

# Newsletter

## August 2017

### Editor's note

Dear Readers,

This edition brings in a milestone - a twist of humor through a cartoon column. Hope you all like and appreciate the wit and satire. Thank you, Poonam Akka (Mrs. Poonam Natarajan) for the advice and guidance.

This edition features two inspiring personalities who believed in the principle of *we can!*

Your suggestion and pat on the back will take us closer towards creating awareness, changing mindsets and making this society inclusive for all.

Happy Independence Day!

Happy Reading!

Regards,

Bhavna Botta



### From The Heart

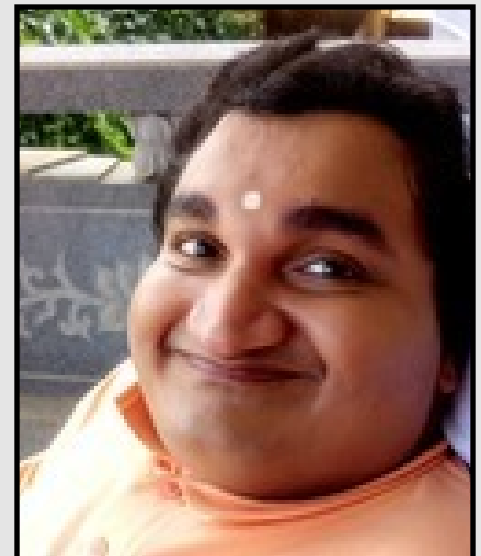
Meet **Mr. Sai Kaustuv Dasgupta**, recipient of *CAVINKARE ABILITY MASTERY AWARD 2017*. Sai Kaustav is a Graphic Designer, Singer, Composer, Motivational speaker and the author of 'My Life, My Love, My Dear Swami' a book that has been translated into Telugu, Tamil, Malayalam, Oriya, Gujarati and Hindi.

### Other than family, who all have been guiding people and support for you?

In my life I got many unique personalities who always helped me time to time and solve my difficulties. First of all, my most wonderful guides are my parents, Kausik Dasgupta and Shila Dasgupta. They are like living angels for me. From morning to night they assist me in each and everything. Without their help, I can't move an inch too. In all my success they are the main pillars and in all my sorrows they are my main consoles. They have sacrificed a lot for my well-being

and happiness. They were very supportive from the time I was diagnosed with Osteogenesis Imperfecta ('brittle bone disease'). They never broke down or complained about their fate. My parents inspired me always to choose what I love to do and it is their greatness which made me what I'm today. I can never repay what they have done for me. They are my ideals.

Apart from them, my younger brother Kushal too is my great inspiration. His love for me knows no bounds. He is always supportive and positive in all my endeavors. He encouraged me to win over situations when life gives me no options. I've received so much love and grace from millions of people worldwide through my work, songs and talks. Actually I believe there is no end of learning and as we grow up, we come across so many people who help us selflessly and teach the lessons of leading a purposeful life. We should respect all of them.



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### Why did you write a book -the genesis, the process, the turmoil, the end result?

Life taught me how to smile after confining into a room for 6 years! I used to feel terribly down in depression. But slowly I started realizing that if I break down like this, then what about the other people with disabilities, who are also struggling to break the barriers. Then I thought to write a book.

I have suffered more than 50 fractures till date. Physically I am unable to do anything on my own. But disability has affected my body and not my mind; it is strong enough to fly high. I became a *Wheelchair Warrior*, defeating all the obstacles. I wrote an inspiring book to show the world the power of positivity. It is about my life, my struggles which went through tremendous turmoil but ultimately won the race.



My hands can't reach the keyboard, but I can type quite fast by using a virtual keyboard. So I completed the 52 pages book in two months by typing it like that with the help of a mouse. The book is in English titled 'My Life, My Love, My Dear Swami' published in 2015. Even our *Prime Minister Narendra Modi* loved and appreciated the book upon receiving a copy of it. That was really an unexpected incident for

me. Millions of people read it and get a dose of positivity. And this book is also available in Bookshare in accessible format for all

### Share with us your experiences as a traveler on wheelchair and winning the wanderer award

Traveling outside is a part of our life as it gives us joy, happiness and a fresh essence of life which is very essential. It also helps us to find our passion by meeting with various cultures and people from different backgrounds. But do you think traveling for a differently able person like me is so easy? That's a million dollar question. The secret is - plan way ahead! Millions of persons with disabilities across the globe have great difficulties in finding accommodation that is accessible for them.

However, accessible can mean different things to different people, so I wouldn't recommend booking a hotel online just because it says that it's accessible. You need to gather detailed and dependable access related information so that you can quickly and easily find places that meet your access needs or preferences. That's why I always prefer to get ideas from the person directly who has already experienced it.



