

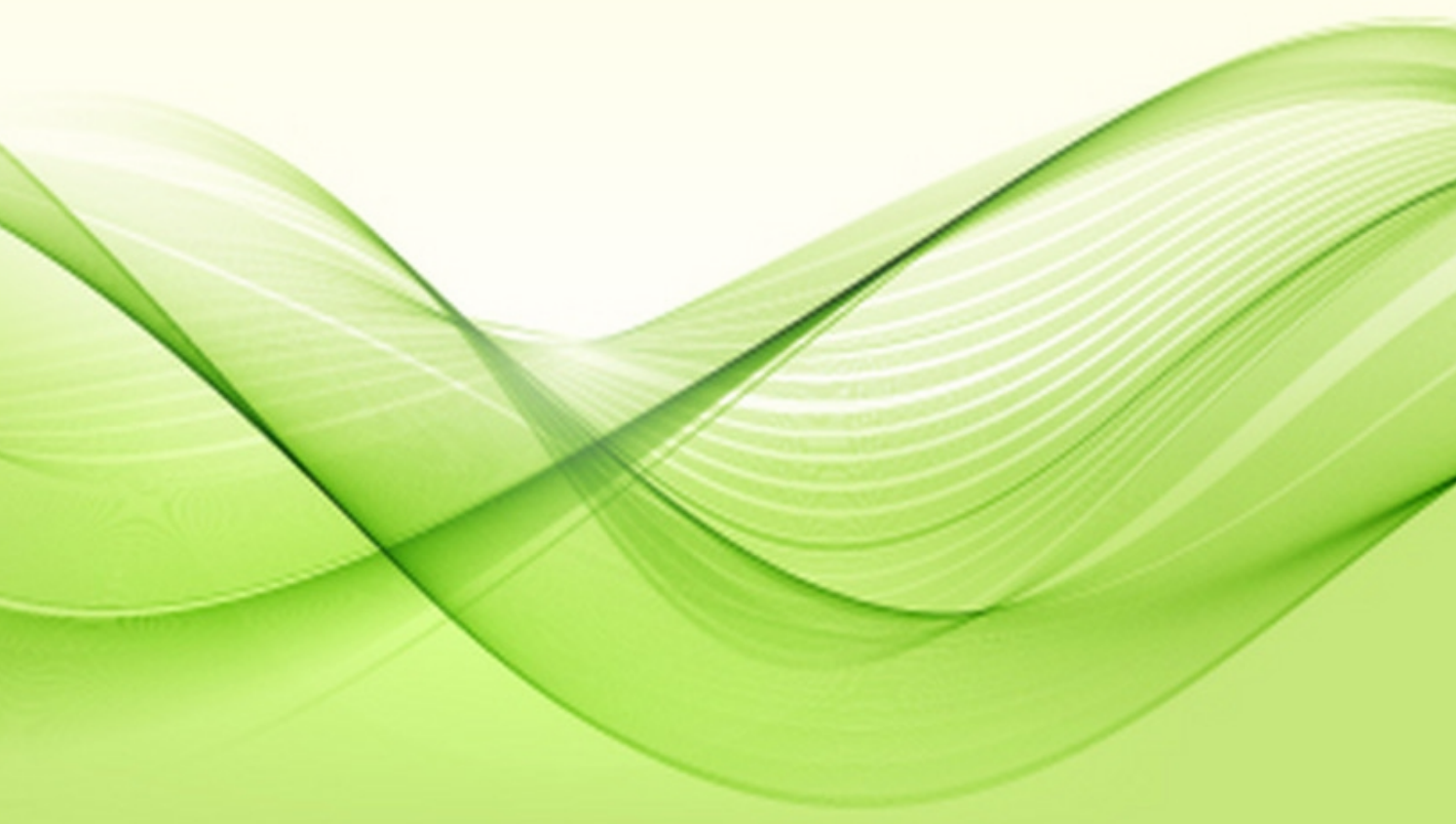
The Journey...

CURE SMA FOUNDATION OF INDIA 2019



Cure
SMA
India

Hope Beyond Boundaries



THE JOURNEY... CURE SMA INDIA 2019

AN OVERVIEW

Cure SMA Foundation of India is a parent led community, initiated in January 2014 by a small group of parents of children suffering Spinal Muscular Atrophy, a rare degenerative, life threatening, crippling neuromuscular disease. Parents of SMA warriors and adult SMA patients came together to collectively raise awareness about the disease, building infrastructure for better management of the disease and advocate for broader access to available approved treatment and clinical trials. In 2018, the community evolved & grew and thus was registered and incorporated.

Cure SMA Foundation of India is a registered public charitable trust with PAN India representation. Since the humble beginning of 10 families, we have grown to represent SMA families and individuals across the country. Each year we support SMA families through our newly diagnosed care and counseling, resource pool, SMA camp and supportive services, patient advocacy and many other direct family support services. We are extensively working to empower SMA patients and enabling them to access existing services and facilities. Using the experience and wisdom from our senior parents and SMA warriors as well as from some of the specialized Doctors we are continuously developing SMA protocols for the management of the disease & its prognosis with an aim to extend lives of our super Smart SMA Warriors. We understand that SMA disease does not give us luxury of time and therefore we are augmenting our efforts on an ongoing basis to bring the lifesaving SMA treatments/therapy & clinical trials to India as well as advocate for indigenous research & development for biologics and biosimilar to make all this accessible, affordable & barrier free.

