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# World Birth Defect Day 2020, 03 March

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**MARCH 03**

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**SPINA BIFIDA FOUNDATION**

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Dr Amrutha K, Ms. Arshiya Kadri



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# World Birth Defect Day 2020

A way forward for Maharashtra state...

Name: World Birth Defect Day Event

Date: March 2, 2020

Location: Hall of Culture, Nehru Centre, Worli

Attendance: 72 registrations + Spina Bifida Foundation office staff and Meyer office staff)

Sponsoring Organization: Meyer Organics Pvt Ltd.



**Dr Karmarkar delivers the Keynote address**



**Attendees register at the welcome desk**

## About World Birth Defects day:

The March of Dimes along with 11 other international organizations working on birth defects including The International Federation for Spina Bifida and Hydrocephalus observed the first World Birth Defects Day (WBDD) on 3 March 2015. The first WBDD was first observed in 2015 with the aim to provide one global voice and a platform to all organizations and institutions engaged in birth defects related surveillance, research, prevention and care activities.

It was created with the aim to raise awareness of this serious global health concern and to advocate for increased monitoring, promote research, find causes, improve prevention, and to promote care so as to help children and adults with birth defects for improving their quality of life and participation in society.

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The WBDD movement, over the next five years, aims at accelerating coordinated efforts to enable organizations and institutions working on birth defects to:

- To reduce the occurrence of birth defects for which there are proven prevention strategies,
- To improve quality of life of all individuals and families affected by birth defects,
- To advance knowledge on epidemiology of birth defects by initiating new monitoring and research programs and strengthening the existing ones to better understand how birth defects impact children, families and communities,
- To secure financial and public support for prevention efforts and for research to find causes of birth defects and identify best practices for treatment and care of children with birth defects,
- To develop training courses and/or disseminate the existing ones.

The Spina Bifida Foundation (SBF) in association with the Go Folic Campaign organized an event on World Birth Defects Day, March 3, 2020. The event began at 3.30 pm at Nehru center, Worli. The event was open for doctors, individuals with birth defects and their parents and the other stakeholders. Out of the total 72 registrations, near to 40 were doctors. Renowned Marathi film Actor **Ms. Varsha Usangaokar** was a special invitee at the event.



Ms Varsha Usgaonkar with Ms. Uma Kalekar



A section of the audience



**Ms. Varsha usgaonkar addresses the gathering      Dr Snehal Deshpande, Dr Taral Nagda  
& Ms. Uma Kalekar in the Panel**

Dr. Snehal Deshpande, a founder member of the Foundation and a leading pioneer in Pediatric physiotherapy welcomed the gathering. Dr. Sanchita Sarang Nadkarni (CEO, SBF) spoke about the beginnings and importance of the World Birth Defects Day.

Dr Anant Bangar, Founder member of the SBF, and Pediatric Surgeon at Lilavati Hospital Mumbai, spoke about the birth and growth of SBF in India. He mentioned that today the SBF has 15 State chapters in India and will be reaching out to all the other States soon.

Dr Santosh Karmarkar the Founder Trustee of the SBF and a Pediatric Surgeon affiliated to the Lilavati Hospital in Mumbai, gave his opening remarks highlighting the need for addressing the issue of Birth defects especially Neural tube defects in India and mentioned the meeting agenda with the audience.

This was followed by Dr Amrish Vaidya's (Pediatric Surgeon from Mumbai, affiliated to the SRCC Hospital in Mumbai talk on an overview about birth defects. He highlighted on the overview of Birth defects.



**Dr Snehal Deshpande welcomes the audience**



**Dr Sanchita Sarang speaks on WBDD**



**Dr Anant Bangar spoke on the SBF**



**Dr Amrish Vaidya gives an Overview of BDs**

Mr. T Sudhakar, who is a core committee member and Treasurer of SBF and President and Chief compliance officer, Kotak Mahindra Bank, Mumbai, shared his real-life experience of raising a child with spina bifida and narrated their journey from a small town in Andhra Pradesh to adulthood and employment of his daughter.

Dr. R. M. Marad a busy Pediatrician and the Medical Superintendent at the bustling Cottage hospital in Jawhar, enlightened the audience with his experiences, facts and limitations about the diagnosis and treatment of birth defects in a rural setting. He mentioned about the

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joint counseling and treatment program for Birth defects conducted by the Cottage Hospital with the SBF and Lilavati Hospital since last year.



**Mr Sudhakar narrates his story of raising a child with SB from Birth to Adulthood**



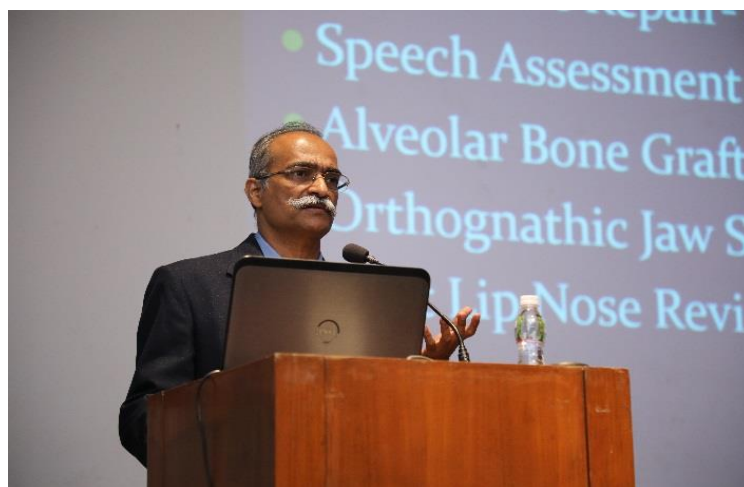
**Dr Marad enlightens the audience about Birth defects in the rural setting of Jawhar**

Dr Nitin Mokal ,Craniofacial Surgeon SRCC and Wadia Hospitals in Mumbai shared insights about the epidemiological prevalence of Cleft Palate and the role the ‘Smile Train’ (Charitable Organization) plays in addressing this birth defect in India and the world.