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My first accessible visit after a gap of six years when I was fully confined into a room, started with visiting nearby places to get accustomed with traveling. Then I visited Nandi Hills in Karnataka, Bangalore and Whitefield. It was a great start with my family who has sacrificed their joy for my sake because they never used to plan any outing as I was not able to go out.

Gradually I started exploring more and more. The main thing was, every time I go out, I had to hire a special wheelchair accessible car which has ramp behind. So my motorized wheelchair can get into it easily. I can't travel in ordinary cars as I can't sit or enter into them. By air too I am having some difficulties as they would not allow sitting in my own wheelchair and travel..I need to shift in their wheelchair and then to the flight seat. That is quite challenging for me. So I went to Goa by car only.

I won the All India *Wheelchair Wanderlust* Competition 2016 organized by an International Travel Portal Company and went for an accessible trip to Goa as part of the Grand Prize. It was my first long journey after so many years. I was privileged to meet the State Commissioner for Disabilities in the Government of Goa: Mrs. Anuradha Joshi. She took my feedback on how to make Goa more accessible.

### **As a graphic designer what assistive technology would increase your opportunities to work and earn**

When I got confined into a room in 2009, I thought to re discover my life and started designing. Now I've become an international graphic designer. As per my opinion, graphic designing needs a creative mind more than

assistive technologies. And India is not so updated in technologies. Especially for designing I think a big screen with voice over facility would be very helpful. But at the end of the day you need to have a good system with good configuration and accessible apps to produce a unique professional output. Clients will come to you only if you have some uniqueness and good communication skills. I always believe that our passion and interest towards our destination make us successful.

### **What according to you is stopping PwDs getting jobs in India?**

The main factor according to me is confidence. In rural areas, where the majority of disabled people live, prospects of formal employment are much slimmer. However, the rapid proliferation of disability self-help groups appears to be empowering disabled people on a huge scale, enabling them to engage in economic activity, as well as raising their status in society. There are so many organizations in India are working on disability employments and they are empowering PwDs to stand on their own.

But the mind set of society, lack of accessibility and awareness leaves them jobless. Our society is still in a comfort zone and is not taking any initiatives towards employment of people with disability. We need to be positive and no matter who you are, what you are, how much capable or incapable you think you are. Just get up, throw your disability and work towards something which you really good at. Explore more to express your true self.



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### Straight Talk

Meet **Siddharth Jayakumar**, co-author of **Simply Being Sidds! My Fight with Life and God**. Siddharth is a banker by profession, an inspirational speaker and a National Award winner. His book which is at pre order stage now and is going to hit the stands very soon, is bound to inspire millions.

#### What inspired you to become an author?

In one of those many meetings I have had with *Dr Kalam Sir*, he mentioned to me that I should write a book and inspire millions! That thought was always at the back of my mind and then my mentor *Paul Abraham Sir* pushed me to do it..... So it happened as per their wishes!

#### Were there any emotional and personal barriers while penning your thoughts, how did you overcome these?

Yes. Lots of times, I struggled to stay focused. I was always thinking about what to write and even at work, my mind was on my book. Time was a big constraint and I had to get up at 4 am, do my writing and sleep again. With my wife and son around, it's never easy to work. But their moral support always kept me going.

#### Your book will inspire many, any further writings in the pipeline?

Hope it does inspire many! No plan as of now to write more as I need a huge big break now!!

#### How are the reviews and response on the book?

Yet to get as now only pre – order

is happening .....

#### Any plans for translation, audio version

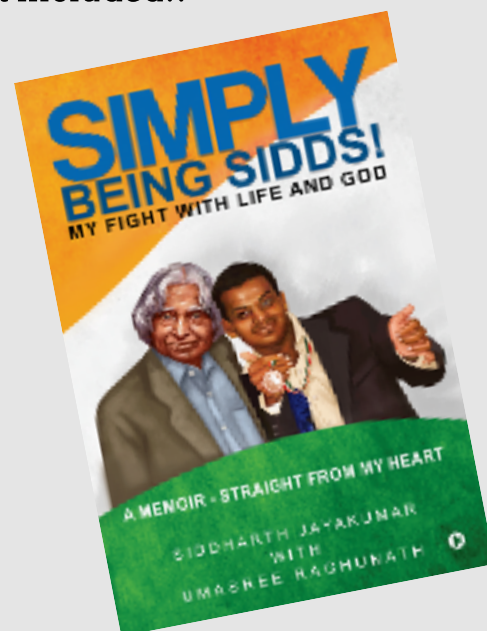
Audio version will definitely happen. Translation may take place if good offers come by!!