At Cure SMA Foundation of India, every decision, every priority, every action is driven by our vision and mission.

OUR VISION

We dream of a SMA free world and a barrier free universal healthcare for all.

OUR MISSION

We are committed for bringing treatment and cure for SMA to India and make healthcare accessible, inclusive and insured for all. We are committed to create awareness about SMA and significance of Genetic screening so that we see a world without Genetic & Rare Diseases. We are committed to collaborate with all other Rare Disease community to work towards the common goal of Universal Health Care.

WHAT IS SMA ?

Spinal Muscular Atrophy (SMA) is an inherited disease where there is progressive loss of motor nerve cells in the brainstem and spinal cord that control essential muscle activity such as walking, sitting, breathing and even swallowing. It is the number one genetic cause of death for infants. SMA is caused by a mutation in the survival motor neuron gene 1 (SMN1). There is an estimated 3 to 4 lakhs affected children in India, although this may be an under prediction as it is from an extrapolation of western data.



OUR VALUES

Our commitment to a treatment and cure is not just about seeking solutions -it's also about creating them

BALANCE

As relentlessly we pursue a treatment and cure, we are also strategic.

We know the fastest way to future without SMA is to take a comprehensive, unbiased approach to research and maintain a balance of optimism and realism.

COLLABORATION

Our community is everything to us. We would not have made it this far in our fight without the invaluable contributions of our researchers, doctors and families. Together we are and always will be stronger than SMA.

RESPECT

No one can conceive of a greater loss than the loss of one's self-respect. At Cure SMA Foundation of India we firmly believe in Right to live a dignified life by the individual patients and families. The society needs to accept and Respect the dignified way of life each SMA Individual chooses to live.

There is no right way to live with a disease like SMA. Every person experience is different ,and it's every family's right to decide what SMA means to them.

COMPASSION

Thanks to Cure SMA Foundation of India, no person is ever alone in battle against this gruesome disease .We offer unconditional support to people affected with SMA and communicate openly and honestly ,giving them clear and accurate information.

DETERMINATION

Our work is not done until we have a treatment and cure ,and we will remain strong in our fight no matter what challenges come our way.

HOPE OF INDIAN SMA COMMUNITY

Cure SMA FOUNDATION OF INDIA is hope for SMA individual and their family. Community is helping patient and family to get over post diagnosis emotional crisis and guiding through the course of the disease. Handling emotional crisis saves parents going into depression and losing previous time. The very feeling that there are many others in the same boat helps them to overcome the denial mode and accept the facts. They get to know about the best practices, SMA protocols and management. The sooner newly diagnosed child is put on the SMA protocols and management the better it is to try & extend life.

At CureSMA Foundation of India, we are constantly working for the availability, accessibility and affordability of the already approved treatment. We keep our hopes very high and stay fully motivated to fight with this draconian disease.

OUR MAIN OBJECTIVES

- To get approved treatment available , accessible and affordable.
- To promote clinical trial of proposed drug in India.
- To advocate for indigenous research and development for biologics & biosimilars of SMA drugs.
- To promote and educate government over necessity of medical insurance coverage for SMA and other genetic diseases.
- Spreading awareness about SMA ,its diagnosis, genetic counseling ,prenatal test , management and treatment.
- To create support/advisory group clinicians, therapists, orthotists, vendors of mobility and assistive devices in all parts of country to support SMA sufferers.
- To establish SMA care centers in different parts of the country.
- Supporting SMA warriors (financially or non financially) for medical needs, educational needs, mobility and assistive needs.
- Campaigning for accessibility and inclusivity in educational institutions and social life.

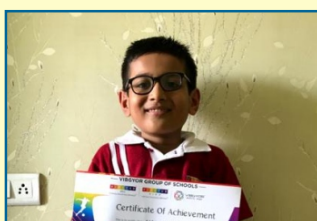
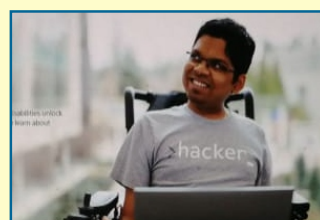
ACTIVITY

- Development & Evolvement of SMA protocols.
- Comprehensive health checkups for SMA warriors.
- Orthotics camps
- Physiotherapy sessions arrangements for patients with poor socioeconomic back ground.
- Liasoning with government departments, civil society groups, medical fraternity, pharma fraternity to make aware of urgent need of available treatment.
- Collaborating with other rare disease patient advocacy groups to work on common goals.
- Awareness campaigns/sessions for various stakeholders.
- Direct financial support for scoliosis surgery
- Representing our community and its needs to various relevant meets and conferences.

Provide support in educational sector, on need basis.

ACHIEVERS AMONGST OUR WARRIORS

They are toppers in differently abled category, Software Engineers, Animal Behaviorist, Writers & many more talented children who could achieve even though they are suffering from this draconian disease. This did not stop them from achieving what they have achieved.



