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### **NINE YEARS** of

Empowering Persons with Spinal Cord Injury to Live Well



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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'. It exhorts people to always focus on doing what needs to be done rather than staying a hostage to the past.



### **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

Enabling Quality
Rehabilitation

Networking
& Peer Mentoring

Livelihood
& Inclusion



Annalakshmi was confined to home for about nine years since her impairment in 2002 amid a hostile neighbourhood. Networking and marathons led to community interaction. In 2018, she became the first female to complete 10 km without assistance. Independent living, national level sportsperson, education, wheelchair skills training, modelling, public speaking and peer training – she packs a punch. Her ongoing training at ICICI Academy of Skills would enable livelihood.

Enabling lives in the same way as Annalakshmi underpins the work of The Ganga Trust.



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### Highlights 2018

### **Acts of Support**

45,500 +

**Conservative basis statistic for 2009-2018** 

### **Lives Touched**

5,000 +

Conservative basis statistic for 2009-2018

### **IIM Bangalore Distinguished Alumnus Award**

The work of The Ganga Trust received a cherished recognition, as IIM Bangalore conferred the IIM Bangalore Distinguished Alumnus Award 2018 on S Vaidyanathan, Co-Founder of The Ganga Trust. He is the first Alumnus with disability at any IIM to be recognised for work in the social space.



### **U.S. Global Sports Mentoring Program**

Justin Jesudas, Inclusion Director & Thought Leader at The Ganga Trust, was one of the 17 from across the world selected for the prestigious Global Sports Mentoring Program, an initiative of the U.S. Department of State. Justin, paralysed neck-down, is an International Swimmer & Rifle Shooter.

### **kNOw Bedsore - Early Intervention & Detection Grant**

Paul Athisayaraj Joshua, an Alumnus of Christian Medical College, Vellore and National Institute of Design, Ahmedabad, had his course project kNOw Bedsore selected Early Intervention & Detection Program Grant by United Way Chennai for extensive roll-out in Tamil Nadu.









### Content

Inclusion Impact - Insights

Thought Leadership

Value of Work

Founder's Message

Roadmap & Progress

Call To Action

Rehabilitation Experts Board

Managing Trustee Report

Spinal India Storyboards

Peer Support Program

**Best Minds Summit** 

Sports & Kotak Wheelchair Marathon

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### **Acceptance Speech - Highlights**

**IIM Bangalore Distinguished Alumnus Award 2018** 



**Dedication** "You will be able to go back to study at IIM Bangalore" - I was thrilled to hear this possibility from an extraordinary human being 28 years ago soon after my spinal cord injury. I was ecstatic when he made it a reality.

I dedicate the IIM Bangalore Distinguished Alumnus Award to Dr Suranjan Bhattacharji, a Gandhian who has shaped spinal cord injury rehabilitation in India, and the former Director of Christian Medical College (CMC), Vellore. His vision underpins everything I do.

**Moving ahead to live well with spinal cord injury** My journey with spinal cord injury was made easy by my Amma's philosophy `Aaghavendiyatha Paaru' – always look ahead. "Would I at least be on a wheelchair?" was my only question to the doctor, an hour after the injury.

It didn't matter that I didn't have the ability to walk apart from losing bladder control and bowel control. Complete loss of sensation below the chest, impaired sexual ability and the spectre of secondary complications lifelong did not either. 'Why me?' never crossed my mind.

**IIM Bangalore** Today, IIM Bangalore offers world-class inclusive education and the best in India. Nothing exemplifies this better than the experience of Jaskaran Singh, Class of 2018, paralysed neck down, and the most disabled person to grace any top academic institution.

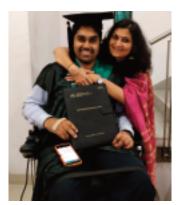
His every need was taken care with an eye for intricate detail. An enabling approach has nurtured 120-plus Alumni with diverse disabilities. Imagine the transformative impact if this model is replicated across India in every school, college and workplace! - S Vaidyanathan

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### **Highlights 2018**

- 7,600-plus acts of support provided to persons with spinal cord injury touching 1500-plus lives in 2018, including 100-plus home visits.
- Team building with diverse skill sets was foremost with an emphasis on engaging persons with spinal cord injury to be peer mentors.
- The formation of a Rehabilitation Experts Board is to ensure best-in-class guidance for the projects of The Ganga Trust and The Spinal Foundation.
- Wheelchair users Shailesh Kumar and Prabaharan travelled extensively across India and Tamil Nadu respectively to share experiences.
- Best Minds Summit, a first-of-its-kind initiative organised by The Spinal Foundation to chart strategy, was completely backed by The Ganga Trust.
- Kotak Wheelchair Marathon 2018, had a 80% rise in runners to 1,500-plus, was well received and also enabled funding for at least 100 Quality Wheelchairs.
- Touch Rehab, a comprehensive rehabilitation knowledge base supported by Class of 1992, IIM Bangalore, is work in progress with core team partnerships in place.
- Partnerships were forged with Chennai Runners and RRD, a Fortune 500 company, for development of sports for persons with disability.
- NeoMotion, an IIT Madras start-up, has developed world-class indoor and outdoor mobility solutions for wheelchair users. The Ganga Trust is a partner.
- 10 Chandigarh Spinal Rehab, backed partly by resources and extensively with expertise, is recognised as one of the top 3 health care providers in Punjab.







Jaskaran Singh graduated from Indian Institute of Management, Bangalore in 2018. He is the most physically challenged person to pass out of any top academic institution. Dr Divya Parashar (left image) and Padya Jamatia (right) played pivotal roles in this journey that we were blessed to be a part of.

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### **INCLUSION IMPACT** Leap in Lifestyle

In 2018, persons with spinal cord injury who have been guided and supported by The Ganga Trust in the past years moved further ahead in life. This is important, as it serves as a reference for other persons with spinal cord injury to lead a meaningful life.



