

# Connect Special

..> Edition 26

## Editor's Desk

Dear friends,

I bring out this edition with joy at the small positive changes happening around us. At last, a beginning has been made in the field of adoption and parenthood for people with disabilities .

***To deny people their human rights is to challenge their very humanity.***

***- Nelson Mandela***

Happy Reading!!

Regards,

Bhavna Botta

**We are on the web**

[connectspecial.in](http://connectspecial.in)

**A dream fulfilled !!**

**A time to rejoice !!**



**One more landmark accomplished- Right to adopt a child by a person with disability !**

Jeeja Ghosh a well known social activist based in Kolkatta , heading Advocacy and Disability Studies of Indian Institute of Cerebral Palsy has adopted a five month old girl baby. It is a time for celebration and welcoming the bundle of joy for both Jeeja and her husband Bappaditya Nag, a law officer with Syndicate Bank.

They have named her Bhujungu and are enjoying the bliss of parenthood .It was not an easy task, a dream which they have been chasing for two years .Innumerable doors to be knocked , many hurdles to be crossed and mind sets had to be changed to ultimately get this parenthood. They have crossed an uphill task , especially Jeeja, to get the authorities understand that cerebral palsy is only a condition and she is very well capable of handling a child .They doubted her communication skills!!This was in addition to the grilling of the couples emotional, financial and physical capabilities.

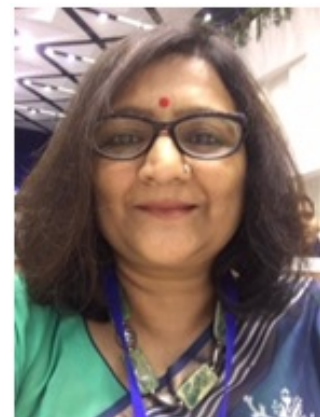
Article 23 of the CRPD explicitly guarantees the right of people with disabilities to adopt ,we need awareness ,perspective changes at all levels in the society to ensure that this right is upheld and many more enjoy this bliss.



## Independent Living - A Reality

Meet Neena Wagh ,poetess, documentary maker, freelance writer, social activist and is a proud mother of a person with autism. She shares her thoughts on a question on every parent's mind "life after us-Independent living ".This is the first part of her series on independent living.

What is the ultimate goal of our lives as parents. To give and provide the best for our children so that they do not have to suffer and can live happily ever after. How much was that possible by our parents.... are we happy, are we satisfied, are we secure and protected from the big bad world out there. What is that magic potion that will ensure that everlasting security and happiness to our special needs children. How far can we go out and help them...?? These are the questions we struggle with on a day to day basis.



Let me tell you we can create as much infrastructures, create bank balances, provide financially but what we will really have to work hard is to create an environment where we can entrust our special needs child's life with someone else in a scenario of "life after us."

Where and how do we begin to create that, what is that first thing we need to do? What would be that "constant"?! That one factor which will sail us all through thick and thin? That- which will protect our children and keep them nurtured?

The only answer I got was LOVE and Compassion towards oneself and others. Yes it may sound super simple and clichéd, but if you really start pondering, you will realize that it is the basic foundation of building any relationship. Every human being, even with his best foot forward, is incomplete -full of follies and the only way to complete oneself is to extend the same understanding and be as nonjudgmental as we expect from others.

Believe me, once we start practising this, we will start getting answers. So parents, get together, find and form your own group, start practising giving unconditional support to each other's children as well as each other and soon you will realize that your child may not have to be alone out there in the big..bad world out there...Yes its possible, I have seen the glimpse of that beautiful possibility and I dare you all to dream that.

I recently was invited in a newly constructed residential model for differently abled people in Kurukshetra started by a highly qualified special educator, Dr J. P. Keshri . He has been working since 1997.The residential facility is called Midway Home a Unit of the project SEED and Ashadeep Chain of Institutions ,is equipped with all the basic amenities.

In a 2.5 acres of serene and specially designed environment with over 40,000 sq ft covered area for around 80 resident, they have a well equipped vocational centre with the future planning for farming and horticulture thus planning for empowerment of Individuals with Developmental Disabilities and independent co -living. The place is the brainchild of parents and professionals in ensuring least restrictive environment towards independent living and decision making.

There are many beautiful dreams ,dream it!!