CBSE NATIONAL TOPPERS FROM SMA COMMUNITY

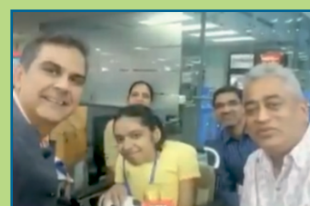
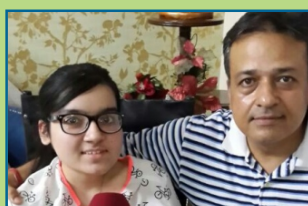
Tanvi Vij, Class XII, 2014



Mudita Jagota, class XII, 2016



Anushka Panda, Class X, 2018



MEETINGS WITH GOVERNMENT & OTHER STAKEHOLDERS

STAKEHOLDER MEETING BY MINISTRY OF HEALTH & FAMILY WELFARE

Mrs. Archana Panda and Mrs. Alka Vij participated in Stakeholders meeting called by Mrs. Preeti Sudan, Health Secretary, Ministry of Health & Family Welfare in Feb 2019. Cure SMA Foundation of India gave all inputs to make Rare Disease Policy sustainable & effective.



MEETING WITH DIRECTOR GENERAL CONTROLLER OF INDIA

Meeting with Director General Controller of India held on 5th Aug '19 in Delhi to get the SMA drug to India attended by Alpana Sharma, Shashee B Vij, Deepti Jagota and Alka Vij of Cure SMA Foundation of India.



ROUNDTABLE DISCUSSION ON RARE DISEASE POLICY

The Roundtable meeting was organised by Health Issue India. They invited discussion about National Rare Disease Policy to take views from various stakeholders. Archana Panda received invitation on behalf of CureSMAIndia.

Points shared from Cure SMA side are:

To incorporate a sustainable economic funding model within the policy so that in future govt should not say they don't have funds. This was the main reason for the earlier policy to fail which is now in abeyance. To incorporate controls to ensure implementation does not fail at any step.

To establish Rare Disease Excellence centres with multi disciplinary specialists so that supportive care can be given under one roof. To establish protocols for all Rare Diseases and if required, seek International expertise. SMA is life threatening, progressive condition and govt has to expedite the process n roll out this policy as we are losing patients. Earlier trend was one patient per month but recently its seen as losing two patients per month. All parents live in fear and therefore govt has to Act now. Creating awareness about Rare disease, inclusion in education curriculum including medical education and also genetic screening, genetic counselling for prevention of rare disease in future. Other stakeholders too emphasised on similar points including better coordination between Central and state governments. Include districts too for better implementation.



LOBBYING WITH GOVERNMENT



Mrs. Alka Vij, Mrs. Archana Panda and Mr. Dhruv Malhotra met Economic Advisor of Government of India to discuss on funding for SMA treatment.



Mrs. Alka Vij, Mrs. Archana Panda and Mr. Dhruv Malhotra met Dr. Harshavardhan, Minister of Health and family welfare, Government of India.

IRDAI



Mrs. Archana Panda, Mr. Arnob Saha and Mrs. Srilakshmi Nalam met The Insurance Regulatory and Development Authority of India (IRDAI) authorities in Hyderabad to discuss possibilities of insurance coverage for SMA treatment.

NITI AAYOG



The Government of India appointed Dr. Paul as a Member of the National Institution for Transforming India, the NITI Aayog, in August 2017 where he leads the Health and Nutrition verticals. He has played a pivotal role in formulating the POSHAN Abhiyaan and the Ayushman Bharat initiative.

Mrs. Archana Panda and Mr. Arnob Saha met Dr. V K Paul. Discussed about the availability, affordability and accessibility of SMA treatment in India.

PARTICIPATION IN SEMINARS, CONFERENCES



Mr. Shashee B Vij, from Cure SMA Foundation of India Participated in SUMMIT 2019 organized by NOVARTIS in Jan 2019



Mrs. Archana Panda, from Cure SMA Foundation of India Participated in SUMMIT 2019 organized by NOVARTIS in Jan 2019



Team Hyderabad participated in BioAsia 2019.



Mrs. Archana Panda met Dr. Soumya Swaminathan in Conference about access to medicines.



Mrs. Archana Panda from CureSMA Foundation of India participated as panelist in International conference on Rare n Undiagnosed diseases organised by Sir Gangaram Hospital n ORDI in April 2019



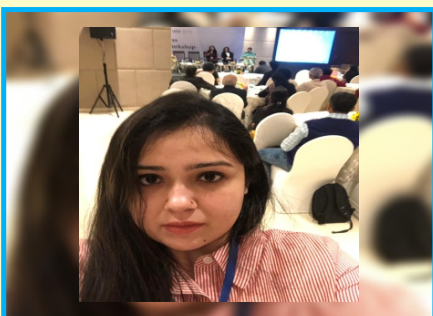
Mrs. Alka Vij participated in Stakeholders meeting organised by National Pharmaceutical Pricing Authority in Delhi, in March 2019.



Mrs. Archana Panda was invited as speaker to represent Rare Disease community in an event organised by MSF Foundation, in April 2019.



