

(A Registered Charitable Trust – Reg No. E25566)



***A SOCIETY IS JUDGED BY THE CARE IT TAKES OF IT'S UNFORTUNATE MEMBERS***

**India is home to almost 3crs people with disabilities.**

**Disability that exists from birth can be even more of a challenge.**

**India is not a disabled friendly country.**

**Health care system is fragmented and therefore proper medical treatment of disabilities is lacking.**

**The State is unable to provide for medical treatment and rehabilitation.**

**The disabled have to fend for themselves for their schooling, employment, transport etc....**



**Spina Bifida Foundation is a charitable organisation that works to support children/individuals (and their families) born with Spina Bifida which causes paralysis and other related disabilities which are more severe than polio.**

**Website: <http://spinabifidafoundation.org/> (under renovation)**

**Email id: [sbfsecretary@gmail.com](mailto:sbfsecretary@gmail.com)**

**Contact no: 9773323400 9820306107**

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Spina Bifida Foundation

## **Spina Bifida – The commonest Birth Defect in India**

As many as 40,000 children are born with Spina Bifida in India each year. Spina Bifida is a birth defect where the lower spinal cord does not form properly resulting in neurological problems.



### **Disability caused by Spina Bifida**

Spina Bifida causes significant disability in the affected individuals. The disability results in severe paralysis of the lower limbs, bladder bowel incontinence, bony deformities and hydrocephalus (water in the brain). The paralysis of the legs is usually more severe than that caused by polio.

Thus, these individuals who are born with childhood paralysis require expert medical care for the management of the related medical and surgical problems as mentioned above.

Although the paralysis of the legs is not curable the other related issues such as incontinence and hydrocephalus are medically treatable and manageable (with proper and expert medical and surgical care).

### **The silver lining of the dark cloud is that all the individuals are mentally normal.**

Thus, if properly treated and rehabilitated Spina Bifida individuals can lead productive and happy lives.

**The primary work of the Spina Bifida Foundation is to support and facilitate the proper and complete treatment of children and adults born with Spina Bifida. The Spina Bifida Foundation also works to facilitates education of these children in normal schools and undertakes many activities related to their social rehabilitation such as Psycho Sexual counselling, Sports activities, Nutrition and obesity care, employment counselling, formation of peer support groups etc.**

### **Spina Bifida is preventable**

More than 75% of cases can be prevented if women take Folic Acid (simple B complex vitamin) before pregnancy.

However, most women are not aware of this in India.

**The Spina Bifida Foundation also works for creating the much-needed awareness regarding prevention and is presently lobbying with the Central Government for launching a National level campaign on the lines of the Pulse Polio campaign.**

## **The Spina Bifida Foundation**

### **The beginnings**

Initially in 2000 the work began as a small support group formed by our founder trustee and few parents in Wadia Children's hospital, Mumbai. Soon as more and more families sought the help of the support group it evolved into a proper organization- "The Spina Bifida Foundation" which was registered as charitable trust in 2009.

### **Our Vision**

- ❖ To enable all Spina Bifida individuals in India to lead productive and happy lives.
- ❖ To prevent all preventable NTDs cases in India.

### **Our Mission**

- ❖ To enhance lives of Spina Bifida and their families- by facilitating proper medical treatment.
- ❖ To enhance lives of Spina Bifida Individuals and their families by facilitating and enabling their socio-economic rehabilitation.
- ❖ To spread public awareness about prevention of NTDs.
- ❖ To encourage proper food Fortification for prevention of NTDs.
- ❖ To lobby for starting a Birth Defects registry in India.

