***Success* & ABILITY**

India’s Cross-disability Magazine

August 2019

COVER FEATURE

**SHOOTING STARS**

EXPERIENCE:

**Beating Bureaucracy**

SPOTLIGHT:

**Chronic Pain**

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**WE’D REALLY LIKE TO HEAR FROM YOU**

Whether you are a person with disability, or a parent, or a friend, or just someone who cares, we would love to hear from you. You are just a [click](mailto:magazine@abilityfoundation.org) away! Do write to us at [magazine@abilityfoundation.org](mailto:magazine@abilityfoundation.org)

**CREDITS**

|  |  |
| --- | --- |
| **Editor** JAYSHREE RAVEENDRAN  **Managing Editor** JANAKI PILLAI  **Deputy Editors** HEMA VIJAY  SUCHITRA IYAPPA  **Assistant Editor**  **& Design**  SRUTHI S RAGHAVAN  **Hindi Translation** MALINI K | **Correspondents**  ANANTNAG: Javed Ahmad Tak +911936 211363  BANGALORE: Gayatri Kiran +919844525045; Dr. Ali Khwaja +9180 23330200  BHUBANESHWAR: Dr. Sruti Mohapatra +91 6742313311  DURGAPUR: Angshu Jajodia +919775876431  GURUGRAM: Sidharth Taneja +919654329466  HYDERABAD: Sai Prasad Viswanathan +91810685503  PUNE: Saaz Aggarwal +919823144189; Sandeep Kanabar +919790924905  USA: Dr. Madan Vasishta +1(443)764-9006 |

**PUBLISHERS:** Ability Foundation **EDITORIAL OFFICE**: New no. 4, Old no. 23, 3rd Cross Street, Radhakrishnan Nagar, Thiruvanmiyur, Chennai 600 041, India. Tel/Fax: 91 44 2452 0016 / 2440 1303.

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**AbilityFEST 2019 Advertisement**

AbilityFEST - India International Disability Film Festival

Cinema by, with and about people with disabilities

At Sathyam Cinemas, Chennai

9-12 September 2019

AbilityFEST - India International Disability Film Festival presents a unique and inspiring array of international films in a completely accessible environment.

NEWS & NOTES

**NEWS & NOTES**

**Is TV making your child prejudiced?**

**Can you** recall a single children’s TV show that has on board disabled characters? Chances are, you can’t. The fact is, TV shows for pre-school kids largely do not include characters with disability. TV shows do make a big impression on kids, and in not representing disability in children’s shows, we are missing a chance to seamlessly sensitise children on disability.

A recent UK study that analysed 50 popular programmes for pre-school children reports that disability is either left out, or worse, misrepresented in most children’s shows. The findings of this study, “Is TV Making Your Child Prejudiced: A Report into Pre-school Programming”, corroborates research done earlier by the GLAAD Media Institute and the Center for Scholars and Storytellers out of Toronto’s Ryerson University and UCLA.

This study reports that only 16% of the children’s programmes studied had a disabled character. Even when disabled characters figure in the programmes, most often, they were side characters or token inclusions to communicate concepts like bullying or presented as villains (shows like Dinotrux and Lego Ninjago)!

The study found that many of these shows thus promote negative stereotyping of disabled characters. Not only does this promote insensitivity and negative bias in children regarding disability, it also leads to a loss of self-esteem in disabled children. Hopefully, producers of children’s TV shows can be sensitised on disability and the right way of presenting it in their programmes.

**Supplying Corrective Eyeglasses Can improve Rural Labourers' Productivity**

**Something as** simple as providing corrective eyeglasses to the masses can help rehabilitate huge numbers of Indians silently suffering from vision disorders and increase their employability and productivity. Presbyopia, or age-related decline in near vision happens to be a major cause of vision impairment globally, but only a fraction of people with presbyopia use corrective glasses.

A study, ‘Effect of providing near glasses on productivity among rural Indian tea workers with presbyopia (PROSPER): a randomised trial’, by a team of researchers has thrown up interesting results.

Tea pickers aged 40 years or older in Assam, India, were studied for this. Comparisons were made on the mean daily weight of tea picked by tea workers given corrective glasses with those of the control group between the four-week baseline period (June 2017) and the 11-week evaluation period (24 July 2017 to 7 Oct 2017). Compliance with using the glasses was assessed by unannounced visits.

Seven hundred and seven (94·1%) of the tea workers received the allocated corrective glasses. Between the baseline and evaluation periods, mean productivity in the intervention group increased from 25 kg per day to 34·8 kg per day (an increase of 9·84 kg per day), demonstrating the huge impact that a small intervention like corrective glasses can have on the productivity of aging persons in rural areas.