#### Do you think People with disabilities are getting equal opportunity in employment -what would be the game changer?

It's really tough to comment. Game changer will be changing our own mindset and give what people want from us. It's easy to keep complaining but practically it will only hurt us more. So stop complaining, focus on making friends and life will be better --- this is what I have experienced

#### Inclusion in education is still happening only in small pockets - your suggestions

Parents have to realize that their kids have to be in normal school and fight till they get included!!



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### **Bonding With Siblings**

#### **What is the positive and negative impact of a child with disability or a serious health condition on the brothers and sisters?**

The quality of the life of family members, as well as of the child with disability, can be hugely compromised in terms of physical effects, psychological distress and social problems.

Siblings can learn to participate in the family and feel pride and love in helping their brother or sister with his or her disability. The positive impact would probably be the sensitizing factor. The sibling naturally grows more aware and conscious as he grows up witnessing how the family handles treatment of the brother or sister and how a doctor is also a part of important decisions. It is something like an emotional hygiene for them or a first aid. The negative impact would be that they often feel lonely and maybe neglected as parents naturally feel more protective towards a child with a condition.

Older siblings in some cases feel a little more sidelined than the younger ones, as the former suddenly feels their share of affection being given away. This is because parents get totally caught up with the child who has a condition if he is born after a normal child, whereas if a normal child is born after a child with a condition, then the parents also feel relieved and pamper the younger one more.

There is also a difference in genders. Girl siblings are often expected to chip in more than their male counterparts in taking care of their brother or sister with a condition. They

are unable to plan activities in advance, such as holidays and family activities, and complain that they lose out on "spontaneity" and "freedom" in their lives.

Siblings often react strongly, being rebellious or faring poorly in school, mainly to get attention of the parents, who they feel are more concerned with their brother or sister with a condition.

#### **Is it okay to assume that siblings play an integral care giving role in the lives of children with conditions?**

It is perhaps unfair to assume that the siblings will do that. As a result, the sibling's childhood is often affected. They feel burdened with a responsibility they do not want. Often some amount of animosity creeps in for their brother or sister who has a condition. They feel even more pressured because they cannot even talk about it with their friends. Their academics may suffer, they often cannot go out with friends and they perceive neglect from parents. They often look for expensive options by which they can make their parents spend more money on them, which, they feel, is their right.

#### **Do siblings tend to resort to 'Parentification', i.e., developing duties similar to those of a parent? What is the usual fallout of this?**

Siblings of children with disability often face a high number of role transitions, as the household dynamic is changed and they must take on new tasks and responsibilities. A child with disability changes family members' roles, responsibilities and boundaries.

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It disrupts their self-images and self-esteem. It results in uncertain and unpredictable futures. And it triggers distressing emotions - anxiety, depression, resentments, feelings of helplessness, as well as illness.

Siblings may face a relationship based more on care giving than mutual companionship.

The result of these role transitions is often a role strain and role overload; role strain refers to the stress a person feels when one struggles to comply with one's given role, and role overload refers to the increase of role strain due to the addition of too many new roles and expectations.

### **Are siblings of children with disabilities at a greater risk than average of developing emotional issues and stress?**

The impact of the disability on families is widespread and profound. Family members are affected in multiple ways across all medical specialties. Siblings do tend to feel they have to hide their feelings from the family members in order to provide support – for many this is very difficult. This emotional impact has a major influence on many areas of their lives, e.g., on health and sleep.

Siblings are not at greater risk perhaps, but research shows that they do develop emotional issues. They even tend to get into drugs, alcohol etc because of stress. They even become suicidal. All this stems from a craving for attention.

They might get angry if they are asked to assume more household chores, than their sibling with a disability.

Siblings might feel quite guilty when they

resent the additional responsibility they are tasked with and they often get embarrassed or even angry when strangers stare at their brother or sister with a disability, or when other children tease their sibling because he or she looks different.

### **Can you share some tips for parents to ensure a 'balanced' childhood for the siblings?**

The presence of a family member with a disability provides opportunities for increased empathy, responsibility, adaptability, problem solving and creativity.

1. Communicate and Support each other.
2. Try to establish some balance between the needs of the child with disability and those of the other children.
3. Spending some time with each child individually may help.
4. Developing a special relationship with each one of the children is very therapeutic.
5. It is important that parents listen and address the questions that siblings have and give honest information about the condition.
6. As much as possible, parents must involve all the children in shared decision making about any health care that affects them.

*Dr Roma Kumar, Clinical Psychologist and Senior Consultant at the Institute of Child Health at Sir Ganga Ram Hospital, New Delhi.*

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## Tech Corner

The **Sunu band** is a smart watch that is specifically designed to help the blind navigate around people and objects. The band emits a high-frequency ultrasound wave up to 13FT away that bounces off objects and back to the band's sensors.