### **Board of Trustees and Chairpersons**

#### **Founder-Trustee**

**Dr Santosh Karmarkar (Chairperson)**

#### **Trustees**

**Ms. Jahanvi Modi (Co-chairperson)**

**Dr. Ujwala Karmarkar**

**Mr. Manish Modi**

#### **Co-Chairpersons**

**Dr Snehal Deshpande**

**Mr. T V Sudhakar**

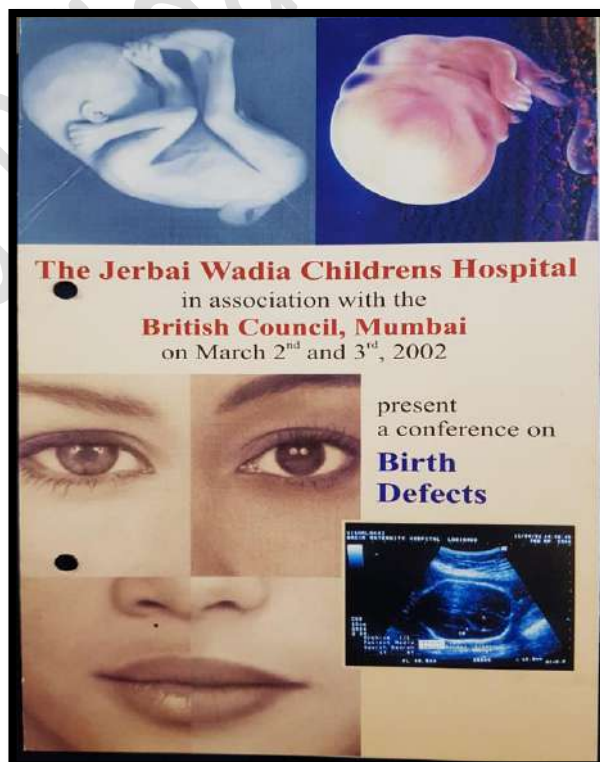
#### **Chief Coordinator**

**Ms. Sneha Sawant**

## Milestones and activities of the Foundation

### From the year 2000 till 2005

- Formation of Parent Support Group for Spina Bifida in India.
- More than 50 parents and children connected and joined this support group.
- Spina Bifida and birth defects awareness program was held in Wadia Hospital under the auspices of British Council and Wadia Childrens Hospital.





- Lectures regarding Spina Bifida Prevention held in New Bombay (Rotary Club).
- Lectures on Spina Bifida Prevention in Shillong, Meghalaya.
- Lecture in Bangalore for Spina Bifida Prevention and Management.
- Spina Bifida Prevention free checkup and counseling camp in Dadar, Mumbai under auspices of MMD Center.
- Exhibition organized by the students of Sophia College.
- Spina Bifida Prevention free campaign in Dombivali under auspices of ACE Hospital.
- Presented Research Papers on Spina Bifida in International conference in Barcelona in Spain





## TREATMENT AND REHABILITATION

In the year 2000-2005

About 25 -30 Spina bifida patients and families were treated in the Wadia Childrens Hospital. The treatment was coordinated in the Pediatric Surgery unit headed by Dr Santosh Karmarkar. The families were then followed up and guided by the Parents support group – which met in the Wadia Childrens hospital every month.

The care and rehabilitation of these patients was supported by the Physiotherapy department of the Hospital and special interest in these activities was taken by Ms. Maureen Wadia herself.

Many of these children have been followed up till date by our Foundation and are completely and productively rehabilitated.

### A CASE STUDY –

Ms Swara Madav



Ms. Swara Madav was born with major variety of Spina Bifida in Wadia Maternity Hospital underwent back closure and has been connected with the support group since then. We have guided and supported her rehabilitation throughout her schooling and her graduation from Ruparel College.

She also underwent surgery for the management of the incontinence and is now self-sufficient and gainfully employed.

### **From the year 2006 till 2008**

- 1<sup>st</sup> national SB conference at Tata hospital. First National Update on Spina Bifida Prevention held in Tata Memorial Hospital Mumbai with National and International Faculty and attended by more than 300 Doctors and Parents.
- Presented research papers in Society for research in HYDROCEPHALUS and Spina Bifida Foundation conference in Cambridge UK.



- Free Spina Bifida Prevention counseling camp in Kutch, Gujarat. Launching of Spina Bifida Prevention Pilot Project in Kutch district under auspicious of NGO – SETU.
- Lecture on prevention to mid wives (Dai) to in Kutch District. Variety of Entertainment Programmes to Children and Families of Spina Bifida at Jolly Gymkhana, Ghatkopar.
- As group started meeting and doing activities more and more parents joined this group.

## TREATMENT AND REHABILITATION

In the year 2006-2008

The Support groups work and activities kept increasing and patients from outside Mumbai also approached us for their treatment and rehabilitation issue.

Approximately 50 patients were treated and/or rehabilitated vis-à-vis their surgeries, incontinence, schooling, mobility aids etc.

The medical treatment of these patients was supported by the Lilavati Hospital Mumbai.

### A case study:

Ms Stuti Vora



Ms Stuti Vora was born with a large meningomyelocele on the back and with paralysis of both the lower limbs. At birth the family was in a state of shock and had refused any treatment considering that she will be wheelchair bound in the future. Later after 6 months when they realized she is likely to be mentally normal and smiles and recognizes them like any other child they got her back to us for treatment.

Because of the delay the back closure had become more difficult due to scarring and because of the large size of the swelling. She underwent a major and challenging operation for the same. We monitored her growth actively and supported her admission in to a normal school. We pleaded with the school authorities to give her all necessary support in school. Later as she was wheelchair bound the school was requested to constructed a lift for her and another of our Spina Bifida patients Viz Ms. Hetvi Parekh.

In due course another 8 hours supramajor operation was done to manage her incontinence. This enabled her to become more independent and fully rehabilitated.

