Beat Foundation** ICICI Academy for Skills India Inclusion Foundation Let's Do Something Good Foundation Mary Verghese Trust **Polagam Foundation** SAVELife Foundation Spinal Injured Persons Association St Louis Institute for Deaf The Challenging Ones The Hope House The Spinal Foundation Thee Trust **Theosophical Society** Trinity Trust Vidya Sagar WORTH Trust

Get Involved. Reach Us

The Ganga Trust 203, 18th Street, Chowdhry Nagar Valasaravakkam, Chennai 600 087 thegangatrust@gmail.com • 0 98394 40883 • 0 96777 72031

Make Your Contribution

Bank: Corporation Bank Branch: Valasaravakkam, Chennai Account No: 520101039062887 IFSC Code: CORP0002085



Volunteers Recognition & Gratitude



Anuradha Narasimhan Mentoring



Floran Jayaraj Volunteering



Peter Van Geit Marathon Planning



Smita Vyas Kumar Creative & Fundraising



Dr Balamurali Medical Guidance



Gaurav Bakshi Film Making & Mentoring



Rohini Rathour Life Coach



Thomas Xavier Design & Mentoring



Bhanu Prakash Event Management



Neville Billimoria Marathon Planning



Sundari Thevar Marathon Planning



Vipul Kumar Marathon Goodwill Ambassador