**Empower 2019: An assistive technology conference**

**Here is** an opportunity for you to interact with Assistive Technology (AT) researchers/experts from all over the country and try out the latest ATdevices available. EMPOWER 2019: An Assistive Technology Conference will be held at IIT Delhi between 14 – 17 Oct 2019. This conference will bring together all stakeholders in the assistive technology sector such as AT researchers, AT industries, users and user organisations, special educators, inclusive designers, entrepreneurs and policy makers involved in the creation, production and dissemination of assistive technology solutions, it will discuss current solutions and also seed ideas on future

solutions. The conference includes talks by international experts, reviewed and invited papers, posters, user forums, panel discussions and an exhibition that would feature several latest assistive technology products with an experience zone for users and others to try out the devices. Registrations are now open for the conference. EMPOWER 2019 follows on the success of EMPOWER 2018 that was successfully held in Oct 2018.

For more information and online registration, click here or email Pulkit Sapra at pulkitsapra.iitd@gmail.com or Himanshu Garg at [Himanshu.Garg@cse.iitd.ac.in](mailto:Himanshu.Garg@cse.iitd.ac.in)

**Indian para athletes rank second in 2019 World Para Athletics Junior Championships**

**Indian junior** Para athletes bagged 23 medals to earn the second spot at the World Para Athletics Junior Championships held between from 1-4 August 2019 at Nottwil in Switzerland. Over 320 athletes from 44 countries participated in the event. 26 Indian athletes aged between 14 to 19 years competed at the event and bagged 11 gold, six silver and six bronze medals altogether, making for a splendid performance, prompting praise from Andrew Parsons, President, International Paralympic Committee.

Tarek Souei, CEO, Asian Paralympic Committee commented, “The future is for India, so please keep investing in these young boys and girls and you will see them also at the top of the table in 2021 Asian Youth ParaGames”.

**Has disability risen among the elderly in India?**

**A study**, ‘Has Disability Risen among the Elderly in India?’, by Veena S Kulkarni who teaches at the Department of Criminology, Sociology, and Geography at Arkansas State University, United States, Vani S Kulkarni who teaches at the Department of Sociology at the University of Pennsylvania, United States and

Raghav Gaiha, (Hon.) Professorial Fellow, Global Development Institute at University of Manchester, England has concluded that increase in life expectancy has not translated into a healthier life among elderly persons in India, as prevalence of disabilities, their severity, and their association with noncommunicable diseases have risen.

The analysis of disability among the elderly and its covariates during the period 2005–12 was done using data from the two rounds of the nationally representative India Human Development Survey, conducted in 2005 and 2012. Their study found that the severity of disability spiked among the elderly (60–70 years and >70 years) in both males and females and among the least wealthy, and that the most severe form of disability (more than four disabilities) spiked especially among the females in both age groups.

The researchers advocate that in the backdrop of lack of access to assistive devices, specialised medical services, rehabilitation, and stigma attached to disability, the temptation to offer simplistic but largely medical solutions must be resisted. Instead, the team recommends a multi-dimensional strategy to help the elderly overcome physical and socio-economic barriers and to address issues related to prevention and treatment of their underlying health conditions.

**Legal support**

**The International** Legal Alliance, a network of independent legal professionals from all over the world, through its founder, advocate and independent counsel Jamshed Mistry, has extended support to the disability sector within India. He stated, “After spending several years of practice as a counsel in the Bombay High Court and travelling to other cities both in India and the world, I realised that there is only so much that an individual lawyer/niche practitioner can take on. The need for a network which was both practical and economical was evident. A network that has small and medium-sized lawyers/firms, on a best friend relationship basis, from around the world was thus founded to meet the ever-growing needs of clients globally”.

This network will cover a spectrum of domains such as business and commercial law, trusts and estates law, intellectual property rights, media and entertainment, income tax and tax laws, sports law, real estate, litigation, alternative dispute resolution, cyber law, disability, cross border transactions, medico-legal, family law, environmental law, companies law and insurance.

---End of NEWS & NOTES-----

COVER FEATURE

**WANDER, OBSERVE, SHOOT!**

***New frontiers are now being breached and new vistas entered by photographers with visual impairment. This month, as we walk past the World Photography Day (19 August 2019), PARTHO BHOWMICK, photographer, writer, curator, founder of Blind With Camera and someone who promotes disability art culture, brings you up close with some of the exciting developments in photography by persons with visual impairment and a glimpse into their amazing work.***

**Today, ever** so many photographers with visual impairment shoot pictures independently. Many of them have turned trainers themselves, and few are being commissioned for photo shoots. For instance, Bhavesh Patel (born blind) who trained under our Blind With Camera project in 2014-15, was commissioned by Unilever and J. Walter Thompson (JWT) in India and Singapore for taking pictures of Indian actress Katrina Kaif for the LUX Perfume Portrait campaign. This campaign went viral on the Internet with over 15 million views in the first three weeks alone. The campaign was rated by Google as the ‘Best in Class’ and received the prestigious ABBY Gold award in 2016.