It is matter of pride for us that Stuti today is pursuing her graduation in Psychology.

## From the year 2009 till 2014

- Spina Bifida Foundation was officially registered as Charitable trust which works for Awareness/prevention of Spina Bifida and Treatment and Rehabilitation of Spina Bifida Individuals.
- Actress Raveena Tandon associated with foundation as brand ambassador
- Launch “Folic Acid Ki Jai” as NTDs Prevention Campaign.



- Made an awareness of Folic Acid film with Actress Raveen Tandon.

<https://youtu.be/shCst2ddKA>



- Spina Bifida Prevention film screened for One month in all Big Cinema Screens in Mumbai to promote Awareness & Prevention of Spina Bifida.

- Participation as a recognized charity in Mumbai Marathon.



- Conducted Campaigns for Awareness & Prevention of spina bifida and free medical camps. Free medical examination, and medical assistance given to the non-affording individuals.
- Awareness campaigns and medical conferences had in Indore with participation of doctors from Mumbai and also Parent group representatives conducted counseling of spina bifida parents and the patients.
- Free medical camps and examination & treatment were given to all spina bifida patients at the hospital of Sri Aurobindo Institute of Medical Science, Indore. Doctors attending were Pediatrician, Orthopedics, and Physiotherapists

- Dr Santosh Karmarkar our Founder-Trustee was elected on the Board of Directors of IFSBH



- Participation in SRHSB meeting Barcelona

## **TREATMENT AND REHABILITATION**

### **In the year 2009-2014**

With the formal launch of the Spina Bifida Foundation, and with improved availability of funding, we could reach out to more patients and families for their treatment and rehabilitation requirements and support them accordingly.

During this period the SBF connected with more than 250 individuals throughout India and since all could not travel to Mumbai, the Foundation initiated the process of formation of State units to coordinate the treatment and Rehab.

### **A Case study:**

#### **Mast Parth Hendre**

Mast Parth was born with major Spina Bifida and was operated for his back lesion at birth. He had weakness in lower limbs with difficulty in walking.

He also has excessive water in the brain (hydrocephalus) for which he required ventriculo peritoneal Shunt (VP Shunt) operation.

Due to complications of the VP shunt he had to undergo several more operations.

The Foundation supported his rehabilitation including his interest and participation in swimming. This was fully encouraged and supported by his parents and led to his remarkable achievements in swimming. Parth has won several paralympic swimming medals and represented India overseas.



He has received the prestigious Chatrapatti Shivaji Award at the hands of the Ex-Chief Minister of Maharashtra.



## From 2015 to 2018

- Launch of GO Folic campaign with Meyer Vitabiotics



- Multiple Outreach Programs





- CME's Throughout India



- Multiple College Lectures



- Launch of National Helpline

## SPINA BIFIDA FOUNDATION

National Helpline +91 7506070616



All these patients contacted us through helpline in last month



ANDAMAN



ORISSA



GUJARAT



HARYANA



UP



MEGHALAYA



KARNATAKA



GOA



MAHARASHTRA

Reaching Out To More & More Spina Bifida  
Individuals And Families Nation Wide

- Get-togethers, picnics





- Swim Coaching for Spina Bifida Individuals



- Asia's 1<sup>st</sup> International Spina Bifida conference in New Delhi in 2018







## **TREATMENT AND REHABILITATION**

### **In the year 2015-2018**

The ongoing activities of the Foundation were further bolstered by the regular assurance of an annual CSR grant by Meyer -Vitabiotics.

With availability of a somewhat stable funding, the Foundation decided to widen its scope of work. Different counselling cells were formed for schooling and education, Employment, Medical treatment, Prevention, Psychological counselling, Sports, Sexuality and Fertility, Nutrition and Obesity, Family and Community activities etc.

The foundation helped several children get admission to Normal schools, which were refusing admission to them due to misconceptions regarding their disability. SBF tied up with Youth4jobs to seek employment opportunities for our members.

We continued to support the treatment of SB children in Lilavati Hospital and an average of 2-3 major surgeries for SB children were performed per month. More than 75 supramajor surgeries were performed on these cases during this period. SB families were provided a unique opportunity to interact with their peers' form across the world by sponsoring their participation in the first ever International SB families conference organised by the SBF in Delhi.

Financial support for needy patients was provided by the SEWA – social service department of Lilavati HOSPITAL and through donations raised from individual donors and well-wishers.

## **CASE STUDY**

### **Ms. Tanishtha Singh**

Tanishtha was born with Spina Bifida in Lucknow, UP. Her back operation was done at birth and initial physiotherapy was given however her bladder and bowel incontinence remained unattended and was a great hurdle in her rehabilitation. Her incontinence also resulted difficulty in schooling due to her soiling and resultant embarrassment.