Mr. Shashee B Vij, from Cure SMA Foundation of India Participated in PAG Leaders Meet 2019 organized by ORDI & Global Genes in April 2019



Mr. Shashee B Vij & Niharika Vij from Cure SMA Foundation of India Participated in Conference organized by IAPG in March 2019



Archana Panda met Mrs. Sarita Chandra and Tamsi Nayak, FICCI, New Delhi.



Mrs. Archana Panda, Mrs. Moumita Ghosh met Mr. Aritj Pati & his team from Cognizant Foundation in Peerless Hospital Kolkata along with Dr. Papiya Khawash

Cure SMA India Demands Treatment Through Court-Legal Affairs

Meeting attended by Mr. Shashee.B. Vij (Director-Legal Affairs) and Ms. Alka Vij with India's Additional Solicitor General Maninder Acharya, Counsel for Delhi govt, Counsel for the Central govt., officials of the Health Ministry, amicus curiae of our PIL in the courts on the directions of Delhi High Court to ponder over and discuss vigorously the points to be mentioned in the newly formed National Rare Disease Policy so the real stakeholders have an inclusive Policy. The court had directed CureSmaIndia (Shashee B Vij) to represent themselves as the real stakeholders in the race for a cure for Rare Diseases in this high level meeting. The meet was very fruitful and CuresmaIndia was the ONLY stakeholder invited at this crucial meeting. I gave 29 points to the committee as important to the cause of our children plus we also gave real life examples to elucidate our points. The committee heard us for more than 1 hr 20 min on each point i had put forward. The ASG directed the Joint Secretary Health to incorporate as many points possible in the National Rare Disease Policy. The counsel for the Centre and Delhi state were very patient and heard us and wrote points of our contention. The meeting lasted 2 hr 15 min. It was assured to our NGO CuresmaIndia that the best shall be incorporated. The 29 points circulated were inputted by all our Trustees.



SOME GLIMPSES FROM KERALA MEET



SOME GLIMPSES FROM HYDERABAD MEET



WORK ON ACCESSIBILITY BY KARAN SHAH

After months of rigorously pursuing to the Municipal authorities and local administration, Karan's demand has finally been accepted. Now 3 public toilets have been made completely disable friendly and many more are on the way to becoming accessible for people like him whom he refers to as "Differently-normal".



ACCESSIBILITY MATTERS

CONTINUED FROM PAGE 1

Since Shaul first set out on his daily marketing rounds in April last year, he hasn't found many wheelchair-accessible public facilities in the city. Once he tried to use a public Shoushuai to visit Park but found it impossible to get up the four stone steps to the entrance. At another facility, where he managed to get in with some assistance, the showers and toilets were not wheelchair accessible and the cubicles were too small for him to get in. He looked at 100 such spots between Colaba and Vile Parle, but only a few of them are wheelchair accessible on wheels/hike. He says the city still has a long way to go to address the disability and people here can't be truly inclusive.

"The two public toilets that are actually accessible are one at the Colaba Police Station and another at Phoenix Mills," he said, adding that while some he visited had ramps, they were not marked as MGNREGS sign labelling them as suitable for the differently-abled, and he said he had never seen a sign there's no means for wheelchair

"And, you consider that the word 'differently-abled' covers hearing and vision impaired, as well as those with locomotive problems, then these facilities fall way short," said Shah, who has been writing to authorities over the last year asking them to make the necessary changes. "But I have received no response from them," he said. Here's what *Mirror* and Shah found during the accessibility spot check in the city:

CSMT
Shub was amused to see that while he could store his wheelchair all the way to the train, there was no ramp access to the disabled compartment. "It's pitiful. You can get all the way to the platform, but then what?" he said, adding that even with assistance, getting the wheelchair onto the train would be tough as it's so small. "And, while the 'air-conditioned' sign makes it sound as though the washroom has a modern design, it's impossible to use—the doorway is too narrow to accommodate a wheelchair."

General Post Office



"The entrance ramp was a little steep, but otherwise the spot was where bus accessible," said Kluks, pointing out that no design modifications had been made with Visually-impaired individuals in mind. Braille nameplates could be fitted on doors, and the elevator, which had piped-in music, could be fitted with a floor announcement.

A man in a wheelchair is positioned in front of a building with a yellow facade. The building has a sign that says "Wahana" and a sign with a wheelchair icon. There are potted plants and a small table with a sign on the right side of the entrance.

Sulabh Shachalaya, Parel and Sewri

"The ramp of Sulabh near Tata Hospital is way too steep. Even with assistance, it's impossible to ascend it as a wheelchair," said Shree. Another facility he visited near Laxmi Arts at KEM Hospital, it didn't have any ramps, even though the WCGR sign outside labelled it as suitable for the differently-abled. The Central Public Works Department has issued directions saying that the design of such facilities must be planned based on the assumption that the user will be operating the wheelchair without help. And though the Department of Public Works has issued guidelines, it did not respond to emails sent by WWC, and its officers were unable to comment. Accessible India Campaign or Suganya Bharati

Ashwin said reports available online state "The ramp of a gradient of 1:10 is preferred and a gradient of 1:12 is the absolute maximum (5.7 degrees) to 4.76 degrees of slope. The 1:12 ratio is the maximum for wheelchair users to ascend independently for many wheelchair users and may result in the wheelchair flipping back-wards while ascending."