Bhavesh happens to be the world’s first blind photographer to shoot a commercial campaign. Earlier this year, he was commissioned by OPPO mobile phone to shoot for a campaign. Bhavesh was paid for both assignments as per industry standards and treated with respect and dignity. Bhavesh is a TEDx speaker and has been part of several other commercial campaigns.

**A Window for seeing inwards**

One of Blind With Camera’s initiatives is ‘The Inner Gallery’, a collection of photographs by visually impaired

photographers, that platforms a reciprocal gaze between sighted and blind photographers of varying ages and types of blindness, ranging from total blindness to partial sight. They use the camera as extensions of themselves, to explore the visual world and gain deeper insights, while recording their imagination and their

point-of-view. They use various tactile and audio clues, visual memories of sight, warmth of light and cognitive skills to create a “mental image” before they make a judgement to take a picture. They are the owners of their uninhibited process of creation.

The photographers provide descriptions alongside the photographs which reveal how they handled challenges that cropped up while creating the photographs, how another sense “fills in” or compensates for

sight. The experience of being a blind photographer is a small slice of the bigger experience of being a blind human being. Their photographic discourses are the union of both these experiences.

Interestingly, as with sighted photographers, photographs taken by one blind photographer differ from those taken by another, depending on their life experience, the nature of their blindness, their ability to recall, the clarity of their visual memories, the attentiveness and sensitivity of their senses, cognitive abilities, and most importantly, their involvement with the subject to be photographed.

**Making photographs accessible**

Along the way, Blind With Camera has also broken ground in making photographs accessible to people with visual impairment. For instance, we conceptualised and designed “inclusive” photo exhibitions, offering a combination of tactile (touch and feel) raised pictures, audio description (AD), large print and braille descriptions to enable people with visual impairment to access and enjoy photographs. In the process, this attempt has opened a whole new experience for people with sight.

Blind With Camera is also exploring 3D printing for tactile pictures and a mobile app for audio description (AD) and other artificial intelligence (AI) based solutions.

**Connecting with “Self”**

Photography triggers an insightful journey that helps one connect with his or her “self” in many ways. When a blind person looks through the lens of a camera, a remarkable transformation takes place – he at once creates, explores, experiments, makes choices, develops ideas and enjoys new experiences. Camera in hand, the blind wake up to shapes, forms, people and activities, as if the camera were a new pair of eyes. In the process, they learn that disability basically means doing things differently. It gives the blind participants a sense of realisation – that they can do things they never thought they could. They surprise themselves, as well as their teachers, parents and friends.

Photography is about self-awareness and learning. The blind sharpen their observation, dreams, ideas and emotions while enjoying the entire process of creative self-expression. In learning and mastering the techniques of photography, they gain sensory development, sharpen their judgement and intuition, amplify and enhance their self-expression. and improve their communication skills, including listening, speaking, spatial awareness, vocabulary, learning skills and academic performance. Moreover, through the photographs they take, enjoy and experience, they express pride and delight in their accomplishments.

Blind photographers give back to the community the valuable discoveries they make through photography in the form of public presentations and exhibitions. The Blind With Camera project brings dignity and purpose to the blind, giving them fresh hope in their newly discovered ability to see, and a new voice.

**Blind With Camera:**

**The Journey**

*It was early in 2004 that Partho Bhowmick accidentally picked up an old magazine on photography from a pavement vendor in Mumbai and came across an article on Evgen Bavcar, who lost his sight gradually and*

*became one of the world's most accomplished blind photographers. It was a life-changing moment. Inspired, Partho decided to teach photography to people with visually impairment in India.*

*After nearly two years of independent research on art and blindness, in February 2006, Partho started Blind With Camera in Mumbai, with just one visually impaired person. There has been no looking back since then. Over the last 13 years, the organisation has helped train over 1800 persons with visual impairment in photography, in India, UK, Singapore, Malaysia and Greece. Blind With Camera has also created a pool of*

*localised sighted trainers through the Masterclass (Train the Trainer) programmes for taking the training ahead and culminate in exhibitions.*

*Over the years, Partho has developed a new methodology and technique to teach photography (and visual arts) to people with visual impairment based on continuous research and his hands-on experiences of photography-centric activities with the visually impaired.*