She connected with the foundation from Lucknow and was called to Mumbai for the incontinence operation. The surgery was successful and she is able to be socially continent.

Tanishtha is now progressing well in school and her further development and rehabilitation is been monitored by the foundation.



From the year 2019 till 2021

- Awareness lectures in colleges in various college in Mumbai
- Launch of Saptapadi Campaign

- Nutrition and obesity and assessment and guidance camp in Lilavati Hospital for Spina Bifida Individuals





- Wheelchair training for Spina Bifida individuals using Wheelchairs



- Birth Defects prevention symposium at Nehru center Mumbai on 3<sup>rd</sup> March 2020



**And then Pandemic started but our work didn't stop**

**We started working online**

**Multiple online activities:**

- Online CMEs
- Webinars for Spina Bifida Individuals and for parents
- Online Counselling and Video consultation

Spina Bifida Foundation



09th MAY, 2020  
7 PM -8 PM

# WEBINAR ON HOLISTIC CARE OF SPINA BIFIDA



**The Speaker**



**LIVING LOVING LAUGHING &  
LEADING A PRODUCTIVE LIFE WITH  
SPINA BIFIDA**



**Dr. Santosh Karmarkar**  
Pediatric Surgeon

Please click the link below to join the webinar:  
<https://us02web.zoom.us/j/83590130100>

*Dr Santosh Karmarkar, one of the foremost Spina Bifida experts in India, will dwell on all the medico-social issues that affect the lives of individuals and families with Spina Bifida. He will discuss different aspects of care and rehabilitation that need attention as the individual goes through childhood, adolescence and into adulthood. The talk will be in Hinglish (Hindi & English) and is prepared for a mixed audience of individuals with SB, doctors treating SB and families of SB individuals.*


## TOWARDS A GLOBAL SPINA BIFIDA & HYDROCEPHALUS COMMUNITY

Date: 25<sup>th</sup> October 2020 | Location: Zoom & Livestream  
Time: 9:00 AM in New York, 3:00 PM Brussels, 6.30 PM India, & 11:00 PM for Queensland



Presentations on Global Scenario & by Country Chapters & Testimonial Stories by Persons with SBH

Together with an International Panel of Experts We Invite You to Participate

25 OCTOBER  
WORLD  
SPINA BIFIDA &  
HYDROCEPHALUS  
DAY



Supported by

**REGISTER NOW**

[www.worldspinabifidahydrocephalusday.com](http://www.worldspinabifidahydrocephalusday.com)



**27 MAY 2020, 6:30PM-7:30PM**  
**WEBINAR ON "MANAGEMENT OF  
URINARY AND BOWEL  
INCONTINENCE IN SPINA BIFIDA"**



*"One of the foremost Spina Bifida experts in India"*

MEETING ID: 698 174 5707

Join Zoom Meeting

<https://us02web.zoom.us/j/6981745707>



Talk in English-  
cum-Hindi

Talk will be  
useful for entire  
Spina Bifida  
community

Discussion on  
all Medical and  
Surgical aspects  
of Incontinence  
management

Question  
Answer Session  
For Audience

"All individuals  
with SB, family  
members of SB,  
Doctors who  
treat SB, other  
caregivers are  
invited"



**WEBINAR ON  
HEART TO HEART  
TALK BETWEEN  
SPINA BIFIDA  
INDIVIDUALS**

A LIVE CHAT WITH  
DHIVYA AND STUTI

**28<sup>th</sup> JUNE 2020  
11am – 12pm**

*"Nothing more exciting than  
meeting new people, hearing  
their stories and being  
inspired"*

**Join Zoom Meeting**

<https://us02web.zoom.us/j/6981745707>

**Meeting ID: 698 174 5707**



**DHIVYA KRISHNAN**

A wheelchair user, affected with Spina Bifida. Working as an IT Specialist for Verizon India.

Providing Peer Counselling for persons affected with Spina Bifida to lead a quality life