KEM Hospital

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CURESMA FOUNDATION OF INDIA AT ROCHE HUB

It gives immense pleasure to share that Mrs. Alpana Sharma, Co-Founder, Director Patient Advocacy, CureSMA Foundation of India was invited as Guest Speaker by Roche India in sept 2018 to speak about Patient Empowerment. She shared about inception and journey of CureSMA India, stories of stellar performance of SMA children and how the disease is spreading like poison in their bodies. She also spoke about self advocacy in rare diseases as it affects miniscule population. As a patient advocacy representative, she also shared about the day today challenges in the lives of SMA patients, about the frustration that there is promising treatment out there but it is unavailable for our children.

With consecutive workshops between Roche India and CureSMA India in Aug 2019 and Oct 2019, Roche team has assured us that together we will work for accessibility and affordability of Risdiplam, when it is launched in market after US FDA approval, which is expected by May 2020. There is no point if clinical solutions are available but not affordable. In fact, the Managing Director, Lara Bazerra, said that none of the pharma companies develop a drug for certain set of countries, that too in cases of rare diseases. They want the drug to be available for all patients irrespective of countries they are living in. Roche has shown exceptional commitment for the SMA community of India. With the launch of Compassionate Use Program for the SMA Type1 Patients in India and consecutively for SMA Type2 and Type3 , we are hopeful for a better future for Patients and parents of CureSMA India.

We are Thankful to the Roche Team in India and Global for their commitment to help us in creating an holistic ecosystem for ALL SMA Patient in India.



MEETING WITH WORLD - RENOWNED NEUROMUSCULAR SPECIALIST DR. ENRICO BERTINI

Dr. K.P.Vinayan, Paediatric Neurologist at AIMS Kochi arranged a meeting for Cure SMA India with world-renowned Paediatric neurologist and SMA expert Dr. Enrico Bertini, during KAN Monsoon Summit 2019 on 14th July held at Kochi, Kerala. Dr. Bertini who has consolidated worldwide known expertise in neuromuscular disorders, is in the advisory board of SMA Research in UK, Italy and many other countries. Dr. Razeena, Tintu.K. John and Solomon Raphael from Kerala represented Cure SMA India in the meeting. Dr. Enrico was kind to hear about our mission, vision, objectives and activities and the issues in accessibility & affordability of SMA treatment in India. Dr. Enrico shared his vast experience in the management of SMA patients with special emphasis for us on how to guide and empower a patient group affected with SMA. He advised on the importance of lobbying with the govt. and Pharma, importance of setting national and international collaborations, and raising funds for SMA care and research. It was wonderful to hear from him the treatment experience of bringing back children who otherwise would have left this world through his hands with Spinraza. It imparted an extra power and confidence to fight SMA and move forward with a smile.



PARTICIPATION AT RACE FOR 7 ZONE WISE

Race for 7 is an awareness run organized by **Organization For Rare Disease India (ORDI)** — a team committed to address the challenges of rare disease patients and their families in India. Its purpose was to raise awareness about rare diseases, to empower patients and their families with access to national and international resources.



INTERNATIONAL CHILD NEUROLOGY CONFERENCE

Curesma Foundation of India participated in the "International Child Neurology Conference". It is one of its kind of exclusive conference on Child Neurology. It is being attended by doctors/ paramedical professionals with interest in child neurology from India/Asia and indeed from across the world.

As The parents support group teams we were able to generate awareness about our presence, our activities and generally connect with professionals in child neurology.

Specialist Doctors, Researchers and Scientists flew in from all over the world. We made a strong representation about our children and their need for SMA therapies. Infact there were doctors who have helped in development and clinical trials of spinraza were there and they were quite empathetic to our cause and promised to help us.

There was positive response from some of the doctors who are using spinraza. They were thoroughly impressed to know that we have started such parent led community in India, in fact they gladly agreed to contribute to our cause, encouraging us with examples of curesma USA, curesma Canada, Curesma Australia and TreatSMA UK. Made few other very important contacts. Hopefully these will be quite useful in our efforts of bringing SMA Therapies in India



PATIENT REGISTRY

CureSMA India Launched its website
www.curesmaindia.org
 patient registry has been initiated
 through website portal



GLIMPSES FROM 1st NATIONAL CONFERENCE ON SPINAL MUSCULAR ATROPHY (SMA)





First National Conference on Spinal Muscular Atrophy was jointly organized by Cure SMA Foundation of India and Peerless Hospital on 9th June 2019 in Kolkata. Care, Management and treatment options were discussed by eminent speakers. Clinicians and parents both participated in the conference. SMA warriors put up a splendid performance on vocal music, education and quiz. We are thankful to Dr. Sanjukta Dey, Dr. Subhrojyoti Bhowmick and Peerless Hospital Management for their compassionate support to make this event successful.