*Partho also launched the world’s first e-school of photography for the blind to provide open source online training material and guidance to visually impaired photographers and sighted trainers around the world. By converging photography and social change, Partho has built an ecosystem and capacity for self-sustainability and Partho Bhowmick has authored ‘See As No Other’, a collection of photographs taken by people with visual impairment, and their experience of taking pictures. Besides print and e-book formats, ‘See As No Other’ is also available in full audio DAISY format, with audio descriptions for over 100 pictures. In fact, ‘See As No Other’ is India’s first audio DAISY picture book and one of its kind in the world. Partho’s second book ‘In Touch With Pictures’ is an inclusive multi-sensory photo book, offering a combination of actual pictures, its raised touch and feel version, audio description, and large print and braille descriptions.*

**NO CHEESE, UNFETTERED CREATIVITY**

***How does a photographer with blindness perceive a subject and capture the moment? PRANAV LAL, one of India’s most talked about photographers with blindness describes the fascinating process and premise of his photography using ‘vOICe’, an artificial vision prosthesis that converts vision to sound.***

**I take** photographs. “Yes, so do we”, would be your instinctive response, which is natural. Everyone takes pictures thanks to mobile phones. The difference is, I do not use my organic eyes to frame the shot. I could, for example, randomly point my camera in any direction, and if I take enough photographs, I will get some good ones. That is not what I do. I use an artificial eye to frame my shots and then capture them. I will describe how the artificial eye works later, but first, I want to answer the basic question, “What do I see?”

When framing shots, I go with shape. If the shape varies or has many sides, then it is one for my camera’s lens. I can also perceive contrast, therefore light and shadows play a big role in my photographs. The foreground and background matter too, as also how the said object is placed in relation to other objects in the scene. You may well wonder, what about colour? I use colour in as much as it influences contrast. I do not have a mechanism to detect colour experientially.

So, how do these eyes work? How can I detect the shape of light and shadow when I cannot touch them? The answer lies in the use of a programme called the ‘vOICe’ which acts like my organic eye. The vOICe is an artificial vision prosthesis that converts vision to sound. This sound is rendered using a defined schema. For those unfamiliar with the word, a schema is the structure behind data organisation. My task is to interpret the schema and understand what is being shown. This takes some practice but is doable. Using the three steps described below, I can decode the image and I get a sense of the scene in front of the camera.

The schema of vOICe is as follows:

1. The sound pans from left to right such that objects on the left of the camera view are sounded in the left year, objects in the middle you hear in the middle of your head while objects in the right of the camera view our sounded in the right ear.

2. The pitch of the sound represents height such that the higher the pitch, the higher the object.

3. The volume of the sound represents brightness such that the louder the sound, the brighter the object.

Traditionally, blind people have been taught to photograph by using sound. That is, they align themselves with a sound that the subject to be photographed is making. Alternatively, if they need to photograph something like foliage, they can feel the foliage first and then step a few paces back and take the picture. These approaches do work and can certainly produce good quality images.

However, when using the vOICe, it is equivalent to having vision. For one thing, you do not need to touch everything. Secondly, concepts such as perspective become significantly easier to represent. For example, consider the following scene. Two lamps are mounted on a railing. There are some plants on one side of the railing. The blind photographer is on the other side. The lamps are significantly taller than the photographer, who wants to capture both the lamps and some of the plants in the background. What can the photographer do?

The photographer can certainly touch the lamps but that won't help too much. He will know that they are higher, so he must reach an elevated position to get both the lamps. However, what about the plants? It is very difficult, almost impossible to fully appreciate the composite scene of the plants and the lamps. If he had a short-range balloon, he could probably position himself at a height, then float over, and check the lamps and plants.

However, most blind photographers do not have such an aerial aid. Using the vOICe, it is easy to make out whether both the lamps are in the camera view. Secondly, the vOICe will also render the background, here the foliage, accurately. Now, once the blind photographer is standing at an elevation, he can position his camera such that he's catching the lamps as well as the vegetation. He then takes his picture and that is that.

Another advantage with using the vOICe is that the blind photographer can operate significantly faster. In addition, he can photograph items that cannot really be touched. For instance, consider the following situation. The blind photographer walks onto a jetty. There are some boats in the distance that have twinkling lights and there is a lighthouse. There are also some rocks. Using touch here is impractical, since it would be difficult to touch the lighthouse, the rocks and the moving boat simultaneously. Using the vOICe, it is a simple matter of getting everything in the camera view and clicking.