Deepak Sharma Happily married and owns a larger shop



Manoj Kumar State-level medallist in rifle shooting



Parthasarathi Giant strides in wheelchair basketball



Trainer for persons with spinal cord injury in Odisha & sportsperson



Rajesh Vinil Starts a job with HSBC, Visakhapatnam



Amit Malhotra Admission to IIM Bangalore in 2018

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### **INCLUSION IMPACT Illustrative Examples (2009 - 2018)**

9,400 +

Experience sharing - individual sessions

2,000 +

Persons guided at rehabilitation stage

260 +

Home visits



3,800 +

Experience Sharing - participants in group sessions

29

Restoration of acutely damaged lives

19,700 + Tele-guidance to live well with spinal cord injury, including repeat callers

200 +

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

450 +

Mobility aids

275 +

**Enabling livelihood** 



1+3 (Pipeline)

Facilitation - Quality Rehabilitation Centres

Work in 2018 - Spinal Cord Injury 7,500-plus Acts of Support

Type of Work	Total
Rehabilitation & Experience Sharing	658
Mobility, Livelihood, Education, Sports	305
Networking Meets	354
Ongoing Guidance & Knowledge Sharing	4,800
Networking & Guidance in Amputation	1,222
Support opportunities in other disabilities	290

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### **INCLUSION IMPACT Lifestyle**

- I made my first income 15 years after my spinal cord injury.
- 2 The day before his death, my father expressed joy that I had a job.
- I struggled for four years after injury. I work for a multi-national now.
- 4 I never imagined I would do an MBA in a top B school. But I do.
- I watched a movie in a theatre for the first time in 24 years.
- Running a marathon on the wheelchair gave confidence in my ability.
- My personality also improved with training at ICICI Academy of Skills.
- My children are in school. I never imagined that when I had my injury.
- I am bringing more persons with spinal cord injury outdoors now.
- I am married. I hope to be a dad soon. I was close to death in 2015.
- I am sitting after seven years after multiple bedsore surgeries.
- 1 go daily to my factory. I do a full day's work. My business is growing.

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### **INCLUSION IMPACT Thought Leadership**

Since 2009, The Ganga Trust drives focussed initiatives towards accomplishing the vision of enhancing quality of life of persons with spinal cord injury. Each of them has shaped well though the journey ahead is long and arduous.



The Spinal Foundation

Pan-India self help group for persons with spinal cord injury



Best Minds Summit

Core 20-member group to chart strategy in the spinal cord injury space

### **Spinal India Helpline**

1800 425 1210

24 x 7 Support In place since 2010 with 1,000-plus callers in about eight years



Chandigarh Spinal Rehab Spread of Quality Rehabilitation Expertise



Dr Mary Verghese Award Excellence in Empowering Ability



Kotak Wheelchair Marathon Enable. Empower. Enrich Lives.

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### **INCLUSION IMPACT Outreach Work**

12 Peer Mentors and two social workers in The Ganga Trust Team have significantly expanded the footprint of outreach work. Their impact will be reflected in a more pronounced way from 2019, as they settle into their roles.

Peer Mentor Program Team now reaches out to about 12 persons with spinal cord injury every day. This will keep rising in the years ahead.





94 Home Visits in 2018 enabled get a first-hand view of reality & needs and reach appropriate support. For many, the visit opened new vistas.

132 persons receive quality wheelchairs in 2018. We intend to expand the reach of our programs across India in 2019.



**Day Out for Cleanliness Champions of Chennai** 

The Ganga Trust Team at Work

Prabu, helped Aarti Madhusudhan, Governance Counts, and team to conduct a day out for Cleanliness of Chennai (Corporation workers) at four locations – a day of fun, food and gratitude. Supporting this initiative was just another day in the office for Prabu, as he has anchored several good causes since 2011.



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### **INCLUSION IMPACT Expertise Sharing**

The Ganga Trust Team offers extensive expertise sharing for specific projects in rehabilitation, mobility devices, para sports and accessibility as well as facilitating networking and user testing across the country for products that could alter lifestyle.

### **Empowerment**

- IIT Madras
- · IIM Bangalore
- ISSICON 2018





### Rehabilitation Capacity

- · Chandigarh Spinal Rehab
- · APD, Bangalore
- Chennai & Odisha Rehab projects

### Social Space

- United Way Chennai
- Polagam Foundation
- · Chennai Runners



**Inclusion Director** 

The Ganga Trust Team at Work

Imran Khan, an alumnus of Jamnalal Bajaj Institute of Management Studies, an engineer and an entrepreneur / freelancer in digital media for eight years joins as Inclusion Director of The Ganga Trust from January 1, 2019 to drive key projects. Imran brings best practices of living well with spinal cord injury.



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### **INCLUSION IMPACT Breaking Frontiers**

Persons with spinal cord injury are starting to live way beyond the comfort zone despite attitudinal and architectural barriers imposed by society. Here are a few such initiatives supported by The Ganga Trust working with like-minded partners.

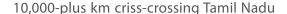
### Scuba Diving in the Open Sea

This was a first-time experience for 10 persons with spinal cord injury as partner with Chandigarh Spinal Rehab & Adventures Beyond Barriers Foundation.



Full Marathon on Wheelchair

Shailesh Kumar became the first wheelchair runner in India to do the full marathon (42.195) km with a timing of 3 hours 44 minutes in his maiden attempt.



Prabaharan, a Peer Mentor in The Ganga Trust Team, travelled 10208 km by bus, train and auto and visited homes of 42 persons with spinal cord injury in 2018.





88.2 km on Independence Day 2018

The Ganga Trust Team at Work

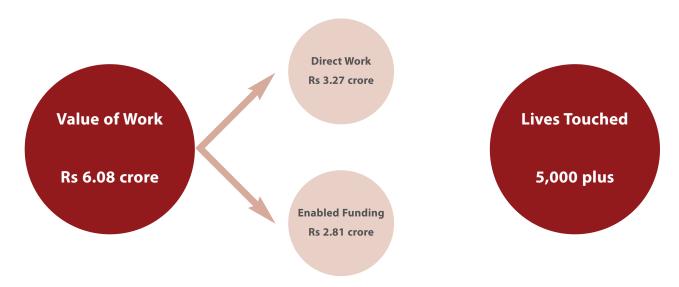
`Till I met Shailesh bhai in August 2016, I thought only death was left in my life' – the same Kamal Kanta has come such a long way that on August 15, 2018, he started from Olatpur at the stroke of the midnight to Puri via Konark on the wheelchair along with Prashanta Nayak – 88.2 km non-stop in 12 hours.