SIPHAP ASSESSMENT PROGRAM

WHEN PRAYERS AND EFFORTS COME TOGETHER, HUMANS CAN FIGHT AND WIN AGAINST ALL ODDS



Mrs. Archana Panda met Direct Relief Vice President Mr. Bhupi Singh, Dr. Himanshu Chauhan, From DGHS, MOHFW & Dr. Madhulika Kabra, AIIMS for the launch of SIPHAP Program in India on 11th March 2019

CureSMA Foundation of India is pleased to inform that "Direct Relief", a US based NGO has initiated SPINRAZA "Individual Patient Humanitarian Access Program" (SIPHAP) in co-ordination with CureSMA Foundation of India for patients with SMA (Type 1,2,3) to make the drug available for Indian patients.

This program will be available for limited number of eligible patients with SMA (Type1,2,3). The last date was 30th July, 2019. The applications had to go through one of the four centers allocated for this as below:

1. All India Institute of medical Science, New Delhi
2. Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow
3. KEM Hospital, Mumbai
4. Baptist Hospital, Bangalore.

This was a pilot program and an Independent Global Medical Expert Committee (MEC) of SMA specialists will decide the limited number of patients (25-30) depending upon the exclusion and inclusion criteria. CureSMA Foundation of India is hoping for the success of this program which will result in more of such programs in the coming course of time and many more SMA patients are expected to get the life saving medicine and get a chance to live a healthy life.

We can only ensure that each and every patient registered with us gets the fair chance of applying for spinraza based on criteria decided by Direct Relief and the team of Doctors in four centers.

Disclaimer: CureSMA Foundation of India or any doctor cannot influence the decision of Independent Global Medical Expert Committee (MEC) of SMA specialists

As on 30th July 2019, Assessment n Evaluation of all SMA patients in India has been completed by team of Doctors in all the fours approved hospitals. Final, review and evaluation and selection by Independent Global Medical Expert Committee (MEC) of SMA specialists is underway. Program Started in Sept /Oct 2019. Direct relief has now Initiated spinraza for all patients below 6 months age.

SMA AWARENESS MONTH : AUGUST 2019

* Bangalore Baptist Hospital (BBH) 15th August

Cure SMA Foundation of India in collaboration with Bangalore Baptist Hospital (BBH) along with Organization for Rare Diseases India (ORDI) hold an awareness Seminar to discuss Standard of Care (SOC) for Spinal Muscular Atrophy. We are thankful to Dr. Ann Agnes Mathew for this initiative. Dr. Ann Agnes Mathew is one of the best Paediatric neurologist in who is working relentlessly to improve the quality of life of SMA affected individuals. Our Co founder and Director Patient Services Ms. Moumita Ghosh and Bangalore city coordinators Mrs. Anchal, Mrs. Ashwini, Ms. Rashmi put their heart and soul to make this event successful. Our senior member Mr. Arnob Saha guided us through the event. Mr. Prasanna Shirol, Mr. Madan and Ms. Pavithra from ORDI supported this event. We must mention Bangalore Baptist Hospital authority and Dr. Madhuri for their compassionate support.



* Roche Pharmaceuticals 26th August

IT gives us immense pleasure to announce that Cure SMA Foundation of India celebrated SMA Awareness Day at Roche Pharmaceuticals.

Roche India Team was greatly moved to learn about the spirits of courage shown by the children with SMA and their parents.

It was an amazingly enriching session for both Roche and Cure SMA Foundation of India. We had a very Positive Discussion. Great to see Roche Walking the talk. Presence of patients Advocacy Group is a proof that Roche believes in patient engagement and patient empowerment. Thanks Roche team for inviting curesmaindia to celebrate #smaawarenessday at Roche. Cure SMA Foundation of India is thankful to Ms. Alpana Sharma for this initiative. We are thankful to Ms. Alka Vij, Ms. Archana Panda, Ms. Razeena Sethunath, Ms. Moumita Ghosh and Mr. Arnob Saha for participating in this event.



*** Sir Gangaram Hospital, New Delhi 29th August**

Sir Gangaram Hospital, New Delhi Cure SMA Foundation of India in collaboration with **Sir Gangaram Hospital, New Delhi** organized 1st Spinal Muscular Atrophy Clinic in Delhi-NCR & North India on 29th Aug 2019. As the newly discovered and US FDA approved medicines are not accessible, available and affordable to Indian SMA patients so far, the only option left for parents and patients is to learn to manage the disease with some best practices established by experience of Doctors, parents and patients from all over the world. These best practices require a multidisciplinary approach which plays a significant role in extending and improving life of SMA patients. Cure SMA India is thankful to Dr. I.C.Verma, Dr. Ratna Puri and the entire team of Doctors from Sir Gangaram Hospital for their support in making this 1st SMA Clinic in Delhi-NCR & North India a reality. A special thanks to Dr. Ratna Puri for helping us organize this in the month of August, which is considered as SMA Awareness Month worldwide. This awareness session and 1st SMA clinic was inaugurated by Dr. S.P.Byotra, Vice Chairman, Sir Gangaram Hospital followed by key note address by Dr. Byotra, welcome address by Dr. I.C.Verma and a session about need for multidisciplinary SMA clinic by our Co-Founder & Director Legal Services, Shri. Shashee B Vij. Dr. Ratna Puri gave away the concluding remarks and vote of thanks. The program was attended by a large number of patients and parents from Delhi , NCR, Panipat, Panchkula and Saharanpur. It was well managed by volunteers from Cure SMA India team along with team of Doctors and volunteers from Sir Gangaram Hospital.