**STUTI VORA**

A 16-year-old teenager with spina bifida and wheelchair bound

cordially invite you to a webinar on

## "Birth Defects: An Overview"

Date: 9<sup>th</sup> January 2022 | Timing: 7:00 pm to 8:30 pm

Faculty	Agenda
<b>Dr. Kavita Bhatti</b> Professor and Head, Department of Obstetrics, GNB, Gurukul, Dehra Dun	<b>7:00 PM – 7:05 PM</b> Welcome Dr. Kavita Bhatti
<b>Dr. Dhruv Ghosh</b> Fetal Doctor (MCh), Fetal Medicine, Queen's Hospital, Nottingham, UK & ICM, Lucknow	<b>7:05 PM – 7:30 PM</b> An obstetrical overview on birth defects Dr. Kavita Bhatti
<b>Dr. Santosh Karmarkar</b> Senior Consultant, Pediatric Surgery, Government of India, Senior Lecturer, All India Institute of Medical Sciences, New Delhi	<b>7:30 PM – 7:35 PM</b> Birth defects and its management Dr. Dhruv Ghosh
<b>Dr. William Bhatti</b> Professor and Head, Department of Pediatric Surgery, GNB, Gurukul	<b>7:35 PM – 7:50 PM</b> NTDs and its causes Dr. Santosh Karmarkar
<b>Dr. Vishal Michael</b> Assistant Professor, Department of Pediatric Surgery, GNB, Gurukul	<b>7:50 PM – 8:30 PM</b> Panel discussion Panelist: Dr. William Bhatti Dr. Vishal Michael Dr. Neel Sukhjit Singh Dr. Santosh Karmarkar Dr. Kavita Bhatti
<b>Dr. Neel Sukhjit Singh</b> Assistant Professor, Department of Pediatrics, GNB, Gurukul	
<b>Dr. Tanvi Goyal</b> Senior Lecturer, GNB, Gurukul	
<b>Coordinator</b> Dr. Yashv Datta	

[Click here to register](#) | [Click here for disclaimer](#)

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**MEYER** In association with **Spina Bifida Foundation**

## Webinar on Birth Defects & Preventive Measures

Date: 17<sup>th</sup> July, 2021 | Time: 05:00 PM to 05:00 PM

**Speakers**

- Dr. Jyoti Sharma**  
MBBS, MD (OBS & GYNAE), KMC Lucknow, G.R. Hospital, Ashby hall, Dehradun
- Dr. Santosh Singh**  
MS, MCh, DNB, PGDIBH, FIAPS, Associate Professor (Pediatric Surgery), Himalayan Institute of Medical Sciences (HIMS), SHL University, Dehradun.

**Coordinator**

- Ms. Sneha Sawant**  
Chief Coordinator, Spina Bifida Foundation.

Meyer pulsar team & SBF invites you to join live webinar: <https://bit.ly/3y09uM8> Passcode: **pregnacare**

An educational initiative from the makers of **Pregnacare** and **ultra Omega-3**

Department of Pediatric Surgery Lilavati Hospital & The Spina Bifida Foundation

## FETAL SURGERY: STATE OF THE ART

**SATURDAY 24 JULY**  
05:00 pm (Indian Time)

**Keynote Speaker**

- DR. AGNIESZKA PASTUSZKA**  
Professor, Fetal Medicine, and Pediatric Gastroenterology of the European Centre for Fetal Surgery (ECLS) and International Conference on Fetal Surgery (ICFSS) at the City of Children, Surgery and Obstetrics Medical University of Warsaw in Warsaw.

**Guest Speaker**

- DR ANITA OLSZEK**  
Chief of Department OB, Obstetrics and Gynecology, Krakow

**Panelist**

- Dr. Ravi Ramadwar**  
Professor of OB-GYN, Senior Fetal Medicine Surgeon and Fetal Medicine Surgeon
- Dr. Shantha Kumari**  
Professor of OB-GYN, Fetal Medicine Surgeon, Fetal Medicine Surgeon, Fetal Medicine Surgeon

**Program Co-ordinator**

- Dr. Santosh Karmarkar**  
Senior Lecturer, Senior Pediatric Surgeon & Lecturer, Assistant Professor, Member, member Board of Directors IITM

**Closing Remark by**

- Mr. Rohit Shelokar**  
Director, Fetal Medicine, Assistant Lecturer, Assistant Professor, Member of the Grand Medical Foundation

In Association With

Sponsored by **Pregnacare** and **MEYER**

For Registration Please Visit: <https://www.lilavatihospital.com/webinar/register> With Code: **SPINA-24JULY2021**