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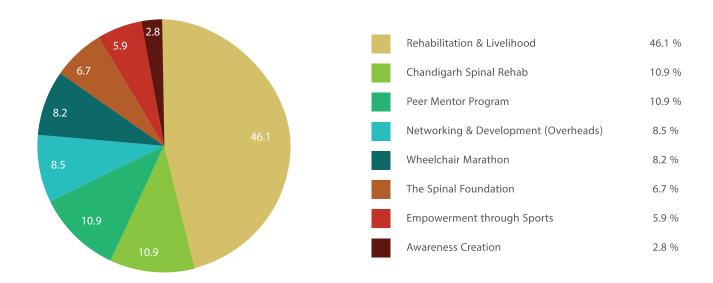


### **INCLUSION IMPACT Value & Flow of Work (2009-2018)**



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 2018 is based on audited accounts, and the bank statement for 2018.

### **Direct Work Flow of Each Rupee**



What We Do

New Injury Guidance
Assistive Devices
Livelihood, Education & Sports Support
24 x 7 Guidance

Facilitation of Rehabilitation Peer Mentors & Skill Trainers Experience Sharing Networking Mobility Aids Home Visits Awareness Creation Rehabilitation Infrastructure

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### **Roadmap Transformative Impact**

Centre for Rehabilitation Excellence This is the most aspirational and ambitious project on our radar - a facility to serve as the benchmark for training to live well with disability.

*Spread of rehabilitation expertise* We will work with partners with good credentials to enhance rehabilitation capacity in India. Chandigarh Spinal Rehab is in place since 2016.

*Back Up India* This will be a structured grassroots program underpinned by the enriching experience of Shailesh Kumar and Prabaharan. We will expand to a team of 20.

Expanded footprint of networking meets A key project will be to encourage anchors hold meets of persons with spinal cord injury in their hometown and one nearby district.

*Rehab Plus Model* Peer training centres, which are also more affordable, can provide holistic training that enables active living.

The Right Wheelchair Program 95% of users in India sit on bad wheelchairs that actually damage their health. We will work with partners, including IIT Madras and CSR programs.

The Spinal Foundation The most important project for The Ganga Trust is the facilitation of The Spinal Foundation with partners across India and making it a robust organisation.

Best Minds Submit As part of a systematic plan to understand the needs and map strategy, a Best Minds Workshop of about 20 persons with spinal cord injury is planned.

Rehab Knowledge Base This will be a well-structured evidence based rehabilitation resource with 24 x 7 guidance will be made available in multiple and vernacular formats.

Wheels At Work Given the wide-ranging expertise available in the ranks of persons with spinal cord injury, Wheels At Work will create employment opportunities.

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

Spinal India Storyboards This will be a systematic program of developing storyboards of persons with spinal cord injury from across India to serve as examples.

### Where We Are

Aspiration

Close to reality – Chennai; 2019. Odisha Rehab likely in 2019-2020.

Implemented - Phase I

Phased implementation in progress

Looking for peers to anchor

Support for IIT Madras Start-Up + Wheelchair Camps + Kotak CSR support

Implementation since 2014

First edition held in July 2018

Concept & partnerships in place

Pilot project under execution

Three pilot projects tried out

Execution mode - target 100 by 2019

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### **Call to Action**



Sponsor a wheelchair



Engage a peer trainer

### **CSR & Foundation Support**

Rehabilitation Facilities & Quality Therapists

# Rs. 20,000

Enable one-month rehabilitation

### Grants

Rehabilitation Knowledge Resources Project



Marathon experience for two wheelchair users

### **Content Writers & Film Makers**

Spinal India Storyboards Project

### **Photographers & Volunteers**

Programs across India

Get Involved. Join Us

The Ganga Trust 203, 18th Street, Chowdhry Nagar Valasaravakkam, Chennai 600 087

goodindian@gmail.com • 73388 00000 • 95030 70230

### **Make Your Contribution**

Bank Corporation Bank Branch Valasaravakkam, Chennai Savings Account No 520101039062887

IFSC Code CORP0002085

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### Co-Founder's Message



Dear Friend,

Quality Rehabilitation was the central theme of the message from The Ganga Trust last year, emphasising how it is in woeful short supply in India. Addressing this is the most pressing need in the disability space. Why and what can we do? To know why, we only need to look at basic numbers. India officially has about 28 million persons with disability according to the Census of 2011 – 2.21 per cent of the population. Even assuming this statistic as capturing the reality accurately, only a small fraction is in the community.

2.21 per cent does not represent reality. In 2012, Canada pegged level of disability in the population at 13.7 per cent.

As of 2016, 12.9 per cent of United States' population are persons with disability. World Health Organisation places disability in the world at 15 per cent. Talk to veterans in the disability space in India, they will tell you that the prevalence of disability in India is anywhere between 8-12 per cent. At the lower end of the band, we are looking at about 100 million persons with disability in India. For perspective, this number will make the disabled in India the 13th largest nation in the world. Disability is a massive hidden health issue in India.

Rehabilitation is a must in every disability. Our health system is based totally on a treatment-based model with little or no space for rehabilitation. Timely rehabilitation can help unleash the power of the disabled; even delayed quality rehabilitation is good enough. Why is it not happening?

- India is acutely short of quality rehabilitation professionals, especially doctors who specialise in rehabilitation and therapists. How many in India have even heard of Physiatry or Occupational Therapy? In rehabilitation, the role of a variety of therapists is more important than that of doctors.
- Education and training produces mediocre therapists with a place such as Christian Medical College, Vellore a rare exception. This issue with quality is akin to the situation in engineering education.
- Additionally, most therapists with good pedigree gravitate abroad, as it is an attractive career outside India. The degree of respect for their roles is also higher.