* Aster MIMS Calicut 31st August

Cure SMA Foundation of India is proud to announce 1st SMA Awareness Programme at **Aster MIMS Calicut**.

It was a very well organised and successful event with enriching informative sessions delivered by the doctors of Aster MIMS that were very much insightful on the particular subjects. Starting with Dr. Smilu Mohanlal's "Introductory session on SMA" there were other sessions too on topics like "Imunisation practises and growth monitoring in SMA children" by Dr. Suresh Kumar E K followed by Dr. Mahendra Varma's brief session on "Spine and Hip Care". Later Dr. Sijith K Raghavan gave us an idea on the "Respiratory care in SMA". Around 4pm, Dr. Divya Pachat spoke about "Genetics of SMA and its prenatal diagnosis" followed by an informative session on "Nutrition and Diet in SMA" by Ms. Sherin Thomas. Lastly, there was the concluding session on "Do's and Dont's of physiotherapy in SMA" by Mr. Ashkar Ali and team.

The Kerala Meeting was from 2 to 3 pm. Thereafter it was the scientific session lead by the eminent medical team @ Aster MIMS. Cure SMA Foundation of India is thankful to Razeena Sethunath one of the Co Founder of Cure SMA India for the initiative.



* PGI Chandigarh 18th -19th Sept 2019

Cure SMA Foundation of India in collaboration with **PGI Chandigarh** held 1st SMA Awareness session and SMA Clinic on 18th & 19th Sept 2019. This was possible only with support from Dr. Naveen Sankhyan fully supported by Dr. Renu Suthar and the entire team of Doctors from PGI Chandigarh. The SMA Awareness session was organized mainly for the parents of SMA warriors on 18th Sept and during this same event was launched "A Family Guidebook- Care of a child with Spinal Muscular Atrophy" prepared by Dr. Renu Suthar and team in collaboration with Cure SMA India. Our Co-Founder & Director Patient Services, Moumita Ghosh and City Coordinator Mr. Prashant supported by Mr. Amarjit were all present in the event along with all families and parents from North India. It was well managed by volunteers from Cure SMA India team along with team of Doctors and volunteers from PGI Chandigarh. SMA Clinic was organized on 19th Sept 2019 which was attended by many patients and parents from Northern parts of India. We are thankful to our co founder Ms. Archana Panda for this initiative.



* BLK Super Speciality Hospital, New Delhi 7th Dec 2019

BLK Super Speciality Hospital, New Delhi Cure SMA Foundation of India in collaboration with **BLK Super Speciality Hospital, New Delhi** organized an awareness session on SMA Support Care for the parents of SMA patients on 7th Dec 2019, between 4 to 6.30pm in BLK Hospital, Seminar Hall. With changing weather, air pollution and upcoming winters SMA patients needed critical care considering their compromised immune system. We encouraged parents and caregivers to participate in this awareness session so that they could do the best for their children. Program started with Introductory session by Archana Panda, Co- Founder & Director Patient Advocacy, to speak and share the journey made so far by Cure SMA Foundation of India. All the Doctors from various disciplines held sessions to share detailed protocols and knowledge about SMA care and support. This program was possible with great support from Dr. Ankit Parakh, Senior Consultant, Pediatric Pulmonology & Sleep Medicine, BLK Hospital who was fully supported by the team of Doctors from BLK hospital. The program was attended by a large number of patients and parents from Delhi, NCR and Panipat. It was well volunteers from Cure SMA India team along with team of Doctors and volunteers from BLK Super Speciality managed by Hospital. We are thankful to our co founder Ms. Archana Panda for the initiative and Mrs. Alka Vij and Mr. Dhruv Malhotra supporting the event.





PATIENT SUPPORT ACTIVITIES

Fund raising for scoliosis surgery. Scoliosis is a major complication of SMA. Scoliosis surgery costs very high approximately 10 to 20 lacs. We support our children who need scoliosis surgery.



This is Shreya from Tamilnadu, pre and post scoliosis surgery.



This is Asna Sharin, Kerala, pre and post scoliosis surgery.



Pawan with his Parents

Pawan is from economically weak background. We did raise fund for treatment support when he was hospitalized with severe pneumonia. Cure SMA Foundation of India, also sponsored his spinal and neck braces.

ORTHOSES CAMP

* KARE Prosthetics and Orthotics 23rd October

Cure SMA Foundation of India, Kolkata chapter in collaboration with **KARE Prosthetics and Orthotics**, Bangalore and organized a Spinal Orthoses Workshop in Kolkata on 23rd October 2019. SCOLIOSIS is a major complication of children with #SMA. Spinal Orthoses plays very important role in maintaining the scoliosis angle. KARE Prosthetics and Orthotics, a Bangalore based Orthoses center with branches in Chennai, Kochi and Kolkata (upcoming) is one of the leader in providing customized spinal braces.

I would like to thank Mr S Sarvanan, founder of Kare and his team lead by Jay Raj Singh for support. Thanks to Subal Chandra Roy of Cure SMA Foundation of India for organizing the event so nicely. Special thanks to Ritesh Bhattacharjee for supporting.