- Formation of India Birth Defects Prevention Task Force

Member Name	Professional Affiliation
Dr. Anthony Asok	Chancellor's Professor/Professor of Medicine, Indiana University
Dr. Aroojis Alaric	Consultant Paediatric Orthopaedic Surgeon Lilavati Hospital, Hinduja Hospital & Bai Jerbai Wadia Hospital for Children, Mumbai
Dr. Bhalla Parveen	Project Lead, Food Fortification Initiative, India
Dr. Dutta Subrata	Executive Director, FARMER
Mr. Dixit Narendra	Tax & Finance Consultant, President, Sukhayu Janmjat Vyadhi Pratibandh Va Sahayya Pratihthan, Sangli
Dr. Karmarkar Santosh	Consultant Pediatric Surgeon & Pediatric Urologist Lilavati Hospital & Research Centre, Member of International Federation of Hydrocephalus Spina Bifida, Convener and Founder Trustee of Spina Bifida Foundation
Dr. Kar Anita	Founder-Director of a research NGO, the Birth Defects and Childhood Disability Research Centre, located in Pune.
Dr. Kancherla Vijaya	Epidemiologist and Deputy Director, Center for Spina Bifida Prevention, Department of Epidemiology, Emory University Rollins School of Public Health, Atlanta, GA, USA
Dr. Kaur Manmeet	Prof. Health Promotion, School of Public Health, PGIMER, Chandigarh, India.
Ms. Krishnan Dhivya	IT Consultant, Verizon India, Chennai
Dr. Mehta Rajesh	Pediatrician, India
Mr. Montgomery Scott	Director, Food Fortification Initiative, Atlanta, GA, USA
Dr. Nanda S K	Advisor NDMA and Director in India International Exchange at Gift city
Dr. Oakley Godfrey	Pediatrician. Research Professor, Department of Epidemiology, Emory University Rollins School of Public Health and Director, Center for Spina Bifida Prevention, Emory University Rollins School of Public Health, Atlanta, GA, USA
Dr. Roozen Sylvia	Secretary General, International Federation for Spina Bifida and Hydrocephalus, Belgium
Ms. Sawant Sneha	Chief Coordinator, Spina Bifida Foundation, India
Dr. Vora Ravindra	PG Teacher for DNB-PS, Community oriented Paediatric Surgery section of Indian Association of Paediatric Surgery

- Meeting with Central Health Minister Mr. Mansukh Mandaviya and Dr. Bharati Pawar for appraising them about Spina Bifida and its prevention

**Meeting with Hon. Ministers  
Mr. Mansukh Mandaviyaji and Dr. Bhagwat  
Karadji**



**Date: 11th November 2021**

**Meeting with Hon. Minister  
Dr. Bharti Pawarji**



**Date: 11th November 2021**

- Closed-door webinar on for young adults on Psycho-sexual issues of Spina Bifida.

## **CASE STUDY**

Ms KHUSHI GANATRA

Ms Khushi was case of Spina Bifida with complete paralysis and wheelchair dependence connected with the Foundation as an adult.

Coming from poor socio-economic background she need support and help for fund her soaring ambitions for participation in various sporting activities.

The foundation has stood strongly behind Khushi and helped fund her participation in a sporting events and competitions across India.

Recently the Foundation did Fundraising Campaign for her requirement of a special customized high-end wheelchair costing Rs. 2,00,000/-.

Inspite of her disabilities she is highly positive individual and a motivational speaker. Khushi was invited in the Sare Gama Pa little camps (telecast- Sony entertainment) to motivate others.



Spina bi

**2022**

- Presentation to FSSAI scientific committee on Fortification standards
- Major achievement HDFC Life CSR have committed to give a grant of RS. 40,00,000/- for Spina Bifida Patients treatment.
- Hon Health Minister of Maharashtra – Mr. Rajesh Tope for the Launch of an Awareness campaign in Maharashtra, BD Registry, and Food Fortification

## **Meeting with Hon. Maharashtra Health Minister**



**Date: 17th May 2022**

- Participation in WHO SEARO meeting on Birth Defects.



**Regional Meeting to Strengthen National Plans for surveillance and Prevention of Birth Defects and Stillbirths towards Accelerating Reduction in Newborn Mortality**  
**22-24 August 2022, New Delhi, India**

Spina Bifida Foundation

- Outreach programs- Free counselling and guidance regarding treatment for Spina Bifida children/individuals:
  1. Jawahar, Maharashtra- more than 100 patients examined (of all birth defects)



Spina B



## 2. Delhi- 25 patients examined (Spina Bifida)



3. Calicut, Kerala- More than 10 Spina Bifida patients examined



4. Dharwad, Karnataka- 22 patients examined (Spina Bifida)



Spina Blind

ation

## CMEs

1. Conference on “Birth Defects: An Overview” (Spina Bifida) in Calicut, Kerala



2. Conference on “Birth Defects: An Overview” (Spina Bifida) in Dharwad, Karnataka



## Recent Webinar's:



**"The disabled can have it all:  
Pregnancy and motherhood"**



*Yes, The disabled can have babies*  
very cute ones might we add!