We have the power to change this crippling reality. Rehabilitation should be an attractive career option in India. Corporate Social Responsibility and Foundation programs that support good causes can drive this change. Funding soft skills – backing quality rehabilitation professionals – must be priority ahead of the obsession with funding physical assets (buildings and equipment). Buildings and hi-tech equipment do not make the disabled ready for the world and livelihood, quality rehabilitation professionals do.

Support for engaging quality rehabilitation professionals is not 'salary'. It is the best investment that can be made in touching lives of persons with disability in a manner that enables them to lead a meaningful and dignified life as an integral part of society. Imagine the socio-economic impact of even the official '28 million' with disability leading lives to their fullest and highest potential. And then explore that on a scale that is four-fold higher. Quality Rehabilitation must be #1 priority in India. So let us invest in top-notch rehabilitation professionals. Wish you a Happy, Healthy 2019!

S Vaidyanathan Co-Founder The Ganga Trust

### The Ganga Trust Film

The Ganga Trust focuses on supporting rehabilitation of persons with Spinal Cord Injury. Join hands with us with your ideas, time, resources, networking, influence, creativity, social media savvy, volunteering and giving. To know why, view The Ganga Trust film at The Ganga Trust YouTube Channel.



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### **Rehabilitation Experts Board**



Dr Suranjan Bhattacharji Physiatrist



Dr Abhishek Sanyal Physiatrist



Dr Balamurali Spine Surgeon



Samson Daniel Occupational Therapist



Sunil Raj Physiotherapist



Dr Divya Parashar Rehabilitation Psychologist



Kannadasan Social Worker



Swostik Sourav Dash **Mobility Solutions Expert** 



Sister Backiyam Nurse



Dr Komal Kamra Peer Mentor



Ambika Raja Peer Mentor



Manoj Dawar Peer Mentor

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### **Report of the Managing Trustee**



Dear Friend,

Year 2018 was marked by further growth in rehabilitation-led efforts at The Ganga Trust. Overall, The Ganga Trust spent Rs. 79.25 lakh on rehab-related activities. The cumulative value of work over the nine years of its existence is now at about Rs. 6.08 crore. The Ganga Trust's efforts benefited 1,500-plus persons with spinal cord injury in 2018, taking the number of people whose lives we have touched to 5000-plus.

We had indicated last year the intent to expand our scale in an accelerated manner. Staying true to this mission, the Trust augmented its efforts around the Peer Mentor Program, home visits, distribution of quality wheelchairs, expertise sharing and sports-based community re-integration.

An important enabler of this ramp up in activity is our focus on team building. We now have a team of 25, out of whom 10 support us on a purely non-gratuitous basis; 12 are wheelchair users acting as Peer Mentors. On a conservative basis, they offer 10 acts of support every day to persons with spinal cord injury across India. Prabaharan, a team member with spinal cord injury, did 42 home visits in 2018 bringing insights on grassroots realities.

We believe strongly in the power of this idea of Peer Mentors; it will play a central role in our strategy over the next few years. In 2019, we promise the strength of the Peer Mentor Program team will increase from 12 to 20.

Another aspect of team building is to draw in ideas from thought leaders. In this regard, we have set up a Rehabilitation Experts Board, which has the very best in spinal cord injury rehabilitation with extensive experience. The Board will also help to enhance conviction of decision makers in charge of CSR & Foundation programs. We have anchored an initiative christened Best Minds Summit to unearth ideas.

Year 2018 saw an expanding list of partners underscoring the importance of collaboration, the cornerstone of our work. Chennai Runners, the organiser of the Chennai Marathon, was a partner for the Kotak Wheelchair Marathon; it has also roped in The Ganga Trust as partner for the focus of Chennai Marathon on Para Sports from 2019.

Much as we can celebrate the efficiency in execution in 2018 and the trek towards the milestone of a decade in existence, the task that awaits us brings sobriety. The Founder's Message clearly sets out the acute lack of Quality Rehabilitation for persons with spinal cord injury. In its tenth year, The Ganga Trust hopes to invest more in people, programs and partnerships to further the agenda of Quality Rehabilitation in India.

We wish to take this opportunity to inform you that a formal change in the name of the organisation to The Ganga Foundation will happen in 2019 once we receive the clearance letter from the Income Tax Department. We welcome Jai Mukundan, a Chartered Accountant, and Jaskaran Singh, an IIM Bangalore Alumnus, who join The Governing Board and The Advisory Board of The Ganga Trust respectively. We wish to thank all our patrons, partners, peers, volunteers and dedicated stakeholders for their unstinted support in 2018. We wish you all a joyful and healthy 2019, a year in which all of us should contribute towards a more inclusive society.

Suresh Krishnamurthy Managing Trustee The Ganga Trust

**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.



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### **Enabling Livelihood**

### Shanmugam

Paralysed neck down, Shanmugam now has a small poultry business taken care by his parents.



### Kasinathan

15 years after his injury, Kasinathan looks ahead to Life. He will start to make his living as a tailor.



Human Resources training & translation work lead to first income for Amartya, paralysed neck-down.







Akash Sardar

Akash is enabled to pursue dance & choreography, his passion since childhood.

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### **Bold Shift to Healthcare**



Akshaya is now a nurse. Yet in 2010, it looked barely possible. Abandoned by her father, and nurtured by her mother who is a cancer survivor with fragile health, Akshaya's life was under duress. She kept plugging away at school.

Her mother's health condition and the care she received at

Christian Medical College, Vellore inspired Akshaya to change course mid-way in Class XI and shift to science group from commerce with an eye on nursing. She pulled the transition well.

This enabled admission into Karigiri School of Nursing, a reputed college in Vellore. Given the stress of her mother's health and economic condition, Akshaya did exceptionally well. She finished among the top three in her college and graduated in 2018.

Akshaya is now clear on pursuing her education further, delighting her mother. The Ganga Trust will stay as a partner in this journey, as she aspires to build a top-notch career as a nurse.