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Dr Alaric Aroojis, Founder member of the SBF, Pediatric Orthopedic Surgeon and Sr. Medical Advisor at MiracleFeet International spoke about Club Foot and the contributions made by MiracleFeet in the treatment of this common BD. Additionally, he conveyed the significance of collaborations and association of various organizations around the world in addressing Birth Defects.

Dr Deepak Changlani (Pediatric Cardiologist) was the next speaker, and he shared his experiences of treating Congenital Heart Diseases.



**Dr Nitin Mokal speaks about Cleft Lip and Palate & role of the “Smile Train”**



**Dr Alaric Aroojis speaks on CTEV and the role of “Miracle Feet”**



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The next part of the event was a presentation by Ms. Arshiya Kadri (MSc. Student at the Nirmala Niketan college and a Jr.Executive at SBF) on the importance of home-visits to families with children suffering from Spina Bifida.

Later, Ms. Sangeetha Chakrapani (Founder Trustee/Chief Co-worker, Together Foundation, Mumbai) shared her experience of raising a child with complex Birth defects and the treatment and multiple surgeries required.

Dr. Ravi Ramadwar, Pediatric Surgeon and President Elect of the Indian Association of Pediatric Surgeons was the next speaker. He eloquently conveyed the importance of the role of professional organizations in addressing all issues related to Birth Defects.

Next part of the event was a short film produced by the SBF- “Kartik goes to school” (in rural Palghar) which demonstrated the every-day challenges faced by a child living with Spina bifida.

Last but certainly not the least, was the important talk by Prof Dr. S Suresh renowned Foetal Medical expert from Chennai. He discussed the significance of maintaining a government-led mandatory standardized birth defect registry throughout India. He also narrated their experience of setting up India’s first such registry from Chennai.



**Dr. Changlani speaks on Cong Heart Defects**



**Ms. Chakrapani narrates her experience**



**Dr. Suresh speaks about Birth Defects registry**



**Ms. Arshiya Kadri spoke on Home visits**

### **An interactive Panel Discussion:**

A Panel discussion about the prevention and treatment of Birth Defects was moderated by Dr Santosh Karmarkar. The Panelists were Ms Uma Kalekar (President, India in-charge Meyer-Vitabiotics, Mumbai, Dr Taral Nagda (Pediatric Orthopaedic Surgeon and committee member of SBF), Dr Snehal Deshpande, Dr Hemant Lahoti (Pediatric Surgeon and HOD D Y Patil Hospital Navi Mumbai and Dr Ameet Patki (Sr.Consultant Obstetrician, Mumbai). The panelists brainstormed and exchanged information about common birth defects in India. All the panelists agreed that efforts for awareness and prevention need to be taken by the government on an urgent basis. Furthermore, they also emphasized the immediate requirement of setting up a Birth Defect Registry through-out India; and dwelled on how Maharashtra should take a lead in many of these issues.



The Panel discussion on Birth defects – Awareness Prevention and treatment.

Moderated by Dr Santosh Karmarkar.

Panelists:

1. Ms Uma Kalekar, President, India In-charge Meyer-Vitabiotics, Mumbai
2. Dr Taral Nagda , Pediatric Orthopedic Surgeon & HOD SRCC NH Children’sHospital
3. Dr Snehal Deshpande, Pediatric Physiotherapist & Director Sneh RERC, Mumbai
4. Dr Hemant Lahoti, Consultant Pediatric Surgeon, D Y Patil Hospital, Navi Mumbai
5. Dr Ameet Patki, Consultant Obstetrician,

After the discussion, a short film produced by SBF- “The movement of life inside of Me” was presented. The film was about a inspiring young woman with SB from Chennai, and how she navigated her life , marriage and pregnancy. She is now a proud mother of a bright baby girl.

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The meeting and Panel discussion ended by reaching a Consensus on two important priorities

### 1. AWARENESS

The first priority is to increase the visibility of birth defects and disseminate what is already known on how to prevent birth defects and to improve the quality of life of affected individuals.

Maharashtra should take the lead and be an example for other states. A Prevention awareness PSA film produced by the SBF can be shown on TV channels. And a Saptapadi Poster campaign can be carried out throughout Maharashtra – and India.

### 2. BIRTH DEFECTS REGISTRY

Maharashtra, should take lead in the areas of establishing birth defects registry, A model has been developed by Dr Suresh, The SBF and the Govt of Maharashtra can initiate and pursue the creation and the development of such a registry, This could become an example for the country to emulate.

Reference:

<https://www.worldbirthdefectsday.org/>

***SOCIETY IS JUDGED BY THE WAY IT TAKES CARE OF ITS  
UNFORTUNATE MEMBERS***