Next, let us consider photographing people. Imagine that I need to take a group photograph. It is going to be extremely difficult to touch every person in the group and then work out the correct alignment for the camera. In addition, capturing expressions by touch is extremely difficult unless the expressions are exaggerated. Therefore, if I want to capture someone laughing naturally, getting a high-quality image will be significantly easier if I am able to judge the position of the face of the person in real-time.

However, the secret sauce behind the above feats is neuron plasticity, which is the ability of the relevant neurons to adapt to visual inputs. The electrical signals generated by the sounds produced by the vOICe in the brain are the same as those sent when someone looks at an object with his organic eyes. This triggers the visual cortex and, at least in theory, vision is what happens. However, this is still being tested. Whatever the case, I can frame shots and take photos.

Finally, a word about creativity. One bit of creativity lies in the framing, but the other portion is in creating the eye. The vOICe works with off-the-shelf hardware like Android phones and smart glasses. I have been able to create different versions of my eyes and thereby get into building my own gadgets. This has had a cascading effect where I am able to build whatever I want and am not dependent on anyone. For example, I

wanted to build a laser light projector. It took some hours at a maker space; some fiddling and I had my projector. The best part is I could see its output. I can release the shutter and do not need to say, “Everybody say cheese!”

---End of COVER FEATURE-----

Advertisement

**DescribABILITY**

A two-day workshop on audio description of films

Chennai will host a first of its kind landmark film event on September 6 & 7 – a two-day Audio Description (AD) workshop conducted by acclaimed AD expert Dr Joel Snyder, President of Audio Description Associates, and Director of the Audio Description project of American Council of the #Blind, who has trained describers in over 60 countries.

SPOTLIGHT

**CHRONIC PAIN: WHY IT IS A BIG DEAL**

***The International Pain Awareness month is just around the corner. DR. ANUBHA MAHAJAN, founder and chairman of Chronic Pain India that works for the welfare of chronic pain sufferers, brings to our attention the many facets of chronic pain, a highly underestimated condition that so many of us are suffering silently.***

**Pain is** that annoying feeling you get when you bump your leg, fall and hurt your elbow; when you get a stomach ache, a cold and cough leading to a sinus issue, broken bones due to an accident, and other similar instances. These instances trouble us for a short duration, prompting sick leaves and sitting at home,

restrictions with daily functional activities, etc. Pain’s something all of us go through sometime or the other in our lives, it is something we understand. But, what if that annoying feeling that we call PAIN turns into a permanent or a constant aspect of our lives and becomes ‘Chronic pain’?

Chronic pain may arise due to various reasons: trauma, illness, genetic or autoimmune condition, etc. However, there may also be no clear cause. The most important aspect of treating chronic pain is in arriving at the root cause of the problem and treating it with a multi-disciplinary approach. Sadly, this approach is not followed properly in India. There are very few clinics and hospitals in India which follow a multi-disciplinary approach. Most of the time, chronic pain and chronic illness warriors are left undiagnosed for years.

Today, chronic pain is one of the most underestimated healthcare problems in the world. It causes major issues in the quality of life, both personal and professional, of the sufferer. It is also a major burden on our healthcare system, and loads of medicines (which are usually not covered by medical insurance) must be

consumed to manage it.

It is not an issue that affects only the elderly. There are many instances of even kids of/below the age of 14-15 having been diagnosed with such illnesses, due to trauma, auto-immune illness, genetic issues, etc.

India is a country with a population of 1.3 billion people, approximately. Imagine, how many Indians must be suffering from chronic pain! There have been (very) few studies done in India to figure this out. According to those studies, 13-18% of the Indian population suffers from chronic pain. We have not come across any pan-Indian study so far.

The widespread condition of chronic pain has been ignored for ages, and if this continues, it will grow into a pandemic issue in course of time. Health problems such as fatigue, sleep disturbance, decreased appetite and mood changes often accompany chronic pain. Chronic pain may limit a person’s movements, which can

reduce flexibility, strength, and stamina. This difficulty in carrying out important and enjoyable activities can lead to disability and despair.

I am a pain warrior myself. I suffer from Complex Regional Pain Syndrome (CRPS) and Central Pain Syndrome (after it slowly affected my whole body) due to a trauma injury I faced because of an incorrectly applied plaster cast on my left leg, back in April 2014. I have had my share of ups and downs along with several disappointments because of my illness, yet it never motivated me or sparked off my curiosity to see the other side of the picture.

It all started when I came across a lady in my yoga class in Bangalore. Somebody had mentioned to her my battle with chronic pain. She met me outside the class with numerous questions and shared her struggle with undiagnosed chronic pain over the last eight years.