### Therapist empowered



An Occupational Therapist - Identity withheld on request - from an extremely economically challenged background and supported by The Ganga Trust completes his course from a top-notch institution.

### **Battling Crisis to Impact Making**



Kumaresan was just 16 when he sustained a spinal cord injury. He hailed from a small village in Tamil Nadu. His home was not even accessible by wheelchair. Walking by crutches to reach it was not easy either. He became lonely as his friends moved out.

Sports kept him going. Marathon running, athletics – he is a National Champion in Shot Put – and wheelchair basketball were his forte. A personal crisis in early 2017 meant he was without an idea on what to do. His urge to work to earn his living even if it meant sacrifices in his sports career stood out. A stint at ICICI Academy of Skills offered a break. It helped in his personality development.

As a resident Peer Trainer at Chandigarh Spinal Rehab, he has had a powerful impact on persons undergoing rehabilitation. He knew no Hindi before he went there. In six months, he is speaking functional Hindi. The Ganga Trust hopes we can find 100 more peer trainers such as Kumaresan.

**Nicky P Kaur Founder, Chandigarh Spinal Rehab, says** 'Kumaresan, as an Independent Living Skills Trainer, has been a great asset. His commitment, sincerity and enthusiasm for improving the levels of independent skills and mobility of each person at Chandigarh Spinal Rehab earned the respect of one and all. He works from morning till late evening without confining himself to regular therapy hours, teaching wheelchair skills, assisting in walking with crutches & outdoors and even teaching stitching to a few to help them lead a productive life. What is remarkable is that he did all this work despite a language barrier'.

**Networking at its best** 

The Ganga Trust Team at Work

Hubert Hernandez is a young boy with amputation from Meghalaya. He requested for guidance on education through a therapist. It was gratifying that Dastagir Mohammed Fasihuddin, a networking expert, had brought him into the fold of The Challenging Ones that empowers persons with amputation in India.



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### **Peer Mentor Program**

### 12 Peer Mentors - 5,000-plus Acts of Support in 2018

"The magical part of the work by Dr Mary Verghese was that she was on a wheelchair and so she never had to tell her patients that life is possible after a spinal cord injury, as they could see she was diagnosing, treating and also operating on them from a wheelchair".

- Dr Suranjan Bhattacharji, former Director, Christian Medical College, Vellore, and Chairperson, The Advisory Board of The Ganga Trust.



Dr Mary Verghese did not just pioneer rehabilitation in India, but was also the first Peer Mentor for persons with spinal cord injury.

As spinal cord injury imposes multiple disabilities for a lifetime, guidance by peers is of utmost importance, as visits to doctors and rehab centres may not always be possible or necessary. This is where peer support becomes vital. And we are determined to follow the path of Dr Mary Verghese and make the Peer Mentor Program, the basic grassroots initiative of The Ganga Trust.

The Ganga Trust Peer Mentor Program that started as a volunteering effort by S Vaidyanathan, Co-Founder, now has expanded with a team of 10 peer mentors across the country.

Our Peer Mentor Program team doubled in 2018. We hope to keep expanding this program so as to maximise support and reach to persons with spinal cord injury, family, caregivers and other stakeholders.

'I was contemplating suicide. I met Shailesh and I thought, if he could live well with spinal cord injury, I also should be able to do' – This was Ravi Kumar from Raxaul on the Bihar – Nepal border in late 2016. Today he is a part of the Peer Mentor Program team of The Ganga Trust.

The Ganga Trust believes that Peer Support is the best impact to enhance the quality of life of persons with spinal cord injury.





### Prabaharan

The Ganga Trust Team at Work

'No person with spinal cord injury must suffer what I had to endure due to lack of knowledge' – this passion drives Prabaharan who is the only person with spinal cord injury who has done 75-plus home visits to guide others. A health issue that would ground most, did not bother him but for a 45-day rest.



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### 100 Lives

100 Lives aspires to touch lives of100 persons with spinal cord injury in 2019 by focussing on three key essential needs:

- · Enabling quality rehabilitation to restores lives
- · Education for children with spinal cord injury
- · Education of children of persons paralysed neck down

We hope to launch 100 Lives in an extensive way in 2019 after a pilot launch last year. Here are a few lives touched by 100 Lives so far.





### **Eveleen Kaur Tandy**

Cared by her grandparents, Eveleen Kaur Tandy, 5, was noticed by Kannadasan, a member of The Ganga Trust Team and a PhD Scholar at Tata Institute of Social Sciences during a visit to a Mumbai slum. She was in acute distress. Well rehabilitated at Chandigarh Spinal Rehab, Eveleen is now set for school in 2019.





Ajay Jakkar

Ajay Jakkar was confined to bed for almost seven years due to multiple bedsores that pushed him to the brink. After massive surgical intervention at Christian Medical College, Vellore in 2015, he was cleared of most problems. After two more years, a minor lingering issue was fixed and he has now started to sit.



Sharmila was diagnosed with issues in her spinal cord a couple of years ago. A surgery that was delayed due to lack of resources did not help. Following a 10-week stint at Chandigarh Spinal Rehab, Sharmila regained her ability to walk, became more independent and is now back to school She is also delighting her parents by being active at home and at play.



### Be a partner in 100 Lives

Enable such impact on 100 Lives by supporting this project. Each life will require two months of rehabilitation. Rs 20,000 is what it takes to ensure Quality Rehabilitation for one month. If you wish to support 100 Lives, please drop a message to 73388 00000 or emil to goodindian@gmail.com



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### **Best Minds Summit 2018**



In a path-breaking initiative, The Ganga Trust anchored the Best Minds Summit – a get together of the finest thought leaders among persons with spinal cord injury as well as the best rehabilitation professionals in India. This is intended as a biennial workshop that will chart the path for enhancing the quality of life of persons with spinal cord injury across India. Best Minds Summit 2018 was a curtain raiser to know each other as well as the priorities from a long-term perspective.