What is it like to give birth as a woman with a physical disability?  
**let us hear, learn & get amazed by the women who  
already embraced this journey in their own voices**

To get more info join Whatsapp & Telegram group

8th MAY 2022  
6.00 pm to 7.00 pm

Join us on Zoom



**"Sport is for all"**

**Celebrating  
Sports For People  
With Disabilities**

Spina Bifida Foundation invites the disabled community and patrons to join us in an insightful conversation on adaptive sports. Discussion includes tips + mindset shifts

100% ONLINE

**SUNDAY**  
18th, September 2022  
03.30 PM - 5.00 PM

JOIN OUR WHATS APP GROUP

**CLICK HERE**

**THE SPEAKER LINEUP**

**SPEAKER 1**  
**Aditya Mandan**  
IT professional  
National level Para  
Powerlifter

**SPEAKER 2**  
**Khushi Ganatra**  
Video editor  
Power Lifter.  
Sports enthusiast

**MODERATOR**  
**Maithili Gaikwad**  
Human resources  
at BOD  
Para Swimmer

**MODERATOR**  
**Harichandana**  
Junior analyst  
Art enthusiast  
SBF Youth team

**MODERATOR**  
**Sameen momin**  
Masters in  
commerce  
SBF team

## Recent a Case Studies:

### 1. Master. Rohit Belkar

Rohit Belkar was born with Spina Bifida in Dahanu, Palghar District in a tribal community.

First, we saw him in Jawahar Outreach program conducted by the Foundation in April and decided to completely provide for his full treatment.

In May he got operated for his back and later he was operated for Hydrocephalus. Spina Bifida Foundation supported the cost of his operations.

The Foundation is monitoring his further rehabilitation.

## दुर्मीळ आजार झालेल्या लहानग्यावर यशस्वी शस्त्रक्रिया

**संतोष आंधळे**  
लोकमत न्यूज नेटवर्क  
मुंबई : अवघ्या पाच वर्षांचा रोहित... खरे तर हे त्याचे खेळण्या-बागडण्याचे दिवस... मात्र, खेळणे तर दुरच साध्या हालचाली करण्यासाठीही रोहितला पालकांवर विसंबून राहावे लागत होते. त्याच्या पाठीवर मोठी गाठ आली होती. तसेच कंबरखालचा संपूर्ण भाग पंगू अवस्थेत होता. घरची आर्थिक स्थिती बेताचीच. त्यामुळे रोहितच्या पालकांना इच्छा असूनही त्याच्यावर उपचार करता येत नव्हते. मात्र, आता रोहित पूर्णपणे बरा झाला असून त्याच्यावर यशस्वी शस्त्रक्रिया झाली आहे. येत्या काळात त्याला फिजिओथेरेपीची गरज भासणार आहे.

डहाणू येथील आदिवासी भ्रग्रात राहणाऱ्या रोहितवर नुकतीच वॉन्ड्रे येथील लीलावती रुग्णालयात शस्त्रक्रिया करण्यात आली. त्याला 'स्पायना बिफिडा' हा दुर्मीळ आजार

पाच वर्षांच्या रोहीतवर लीलावती रुग्णालयात शस्त्रक्रिया झाली.

असल्याचे निदान झाले होते. त्यावरील उपचारासाठी लाखो रुपये खर्च येतो. त्यामुळे रोहितच्या पालकांची कुचंबणा होत होती. परंतु त्यांच्या गावात स्पायना बिफिडा फाउंडेशनचे वैद्यकीय शिबिर झाले आणि रोहितचे भाग्य उजळले. संस्थेनेच खर्च उचलत त्याला लीलावती रुग्णालयात भरती केले.

### खर्चाची जबाबदारी फाउंडेशनने उचलली

आमच्या भ्रग्रात स्पायना बिफिडा फाउंडेशनने वैद्यकीय शिबिर आयोजित केले होते. तेव्हा या आजाराची माहिती मिळाली. याबाबत कुठे उपचार होऊ शकते, हेही संस्थेने सांगितले. मात्र, आमची परिस्थिती नमल्यामुळे फाउंडेशनचे मुलांच्या शस्त्रक्रियेची जबाबदारी उचलली.

- अनंत वेलकर, रोहितचे वडील

### हजारपैकी चौघांनाच होतो हा आजार

स्पायना बिफिडाने त्रस्त मुलांना तक्राळ उपचारांची गरज असते. अन्यथा बालकाच्या मेंदूची वाढ खुंटते. त्याच्या जीवावर बेतू शकतो. आर्थिक स्थिती पाहता मानधन घेतले नाही. देशात १००० मुलांमध्ये ४ मुले या आजाराने पीडित आहेत.

- डॉ. संतोष करमरकर, बाल शल्यचिकित्सक, लीलावती रुग्णालय

### जनजागृती होणे महत्त्वाचे

श्रमण भ्रग्रात स्पायना बिफिडाबाबत म्हुणाची तशी जनजागृती झालेली नाही. आम्ही विविध भ्रग्रात वैद्यकीय शिबिरे घेत असतो. रोहितशाबेत कसा जाऊ शकेल यासाठी आमचे प्रयत्न असतील. या आजाराबाबत माहितीसाठी आमची हेल्पलाइन असून, क्रमांक ७५०६०७०६२६ हा आहे.