Somehow, I could never get in touch with her since then. This incident made me wonder, like me, how many

people would be there in India, fighting their personal struggles, mentally and physically, getting mocked and misunderstood because of their suffering, still fighting it with their heads held high, feeling alone inside – the loneliness of not being understood at home, workplace or hospitals – and yet moving ahead with life.

I came across several different situations and stories while connecting with people facing similar issues; some diagnosed, some undiagnosed, few fighting personal family battles – ignorance/ separation/ divorce/financial issues – to people having a tough time dealing with their illness for various reasons. It struck me then that there are a number of people who are not blessed with the right amount of knowledge about this issue, many of them probably struggling to even get out of bed.

I started Chronic Pain India with the sheer will to help, and the more people I connected with, the more I came to see other sides of the story, motivating me to get Chronic Pain India registered and make it an important and indispensable part of my life. My parents, and all the volunteers of Chronic Pain India, have been of great help and support in all this. It would never have been possible without all of them.

Chronic Pain India is an organisation which has been working for, with, and run by people facing similar issues. Chronic Pain India intends to be the voice of this cause in India and will continue to focus on bringing a change by raising awareness on chronic pain and reach out to as many people as possible.

We at Chronic Pain India strive to create awareness about the numerous chronic pain conditions, they are almost always invisible. We talk about the early signs and symptoms, prevention and treatments. But most importantly, we are just trying to be there for those who need us the most. We’re building a community of support for all the chronic pain warriors across our country, and while at it, we hope that it also helps medical practitioners understand and give appropriate and timely treatment, as and when required.

So far, we have come across and helped over 200 chronic pain warriors. Many people have benefited from our Facebook support group. They no longer feel alone. This support group gave people opportunities to interact and share with others; a few of these interactions have evolved into friendships over time.

When you have a person to talk to, life as a pain warrior becomes easier. Chronic pain India has been able to

help people accept their illness and move forward in life and not hide in the shadows. Some of them have started taking small steps towards healing and have got back on their feet and have started earning again. Many have got back to jobs and a better life. We were able to help a few people who had been silently suffering chronic pain get a diagnosis of the same. We were able to help people reach out to the right doctors and get better management protocols to heal. We have been working on and finding various ways to reach out to more people, mostly through social media, and when we get lucky, to reach newspapers or magazines. We have shot a few videos with doctors to help people with chronic pain understand why they need a doctor managing their case, and how diet, exercise and other aspects play a major role in healing, not just medicines, and why one shouldn’t ever ignore pain.

Celebrating September, the international Pain Awareness month, we have been able to motivate people

to come forward and share their life stories with the world through Facebook and Twitter, and arrive at a

sense of acceptance of the issues they face.

So far, we have organised three workshops (support group meetings with a twist), one in Delhi NCR (Gurgaon) and two in Bangalore, using theatre, art therapy and talking as a medium to help people accept pain and make peace with it. We came across new people and happy faces. The Gurgaon workshop was a six-day event. It was a collaboration between UK and India. A pilot study named “Visualising Pain” was conducted by Dr. Deborah Padfield, co-facilitated by disability specialist Dr. Mary Wickenden (Sussex University, UK) in collaboration with Dr. Navjeevan Singh and Dr. Satendra Singh, India’s foremost experts in medical humanities and participatory creative practices (UCMS, Delhi), me, international artist Himani

Gupta (Delhi, India), and artist and facilitator Mariana Gomes Gonçalves (alumni Slade School of Fine Art, UCL, UK).

So far, the going has been good, but it’s a long journey. There’s a lot more to do, a lot more to learn, a lot more people to reach out to, a lot more cities and towns to cover, and someday with the right amount of funds, we will reach out to rural India. This will be an interesting journey with plenty of bumps and smooth roads ahead.

--Box—

Chronic pain is pain that lasts more than several months (variously defined as one to six months, but longer than “normal healing”).

Source - US’s National Institute of Health

A World Health Organisation (WHO) study found that people who live with chronic pain are four times more likely to suffer from depression or anxiety.

Source - BMC Medicine

25-30% of the world’s population faces chronic health issues.

----End of Box---

*Dr. Anubha Mahajan, a pain warrior herself, was diagnosed with CRPS (Complex regional pain syndrome) in 2015 due to a nerve injury that occurred in 2014. She is a dentist by profession. She can be reached at chronicpainindia@gmail.com*

---End of SPOTLIGHT-----

EXPERIENCE

**I’D RATHER SCALE MT. EVEREST THAN BUY A CAR!**

***Perhaps the first person with disability in the country to get a GST refund on his newly bought car, VISHANT NAGVEKAR, along with MONIKA KSHATRIYA, recounts the bureaucratic quagmire he had to wade through to make this happen.***

F**or most** people, a car is not just a mode of transport, it’s a display of their success and aspirations. But for me, it’s a lifeline. I have 75% disability in both the lower limbs. Getting to the bus stop or a taxi stand is a near impossibility, unless I want to risk injury due to potholes, damaged roads or mutilated footpaths. In any case, in the absence of accessible public transport, I need a motor vehicle to commute to office. For a person with disability, a private vehicle is not a luxury, it’s a necessity.