Participants hailed from a diverse socio-economic background. Working groups will be formed to focus on specific areas and tasks with a time-bound plan for execution. A wide range of perspectives were shared with a particular focus on persons with spinal cord injury from an economically challenged background. Lack of adequate quality rehabilitation capacity and livelihood were identified as the most daunting challenges ahead. A few focus areas identified for action upfront as roadmap to 2023 were:

- · Identify one peer trainer in every district in India, train them in the best practices of living with spinal cord injury and empower them ..
- Use sports as a major platform for community integration, as we have grassroots evidence of this approach delivering good outcomes.
- Address the lack of rehabilitation capacity with a knowledge platform that will be delivered in multiple formats and in regional languages.

The Spinal Foundation, the pan-India self-help group, for persons with spinal cord injury, will also push the Government of India to set up a registry for every disability, as it is the only way by which the nation will know where every person with spinal cord injury is, as is the case in Canada. India Spinal Cord Injury Registry is the goal.



Dr Divya Parashar, Rehabilitation Psychologist shares on `HOPE'



Dr Abhishek Sanyal, Physiatrist, stressed collaboration & networking

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### **Best Minds Summit 2018**

Best Minds Summit 2018 was not just traditional workshop sessions. Considerable conversation was also beach-side amid exposure to the sea for the first time in many years for most participants.













Field work on sexuality & spinal cord injury

The Ganga Trust Team at Work

Kannadasan, a Social Worker for five years at Christian Medical College, Vellore, is doing his PhD from Tata Institute of Social Sciences. He partnered with a therapist team from Canada and Amar Seva Sangam to develop a guide on sexuality & spinal cord injury. He heads Programs at The Spinal Foundation.



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### **Chandigarh Spinal Rehab**

Chandigarh Spinal Rehab is an initiative of Sai Aasra Paraplegic Rehab Centre led by the imaginative and dynamic Nicky Pavan Kaur. The Ganga Trust offers extensive support by way of expertise, governance and resources. We are gratified by the multi-faceted progress in two years.















### **Exemplary Support**

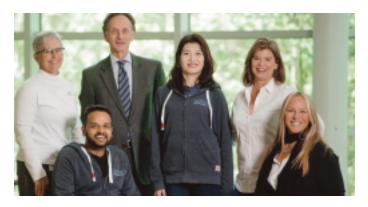
For Chandigarh Spinal Rehab, ICICI Bank set an excellent example in creating a support system to take care of compensation for a high quality therapy team for two years as of now. We deeply appreciate the understanding shown on the importance of quality therapists in rehabilitation.



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### **Sports & Community Integration**



### Access to world-class para sports expertise

Justin Jesudas, a key member of The Ganga Trust Team, took part in the Global Sports Mentoring Program, an initiative of the U.S. Department of State. A few significant outcomes were:

- Exposure to Lakeshore Foundation, a dedicated facility for Paralympic sports, where on a daily basis about 400 persons with disability come to train for fitness, recreation and sports in a world-class facility.
- Interaction with experts in sports for the disabled with a dedicated mentor and sharing experiences with fellow athletes from 17 countries offered insight on best practices in a cross-cultural context.
- Review of a plan to develop Paralympic sports in India based on experience in the program.
- Access to Grants provided by the program as an Alumnus of the program. A grant of USD 10,000 in 2018, we hope, will be a good start for a long-term engagement.
- Ability to source trainers, used sports equipment and peer network for development of Paralympic Sports in India. The first set of equipment from the Lakeshore Foundation is in transit to India.

### Justin Jesudas on his experience:

"Global Sports Mentoring Program made me realise how an empowering environment can change even the lives of persons with severe



disabilities. A simple thought shift from looking at someone's disability to looking at that person's ability not only enables that individual to achieve excellence but also creates an ecosystem that has inclusion and equity for everyone to thrive. The barrier-free environment provoked a thought that people only have impairment, not disability. It is the environment that makes them disabled".

### **Asian Games**

The Asian Para Games 2018 at Jakarta, Indonesia was my first Asian Games and was sort of a dream come true. Four years ago when I started swimming, little did I think I will be a part of the Indian team for the Asian Games. Rubbing shoulders with Asia's best, close to 3000 athletes with disabilities across 43 countries was an unique experience. Competing fiercely during the day in our respective events and yet enjoying the camaraderie in the evening over live music sums up the spirit of the games!

### Sports as rehabilitation

In India, sports plays a major role in reintegrating persons with disability into the community. It is an opportunity to pursue excellence. Sports promote overall well-being and fitness. Persons with disability who are into sports tend to lead more active lives. Pursuing a sport not only provides functional rehabilitation but also psychological and social rehabilitation through exposure to competition, travel, social interaction, multiple environment and recognition.

**India's Fastest Half Marathon** 

The Ganga Trust Team at Work

Shailesh Kumar continued his remarkable progress in the Half Marathon. He notched a best of 1 hour 44 minutes for 21.097 km. This is the fastest Half Marathon time in India by a runner using a wheelchair. He also did a Half Marathon in sub five-degree temperature in Amritsar.



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### Sports4All



### **Running For Ability**

100-plus persons with disability took part and completed regular distance at The Chennai Marathon 2017. Many of them have used this as a launch pad to develop into national-level para athletes. Three of them have made it to the international level. Running For Ability is The Ganga Trust's platform to enable persons with spinal cord injury to take part in endurance events. Since 2012, we have had 200-plus unique runners with disability take part in the Chennai Marathon.

### World-class racing wheelchair

Wheelchair runners of such high calibre as Shailesh Kumar, India's first full marathon runner on the wheelchair and the fastest as well, and Kumaresan, a half marathon runner, have been on regular wheelchairs. Access to a world-class racing wheelchair, mobilised via crowd funding, will help unlock their potential.

### World-class rifle for Manoj

Manoj Kumar sustained a spinal cord injury when he was about five. He is now in Class VII. Two years ago, he took to rifle shooting as a recreation with a basic rifle, and became a state-level medallist.

He has a world-class rifle now to nurture his ambitions in sport.