## **BLINK TO SPEAK: The world's first eye sign language**

*Dr. Hemangi Sane who is founder president of Asha Ek Hope Foundation & Deputy Director at NeuroGen BSI and has ALS disorder says "Blink to speak will break all the barriers of communication and set people free from limits of paralysis."*

**BLINK TO SPEAK** is the world's first eye sign language created for paralyzed patients who cannot speak. Asha Ek Hope foundation for ALS/MND and NeuroGen Brain and Spine Institute and TBWA has launched the first book of *BLINK TO SPEAK* on 16th April 2018.

### **A very unique but absolutely vital communication system ,who is the brain behind this ?**

The inspiration of the idea came to Geet Rathi (Creative Director at TBWA and volunteer at Asha Ek Hope Foundation) when she was struggling to communicate with her uncle, a last stage ALS (Motor Neuron Disease) patient. Her frustration led to her idea of creating a simple language with eye signs. With valuable inputs from Asha Ek Hope Foundation ( Dr. Hemangi Sane & team) and NeuroGen BSI (Dr.Alok Sharma & team), TBWA team ( Parixit Bhattacharya , Arshia Jain & team) created the Blink to speak eye language for patients struggling to communicate using existing methods like speech and writing.

### **What is blink to speak?**

Blink to speak is a set of 50 commands which can be used by anyone to speak with their eyes. With the help of patients and doctors a specific message was assigned to basic eye actions, covering the most common phrases needed in daily life. Patients whose body is paralyzed and has speech difficulties can use their eyes for communication. It is helpful for patients suffering from ALS / MND (Amyotrophic Lateral Sclerosis / Motor Neuron Disease), Spinal Cord Injury (Quadriplegia – paralyzed below neck), Stroke, Cerebellar Ataxia, Multiple Sclerosis, Cerebral Palsy, Head Injury, Parkinson's Disease, Muscular Dystrophy and any other Neuro-degenerative disorder. Patients on a mechanical ventilator, with an alert mind, can also use it. These can be patients in an ICU (Intensive Care Unit) or patients with Bi-pap, C-pap or a home ventilator.

This language will ease communication between patients and caregivers / family members. It can be a permanent or temporary aid for communication.

### **Do we need it what does the statistics say ?**

The worldwide prevalence of ALS is 6 per 100,000 of total population that is 4.5 lakh patients. The male to female ratio is 2:1. According to Foundation for Research on Rare Disease and Disorders (FRRDD), the frequency of ALS cases in India is 5 in 100000, that is 67 thousand patients.

Other diagnosis that will be benefited are - Worldwide numbers: Spinal Cord Injury- 5.6 million, Stroke- 35 million, Cerebral Palsy: 17 million. Indian Statistics: CP- 25 lakhs, Stroke- 33 lakhs, SCI- 15,000 new cases per year.

People with Ataxia, dystonia , muscular dystrophy etc will also benefit. Millions of patients worldwide who are on ventilator in ICU can use this language to communicate with hospital staff and their families.

### **Why is communication a challenge?**

Thousands of patients suffering from ALS/MND, Spinal Cord Injuries and Paralysis from around the world get in touch with Asha Ek Hope foundation and NeuroGen Brain and Spine and Institute. Many of these patients and their families feel helpless when it comes to communication. Towards the last stages of the disease, these patients are unable to use their voice or any hand sign language. And the struggle to communicate becomes more frustrating than the disability itself.

There are many alternative communication solutions. But they are either tiresome or very expensive, like using fancy equipment to catch the eye ball movement to type words on the computer.

## Solution to this challenge

Even when most of the functions fail, there's one muscle in the human body that stays intact till the very last.....**The Eyes !!!**

### What is Eye Language?

Ø When we want to express our thoughts and emotions we use verbal language to speak

Ø What do we do if we can't speak, we use hand gestures to emote

Ø But imagine if we can't speak and can't move our hands what can we do?

Ø We can use the Eye movements to speak.... This is precisely what Eye Language is

For example:

1 Wink symbolizes: Lets Talk

1 Blink and 1 left eye movements symbolizes: Call guardian

Furious Winking symbolizes: Emergency

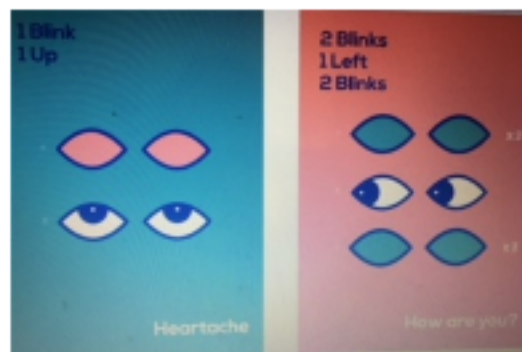
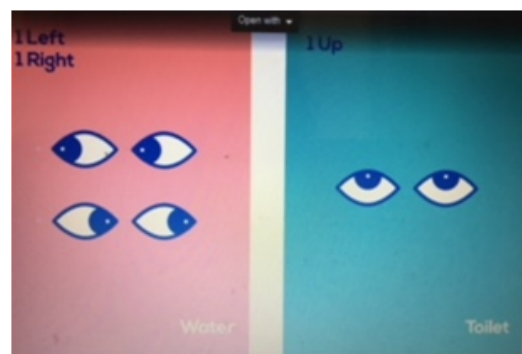
3 Wink symbolizes: I Love You

Also each English alphabet has been assigned

a specific eye movement.