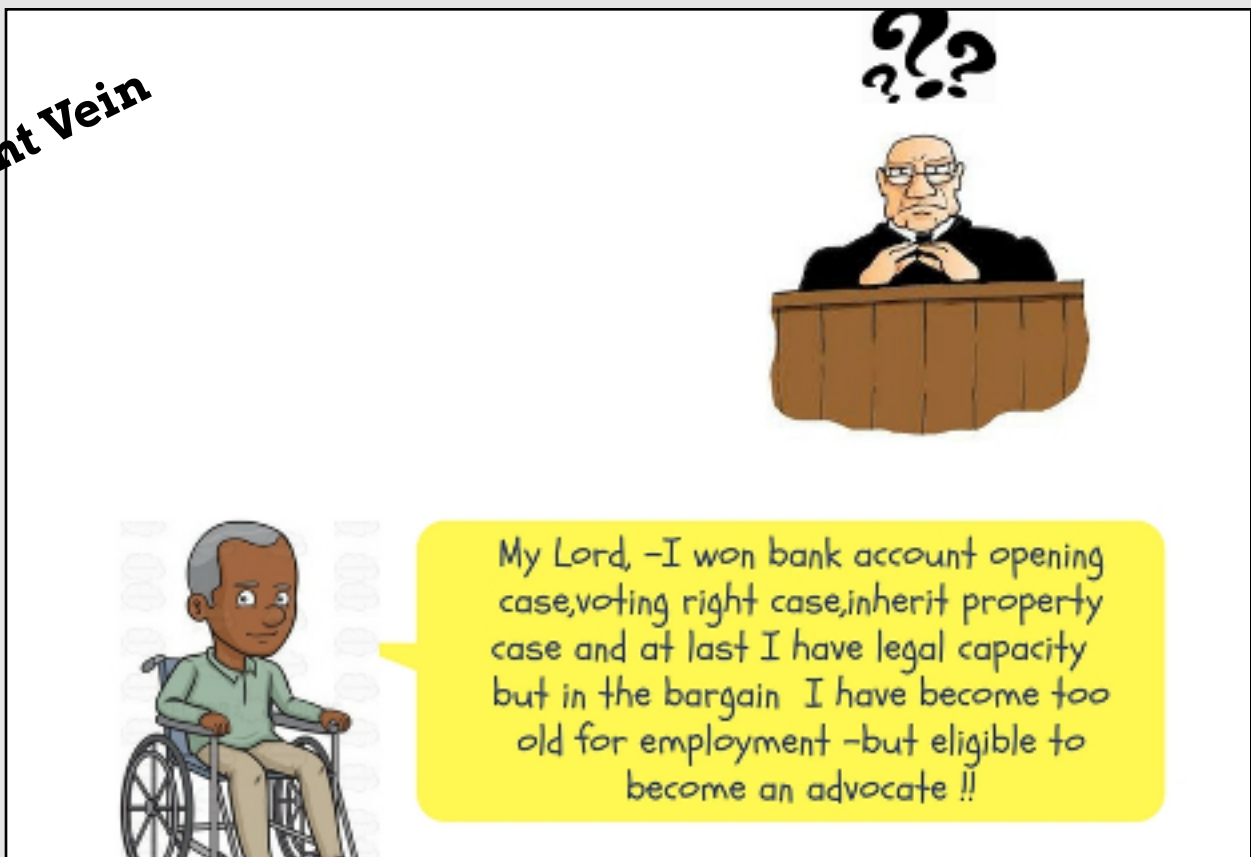
The band can detect the strength of the wave's return and then sets off a vibration, which gets stronger or weaker based on how far away an object is. The Band can also detect moving objects, like pedestrians, as they move toward and away from the wearer. The range and feedback are fully customizable by way of an app. The Sunu Band can be paired to phone by Bluetooth.



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[Access and Inclusion through Technology](#)

## In Light Vein







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### **Communication -A problem solver**

**--Sayomdeb Mukherjee**

In my life for a significant time I have been an Augmentative and Alternative Communication(AAC) user. During that time I thought communication was difficult and observing people was easy. People would think "the poor chap cannot speak, thus have no clue about the things going around him."

In short, the idea was, if you cannot speak, you lack cognitive ability as well. Silently I used to laugh when some quarrels happened in front of me. Most of the quarrels initiated due to lack of communication and miscommunication. God has given mankind the ability of speech and it is ironic that this ability is undermined, which is a root of many unfortunate events.

Some people even say " I don't have to give any clarification," but if your clarification avoids a misunderstanding which would obviously create strain in your mind, may give you sleepless nights or make your loved ones move away from you, would it be ok?

At the end, being an AAC user gave me the realization that communication solves problems rather than creating them. Utilization of speech and language enables the mankind to move ahead in evolution. Every person has been given an opportunity to communicate their ideas, needs. It is a human right. Let us move towards a "*World of friendship*" where speech will not be a barrier in obtaining rights.

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