### **Wheelchair Basketball Star**

Parthasarathi has been supported in a wide-ranging way since the start of his rehabilitation. It is gratifying that he has emerged as one of the best basketball players in India. He is not only the captain of the India Under-23 team, but is also in the Indian men's team. He is moving ahead with his graduation, too.

### Para Sports Partnership - Chennai Marathon

Skechers Performance Chennai Marathon is the second largest marathon, and the second biggest running event in India. Chennai Runners, the organiser, has decided to focus on Para Sports from 2019, and selected The Ganga Trust as the Charity Partner that will also help in sharing expertise and in executing the plans.

We will have more to share in the months ahead. This event was known as The Wipro Chennai Marathon between 2012-2017.

### **RRD Corporate Games**

RRD, a Fortune 500 company, has chosen The Ganga Trust as the partner for the first Corporate Para Games in India. The first edition of the event will be held in 2019. Justin Jesudas, Inclusion Thought Leader at The Ganga Trust will champion the planned annual event with Team RRD.



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### **Kotak Wheelchair Marathon 2018**





1500-plus runners made for a 80% growth in Kotak Wheelchair Marathon 2018. About 300-plus runners with disability took part and had an exposure to an endurance event.

- · Runners came from across the disability spectrum with a team of vision-challenged runners from Darshini making for a first in Chennai.
- · Shailesh Kumar did an unofficial full marathon (42.195 km) in 3 hours 44 minutes as part of a research project of IIT Madras.
- · Runners with disability came from Maharashtra, Bihar, Jharkhand, Odisha, Kerala, Karnataka, Telangana, Madhya Pradesh and Delhi and from Nepal
- Chennai Runners, organisers of the Chennai Marathon the largest running event in the city came on board as a partner.
- · Breakfast plates and one set of mementoes were made by children and young adults with learning disabilities.
- Major D P Singh, war hero, India's first blade runner and founder of The Challenging Ones for persons with amputation, enthralled the runners.

`Equal Opportunity for All' is the central message of Kotak Wheelchair Marathon, as that is the only way persons with disability can become an integral part of society in India. Kotak Wheelchair Marathon offers equal opportunity for runners without disability and runners with disability to run alongside each other. This inclusive experience helps break attitude barriers in society. Kotak Wheelchair Marathon will ensure Quality Wheelchairs for at least 100 persons with spinal cord injury across India. Given the extraordinary floods that ravaged Kerala, Kotak Mahindra Bank, the title sponsor, supported wheelchairs for 50 persons with spinal cord injury as an additional commitment.

### 50th Year of Abebe Bikila Olympics Medal with a Message

Kotak Wheelchair Marathon 2018 Medal was a tribute to a legendary marathon runner, Abebe Bikila of Ethiopia, the first African to win an Olympic Gold and back to back gold medals in 1960 and 1964. Year 2018 is the 50th year of his final Olympic appearance in which he was set for gold before sustaining an injury midway. A year later he sustained a spinal cord injury, became a Paralympic Archer and passed away in 1972 at the young age of 41. This was an indication of how living with spinal cord injury then meant a short life span for a fit and strong person.





The Right Wheelchair supported by Kotak Mahindra Bank

Kotak Mahindra Bank has been a pillar of support for Kotak Wheelchair Marathon since 2015. Kotak's backing for stamping out abysmal quality wheelchairs offers a great reference point for other CSR Programs to follow than just donate for the largest number of wheelchairs without emphasis on quality.



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### **Wheelchair Camps**



A pleasant interaction on sidelines of the wheelchair camp

Over 90% of wheelchair users in India use abysmal quality wheelchairs that damage lifestyle and health. This is due to the lack of awareness and the lack of availability of quality wheelchairs.

The market is swamped by low-cost, one-size-fits-all products, a vast proportion of them imported from China. The use of such wheelchairs even for short periods can hurt health. Imagine what would happen to a person with spinal cord injury who uses such a wheelchair for lifetime. Even medical professionals barring a few are unaware of what makes a good wheelchair. The rot starts there. Such one-size fits all wheelchairs went out of use in the developed world about four decades ago.

A massive push is needed to alter the landscape towards quality mobility devices. In partnership with Kotak Mahindra Bank, The Ganga Trust aspired to drive change with pilot projects involving distribution of quality wheelchairs. This is the core goal of Kotak Wheelchair Marathon.

In 2018, The Ganga Trust, in partnership with The Spinal Foundation, the Pan-India self-help group for persons with spinal cord injury, enabled distribution of 127 wheelchairs made by Motivation across India.

Kerala, Jharkhand, Uttarakhand, Odisha, Tamil Nadu, Telangana, Assam, Karnataka and Chandigarh are states that have been covered after identifying credible local anchors who are also persons with spinal cord injury or institutions that offer quality medical care at affordable cost. We will expand the footprint of this initiative in 2019.



Experienced professionals help set the appropriate settings



Assessment in progress on the watch of experienced therapists.



Wheelchair camps also provided a forum for networking.

### **Man Friday**

The Ganga Trust Team at Work

For persons with spinal cord injury, Praveen Rajendran is Man Friday and more. Medical emergency to rescue in a flood to partying, Praveen does everything for them. If somebody has to be taken two floors up and down, even that would be done. Amazing volunteer. He also runs regularly for good causes.



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### **Gratitude - Our Volunteers**



D Balamurali Class of 1992, IIM Bangalore



Himanshu Chakrawarti Class of 1991, IIM Bangalore



Jay Jay Raman Runner & Brand Ambassador



Jayendra Soni Runner & Brand Ambassador



Minnur Magadhevan Writer & Film Maker



Nirupama Kaushik Class of 1991, IIM Bangalore



Prashant Nori Student, Harvard University



Swarnalatha Passionate Photographer



Sindhu Raam Volunteers Team Leader



Syabin Sangbo Namaste Foundation Volunteer



Vijaykumar **Backend Process Advisor** 



Venkatraman Pichumani Founder, YOU TOO CAN RUN

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### Recognition

### **Quality Mobility Solutions**

NeoMotion, an IIT Madras incubated start-up, and extensively supported by The Ganga Trust in terms of expertise and networking, was selected as one of eight winners (out of 993 entries) for Design: Impact Awards for Social Change by Titan Company in collaboration with Tata Trusts.