For example: A is one blink.

This way one can spell out any word.



Blink to Speak Eye language Guidebook is freely available to all patients free of cost and can also be downloaded from <http://www.ashaekhope.com/blink-to-speak/> . In near future, it will be released in 5 languages, English, Hindi, Marathi, Gujrati and Malayalam.



## Free Assistive Technology Software for Speaking, Typing, and Environmental Control

*Originally published at-*

*Access and Inclusion through technology*

[-https://gettecla.com/blogs/news/free-assistive-technology-software-for-speaking-typing-and-environmental-control](https://gettecla.com/blogs/news/free-assistive-technology-software-for-speaking-typing-and-environmental-control)

Individuals with disabilities have hundreds of software and hardware to choose from that enable them to communicate, control, and connect with the world. From speech-generating software to page turners, these highly specialized tools have the power to change the ways users interact with their environment and their peers, but unfortunately, create barriers in other ways.

Innovations in technology have made it possible for developers to create free, open-source software that offers complex solutions that outperform expensive assistive technologies.

### **For Speech:**

#### **1. [Balabolka](#)**

Translating to “chatter” from Russian, Balabolka is a free text-to-speech (TTS) and voice synthesis technology that is based on Microsoft's Speech API (SAPI). The software creates a more user-friendly experience with added features including the ability to:

- Alter a voice's rate, pitch, etc.
- Apply a special substitution list to improve the quality of the voice's articulation
- Switch between 31 different languages

Overall this solution turns artificial speech generation, like Microsoft Anna, into a more natural sounding voice. This Windows software is useful for individuals with speech impairments that would benefit from a natural sounding voice that converts their text into sound.



## 2. [NaturalReader](#)

NaturalReader is a text-to-speech software that is available for personal and commercial use and can be used online or in a downloadable interface. This easy-to-use software can read allowed any text from platforms such as web pages, PDF files, and Gmail. NaturalReader can also convert printed documents and screenshots to digital text, so it can read scanned documents or screenshots from an eBook.

Features available in the free version of the downloadable software include:

- Text to Speech
- Works with PDF, Docx, TXT, and ePub
- Change speed and speaker
- Floating bar to read the text in other applications

## For Typing

### 1. [Macbook Accessibility Keyboard](#)

Mac OS's Accessibility Keyboard allows users to type on their laptop without a physical keyboard. It provides advanced typing features and navigation that users can customize to their vocabulary . [Apple's support page](#) contains information on the Accessibility Keyboard and how to use the Panel Editor to customize the Switch Control or Accessibility Keyboard panel collection and streamline common actions for different apps.

### 2. [Windows 10 On Screen Keyboard \(OSK\)](#)

Similar to Mac's Accessibility Keyboard, the Windows OSK offers a solution to users who are unable to use the physical keyboard or touchscreen interface to type on their computers.

Some additional accessibility features include:

- Scan through keys: allow the OSK to continually scan and highlight keys on the keyboard.
- Use click sounds: to hear a sound when a character is selected on the OSK.
- Show keys to make it easier to move around the screen: to have the character light up on the OSK when it is selected.

Both Mac and Windows computers also have dictation features that recognize a user's speech and turn their voice into words on the screen.

### **3. Grammarly**

Grammarly is a free app and Google Chrome Extension that automatically checks your grammar, spelling, punctuation, word choice, and style on many applications including Facebook and Microsoft Office.

### **For Environment Control**

**IFTTT** (acronym for "If This Then That") is a free automation platform that communicates between different apps, web services, and devices to trigger user-specific actions through Applets. **Tecla App** allows users to manage their tecla-e hardware and control their smart devices in one place.

**Built-in Voice Assistants** Apple's Siri, the Google Assistant, Microsoft's Cortana, Amazon Alexa and Samsung's Bixby are voice assistants that recognize a user's voice and respond to their questions using the power of artificial intelligence and machine learning.