I purchased my first car, a Maruti Wagon R, in 2009. It had manual transmission and was quite inconvenient. But, back then, there were very few automobile manufacturers producing automatic transmission cars. If they were, the price was beyond my reach. Add to that the near absence of mechanics who could fix an automatic transmission car and the lack of spare parts, this took them out of my reach. My Wagon R was retrofitted with a hand-controlled brake, clutch and accelerator. But the clutch cable would break every so often making the car unusable, calling for ordering the cable from Pune and then hunting for a trained mechanic to fix it. Fed up with this problem and the expensive repairs, I decided to buy a new car with automatic transmission.

After a brief search, in September 2017, I found out that Maruti Udyog Ltd. Manufactured cars with automatic transmission (AMT). Compared to other manufacturers, they were affordable. Moreover, repairs and maintenance of these cars was quite inexpensive and accessible. Being a disability rights activist, I was aware

that there are two types of concessions for persons with disabilities on purchase of cars: Total exemption of road tax & concession in GST and compensation cess.

Enthused by the prospect of a new car, in September 2017, I approached the Goa Medical College, Bambolim (GMC), for the certificate in the format prescribed by the Department of Heavy Industries. My experience in the hospital was humiliating and frustrating. GMC demanded that I display my disability in a photograph. That meant I had to strip down and get photographed for the purpose. I felt like a Jew in a Nazi concentration camp.

I submitted my forms, and a few days later, went to enquire at the hospital. My application couldn’t be found. After hours of pushing and cajoling, the clerk began a search and found my application in an old dusty file hidden in some corner of her untidy desk. There was no apology, and worse, GMC did not issue me my medical certificate. I then approached District Hospital, Mapuca, North Goa. Thankfully, the certificate was issued on the very day of the visit.

Simultaneously, I wrote an e-mail to Maruti India Ltd., asking for the manufacturer’s certificate as mandated by the Directorate of Heavy Industries. However, the application was rejected by the company, with the statement that their car with automatic transmission was suitable only for persons with left leg disability and that the car in its present form was not suitable for me, since I had disability in both the legs.

The officials at Maruti Udyog Ltd. were effectively denying persons with disabilities their rights to GST concession by misinterpreting the rules. Despite several e-mails from me and separately from Monika, my fellow activist from iDare, Goa, Maruti refuses to acknowledge this circular that the Ministry of Finance issued on 24 June 2002. This circular can be accessed here. The circular clearly states that “This condition does not require or state that the particular car should be specially designed or manufactured for use by the physically handicapped persons”. In fact, the whole emphasis appears to be more on the end-use rather than the nature of the product itself. Therefore, so long as the car has some special features and an officer, not below the rank of Deputy Secretary in the Ministry of Industry, clarifies that the car is capable of being used by a handicapped person, concession cannot be denied.

As if this wasn’t frustrating enough, officials at the transport department displayed even lesser understanding of issues, especially when it did not in any way benefit them. I made an application dated 9 February 2018, mentioning the make and model of the car I wished to purchase, and submitted it to the Assistant Director Transport (North), requesting for the Certificate in Annexure – G (old guidelines). But they rejected it orally, saying that they needed to inspect the car before issuing the certificate since the car would be retrofitted.

It was a strange chicken-and-egg situation. The new guidelines required me to get a certificate from the RTO for a car I wanted to purchase and retrofit. And here the RTO demanded to see the car that I had not purchased yet!

Nearly six months after embarking on this “car purchase” adventure, frustrated and desperately in need of private transport, I purchased a car without any concession from Chowgule Industries, a Maruti dealer in Panjim on 14 March 2018.

Getting the car delivered was another ordeal. The car needed to be retrofitted. How could I do that unless the car was registered and could be driven on the road to a specific workshop for fitting the hand controls? After a lot of brainstorming, I managed to get a mechanic to fit the hand controls at the dealer’s office itself.

Since the car was retrofitted with hand control unit by me, the car was registered as 'Invalid Carriage' by the Assistant Director Transport (North), Panaji, Goa. And, the desired certificate in Annexure G was issued to me upon inspection of the car on 12 April 2019 by the Assistant Director Transport (North), Panaji, Goa. I think this happened purely because of the goodness of the officials, since the definition of Invalid Carriage in the

Motor Vehicles Act is an obsolete one.