# SS/CON CHENNA

### **Recognition for Care**

At the International Spine and Spinal Injuries Conference (ISSICON) 2018, the Spinal Cord Society and International Spine Academy recognised the work of The Ganga Trust and S Vaidyanathan, its Co-Founder, for the outstanding contribution for spinal cord injury care in India.



Shailesh Kumar, Inclusion Role Model of The Ganga Trust, was a recipient of the SwachhAbility Award, which is given by The Challenging Ones, an organisation founded by Major D P Singh that empowers persons with amputation, for his exemplary influence on persons with disability.



# WOMEN ECONOMIC FORUM AMILINADU LEADING IN WOMEN EMPOWERMENT, INCLUSIVENESS & PROGRES AUGUST 18<sup>51</sup> & 19<sup>511</sup> 2018

### Awards galore for sports & lifestyle

Justin Jesudas continues to be recognised for his sterling accomplishment in sports and his lifestyle as a person paralysed neck down. Rotary International, Women Economic Forum and Heroes of Chennai were notable awards in 2018.

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### **The Governing Board**



Elango Thambiah Alumnus, IIM Bangalore Co-Founder, The Ganga Trust



Suresh Krishnamurthy Finance Professional Managing Trustee



Vaidyanathan Singararaman Alumnus, IIM Bangalore Co-Founder, The Ganga Trust



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



Amruthalakshmi Rajagopalan Alumnus, NID Ahmedabad Trustee



Sekhar Ramamoorthy Chartered Accountant Trustee



Vidya Subramanian Asian College of Journalism Trustee



Jai Mukundan **Chartered Accountant** Trustee

### **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.



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### **The Advisory Board**



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



Jaskaran Singh Alumnus, IIM Bangalore Emerging Markets Analyst

### **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.



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### **The Ganga Trust Team**



Vaidyanathan Singararaman Inclusion Leader - Grassroot Work



Justin Jesudas Inclusion Thought Leader



Imran Khan Inclusion Director



Shailesh Kumar Inclusion Role Model



Kannadasan Inclusion Manager - The Spinal Foundation



Dastagir Mohammed Fasihuddin Inclusion Manager - Outreach



Anurag Sankrityayan Inclusion Manager - Projects



Prabu Inclusion Manager – Programs



Meera Srinivasan **Inclusion Treasurer** 



Paul Joshua Freelance Designer



Vasanth Sankar Freelance Designer



Smita Vyas Kumar Freelance Designer

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### **The Ganga Trust Team**



Kamal Kanta Inclusion Peer Trainer



Naveen Iyer
Inclusion Peer Trainer



Kumaresan Inclusion Peer Trainer



Prabaharan Inclusion Peer Trainer



Ravi Kumar Inclusion Peer Trainer



Ganesan Nagarajan Inclusion Peer Trainer



M G Karthikeyan Artwork & Page Making



Sheik Fareed
Support Staff & Best-in-Class Caregiver



Vasanth Sampath Access Custodian

### **Naresh Sundaraman**

The Ganga Trust Team at Work

Naresh, only Class II but skilled, is a pillar of support for several projects of The Ganga Trust as he handles documentation. In 18 months, Naresh has come so far after being confined to home for 24 years. A pair of shoes for his dad with his earnings topped his first movie, scuba diving and marathons on wheelchair.



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### **Networking & Collaboration**

### **Gratitude & Thank You Partners**

C	O	r	b	0	r	a	t	e
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**Accel Partners** 

Aditya Birla Fashion & Retail

Airtel

Banyan Tree Advisors

CL Educate

**Delight Foods** 

Fuel A Dream

FundsIndia

Grand by GRT Hotels

ICICI Bank

**IIMPOWER** 

Kotak Mahindra Bank

LetzChange

Marathon Needs

My Race Timing Solutions

NeoMotion

Pitchfork Partners

Quantum Leap

RAGE

R R Donnelley

Scripbox Seed Design

Studio E

Sundaram Finance Group

Vindhya e Infomedia

VA Tech WABAG

YOU TOO CAN RUN

### Rehabilitation

APD, Bangalore

Broadwell Mission Hospital, Fatehpur

Chandigarh Spinal Rehab

Duncan Hospital, Raxaul

Herbertpur Christian Hospital

Kauvery Hospital

Nav Jivan Hospital, Satbarwa

REHAB Facility in Tamil Nadu

St John's National Academy

Swami Vivekanand NIRTAR

### **Partners & Institutions**

Class of 1991, IIM Bangalore

Class of 1992, IIM Bangalore

IIM Bangalore Alumni Association

**IIM Bangalore** 

IIT Madras

IIM Calcutta Alumni Association

### **Awareness Partners**

Kamal Haasan

Unnikrishnan

Know Your Star

Suryan FM

The Better India

The Hindu Group

### **Social Sector Organisations**

Ability Foundation

Chandigarh Spinal Rehab

Chennai Runners

**CRISIL Foundation** 

Dr Mary Verghese Award Foundation

Dream Runners

Enable India

ICICI Academy for Skills

India Inclusion Foundation

Let's Do Something Good Foundation

Mary Verghese Trust

Olcott Memorial School

Polagam Foundation

Rotary Renaissance District 3232

Sai Aasra Paraplegic Rehab Centre

**SAVELife Foundation** 

Spinal Injured Persons Association

St Louis Institute for the Deaf & the Blind

The Challenging Ones

The Hope House

The Spinal Foundation

The Theosophical Society

Thee Trust

Trinity Trust

United Way Chennai

Vidya Sagar

**WORTH Trust** 

**India Inclusion Summit** 

The Ganga Trust Team at Work

Johan Dhinakaran from The Ganga Trust Team, as Alumnus of India Inclusion Fellowship 2017, was the one the three curators for the 2018 edition. An extensive process of interviewing, assessing and selecting six candidates as well as coordinating the one-week fellowship was an enriching experience.