- स्नेहा सावंत, समन्वयक, स्पायना बिफिडा फाउंडेशन

### स्पायना बिफिडा आहे तरी काय?

- या आजारात बहुतांश वेळा पाठीवर गाठ असते, शिवाय कंबरखालील भाग लुळा पडलेला असतो.
- विशेष म्हुणजे मेंदूत मोठ्या प्रमाणात पाणी साठलेले असते. त्यामुळे मेंदूची वाढ होत नाही.
- हा आजार जन्मात असून पाठीच्या कण्याची वाढ त्यात खुंटलेली असते.
- अशा परिस्थितीत या मुलांच्या वैद्यकीय चाचण्या करून त्याचे योग्य निदान करण्याची गरज असते.
- अनेक वेळा या आजाराच्या उपचारांचा भाग म्हुणून मोठी शस्त्रक्रिया डॉक्टरांना करावी लागते.
- खासगी रुग्णालयात या आजाराच्या शस्त्रक्रियेसाठी ५-६ लाखांचा खर्च अपेक्षित असतो.
- अनेकदा एक किंवा अधिक शस्त्रक्रिया कराव्या लागतात.





Spina Bifida Foundation



## 2. Master Ariz Hussain

Ariz Hussain is now 8month old baby from interior Jharkhand near Ranchi. He was born with big back lesion since birth. Till the age of 5months he was going to pillar to post trying to get guidance about his treatment. The Doctors in Jharkhand were reluctant to treat such a case.

He got connected with us through our helpline number. We asked the parents to come here for his treatment. He got operated in August for his back and VP Shunt was put and the entire treatment was funded by Spina Bifida Foundation.

Now this boy is growing well and we will supervise his further rehabilitation.





Smiling baby from Jharkhand

Spina Bifida Foundation

## **NOTEWORTHY ACHIEVEMENTS OF THE FOUNDATION SO FAR (A SUMMARY)**

**INITIATED, FACILITATED AND SUPPORTED THE MEDICAL AND SURGICAL TREATMENT OF OVER 500 CHILDREN AND ADULTS BORN WITH SPINA BIFIDA**

**RECENTLY OBTAINED MAJOR CSR FUNDING FOR TREATMENT AND REHABILITATION OF MANY MORE PATIENTS FROM ACROSS THE COUNTRY**

**FACILITATED AND PUSHED FOR ADMISSION AND INTEGRATION OF SPINA BIFIDA CHILDREN INTO NORMAL SCHOOLS – WHEN MANY-A-TIMES SCHOOLS WERE RELUCTANT TO ADMIT THESE CHILDREN.**

**FREE COUNSELING AND GUIDANCE TO MORE THAN 500 PATIENTS AND SEVERAL DOCTORS ACROSS THE COUNTRY FOR THEIR PROPER TREATMENT AND REHABILITATION.**

**CONDUCTED MORE THAN 25 OUTREACH PROGRAMS FOR PATIENTS THROUGHOUT THE COUNTRY. AND REACHED HUNDREDS OF PATIENTS AND FAMILIES.**

**CONDUCTED MORE THAN 50 CONTINUING MEDICAL EDUCATION PROGRAMS FOR SPECIALIST DOCTORS WHO ARE REQUIRED TO TAKE CARE OF SPINA BIFIDA**

**CREATED 4 SPECIALIST TEAMS FOR TREATMENT AND REHABILITATION OF SPINA BIFIDA IN DIFFERENT REGIONS OF THE COUNTRY**

**ORGANISED THE FIRST INTERNATIONAL CONFERENCE FOR SPINA BIFIDA INDIVIDUALS AND FAMILIES IN DELHI IN 2018 PROVIDING A UNIQUE OPPORTUNITY TO LEARN AND SHARE.**

**FORMATION OF AN INTERNATIONAL TASK FORCE FOR PREVENTION OF NEURAL TUBE DEFECTS FOR INDIA**

**OUR FOUNDER TRUISTEE WAS ELECTED ON THE BOARD OF DIRECTORS OF THE INTERNATIONAL FEDERATION HEAD QUARTERED IN BRUSSELS**

**PUBLISHED PAPERS IN INTERNATIONAL JOURNALS REGARDING THE SITUATION OF SPINA BIFIDA IN INDIA AND ITS PREVENTION**

**PARTICIPATION AND INITIATION OF A LANDMARK STUDY FOR FORTIFICATION OF TEA WITH FOLIC ACID TO PREVENT SPINA BIFIDA**

Spina Bifida Foundation

## Major Supporters of the Foundation





**Address: G-1, Enid's CHS, Chapel Road, Near Lilavati Hospital and opposite to Shri Padmavati Xerox and Lovely Stores, Bandra West, Mumbai- 400050.**

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