I have heard many stories of how RTOs usually refuse to give Invalid Carriage certification. But it seems my stars were aligned right, and to their credit, Maruti Insurance gave me 50% discount on car insurance (own damage) mandated under IMT – 12.

The refund application in GST RDF 01 was submitted by me on 4 March 2019, along with the required documents to the Assistant Commissioner, CGST, Division II, Patto, Panaji, Goa. And lo and behold, on 8, April 2019, a payment advice was issued to me!

Though I have received the CGST Refund, the SGST is still awaited. I am told, I am perhaps the first person with disability who has managed to get a refund of GST on my vehicle.

This article cannot begin to express the bureaucratic quagmire I have had to wade through, the almost one and a half year of an emotional rollercoaster, and the intense pressure to give up. But when I did receive my GST refund order (which can be accessed here. I felt it was all worth it. The money is hardly an issue. What’s of bigger value is the sense of achievement in having set the right precedent.

My advice to those who are waiting for a refund after purchase of the car is, first, be patient. Second, be prepared to encounter negativity; people will tell you that you are in the wrong or that there is no hope. But

carry on soldier. There may be a delay, but justice will be done. I had to suffer because of the inability of various public authorities to interpret the rules. Also, I suspect they had a reluctance to read it in the first place. There is another problem with the new guidelines of the Directorate of Heavy Industries. According to these guidelines, a certificate from State Transport Authorities is a prerequisite in case the car is to be retrofitted. But clearly, how can RTO issue a certificate without inspection of the car? The third point – “On cars meant for physically handicapped persons”, it specifies that for those cars that are meant for use by persons with disabilities, one may avail GST Concession mandated vide HSN 8703. But the Department needs to clarify further that the car may not necessarily be driven by the person with disability. This GST concession is meant for people who are physically challenged, but may not drive, like the visually challenged.

Well, there’s a lot in the rules that needs to be rectified. My organisation, iDare, intends to take up the matter with various authorities. For the moment, I am basking in the glory of my victory and busy maintaining my car. After this ordeal, I would rather climb Mt. Everest than buy a car!

---- BOX-----

To avail concession in GST and compensation cess, the major requirements are:

1. Affidavit declaring that this GST Concession has not been availed in the last five years and that the buyer shall not avail it again in the next five years. Additionally, the affidavit must declare that the car shall not be disposed of in the next five years.
2. Certificate from the Directorate of Heavy Industries, New Delhi.

For those unaware about this, the Directorate of Heavy Industries, New Delhi has published guidelines on

availing their GST Concession Certificate, available online. The documents required by the Directorate of Heavy Industries, New Delhi are:

1. Certificate from Medical Superintendent in the prescribed format

2. Certificate from RTO in case of retrofitting or certificate from the manufacturer saying that the car is fit to be driven by the person with disability.

3. Declaration, etc.

GST refund claim in GST RFD 01 format requires supporting documents such as:

(1) Certificate issued by the Directorate of Heavy Industries, New Delhi

(2) Affidavit

(3) Car purchase invoice having GST paid by you

(4) Cancelled Cheque. If the same is rejected, you may appeal against the same with the GST Commissioner Appeals.

Directorate of Heavy Industries mandates for GST concession under the following conditions:

- On cars that can be driven by the physically handicapped; or

- On cars suitably designed to be driven by the physically handicapped; or

- On cars meant for physically handicapped persons.

---End of EXPERIENCE---

QUOTE UNQUOTE

**QUOTE UNQUOTE**

Man needs his difficulties because they are necessary to enjoy success.

* A. P. J. Abdul Kalam

A dreamer is one who can only find his way by moonlight, and his punishment is that he sees the dawn before the rest of the world.

* Oscar Wilde

I shut my eyes in order to see.

* Paul Gauguin

Everyone speaks of himself with regard to his own self, "I am above, and the others are below," whilst all of them are around the globe like the blossom springing on the branches of the Kadamba tree.

* Varahamihira

Failure is unimportant. It takes courage to make a fool of yourself.

* Charlie Chaplin

In the information society, nobody thinks. We expect to banish paper, but we actually banish thought.

* Michael Crichton

Your grown-up children are your best friends.

* Chanakya

You’re never going to learn something as profoundly as when it’s purely out of curiosity.

* Christopher Nolan

When we talk to God, we're praying. When God talks to us, we're schizophrenic.

* Jane Wagner

Never say never because limits, like fears, are often just an illusion.

* Michael Jordan

------End of QUOTE UNQUOTE-----

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