SAKSHAM

Mr. Shashee B. Vij and Alpana Sharma from Cure SMA India have enrolled themselves in SPJIMR & Novartis sponsored Organisation Development Program **SAKSHAM**. It is a capability development programme for patient organisations with 30 participants from 12 states. The course is immensely helpful in making the organisation work optimally. It's a leadership training program that would enhance organisation acumen and help us in building Cure SMA as a successful platform with an engagement model for all the stakeholder.



GAINING SUPPORT FROM MEDICAL FRATERNITY

INDIAN MEDICAL ASSOCIATION

Dr. Santanu Sen, National President of Indian Medical Association and Member of Parliament blessed our SMA warriors on the occasion of the first National Conference on Spinal Muscular Atrophy which was held in Kolkata jointly by Peerless Hospital and Cure SMA Foundation of India. IMA agreed to support our cause.



Dr. Santanu Sen, National President of Indian Medical Association and Member of Parliament

INDIAN ASSOCIATION OF PAEDIATRICS, GURGAON

Our co-founder Ms. Archana Panda presented our cause to IAP, Gurgaon. They agreed to support our cause.



Dr. Ajay Karkra, President, IAP, Gurgaon.

OUR ANGELS



ME without YOU

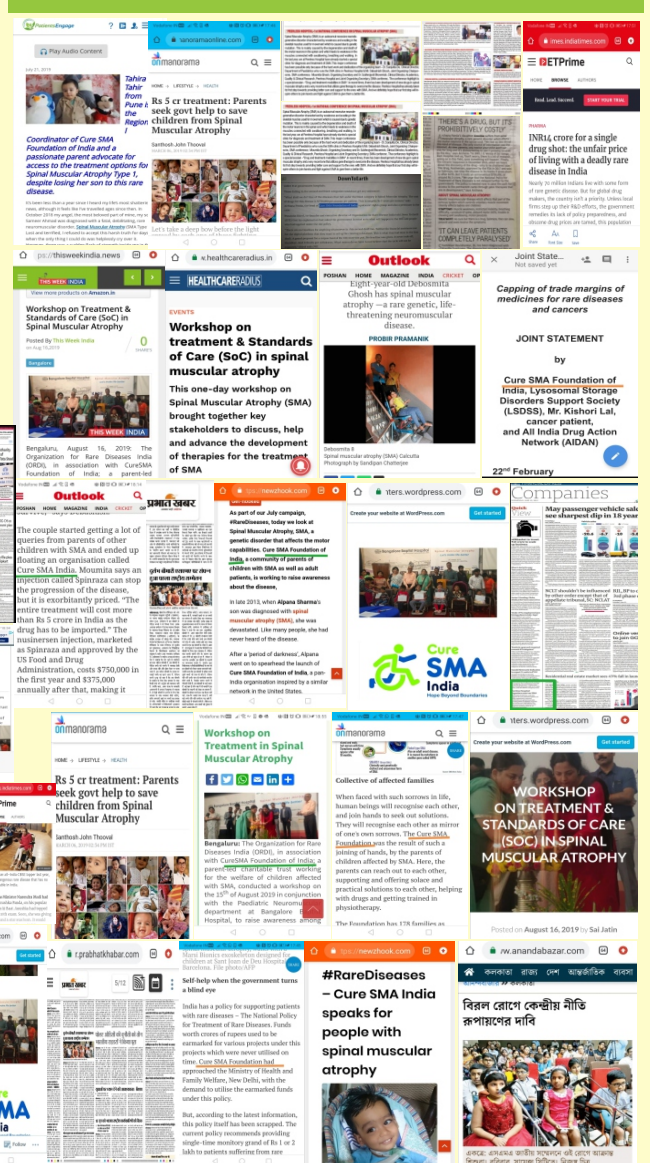
It's been a month since you left us and yet your smell remains. As I look for your smell on your pillow that still sleeps beside me, a tiny bulb reminds me, you're still here. This bulb had come into our nights to wipe away your fear, the only change it has undergone is that fear is now ours. As I long for the little cries you made through the night asking me to help you turn, I soothe myself with the teddy you'd smile at as it still has your warmth. My mornings miss your exercises, your poems still fill my ears. Your best friend mickey still awaits you but you're not here. As I switch on the television, your favourite cartoon still flashes right there. But now instead of a smile it brings me a tear. My mind is left wondering, what brought you a smile every time you watched his face as that was all you could do. As I try to see the world through your eyes, I can still see you sitting on your seat and watching me as I moved to and fro waiting for me to hold you. How times have changed as I'm the one who's waiting now. As I do the dishes, the sound of water still warns me of blocking your voice. The pressure cooker whistle that used to make you cry still scares the hell out of me. My fingers long to brush your hair, my lips long to kiss your feet. The dreams in which you crawled, you sat, you walked, you ran have suddenly vanished. May be because they've taken the face of reality in God's sweet arms. I wish you're doing all of it there, all that you couldn't do here. There's no one to smile while I'm humming your favourite poems, no one to sing along, no little fingers to bite on while still getting smiled at, no one to pull my hair as I bow in prostration, no one to smile as I unbow. Our home without you is reduced to a mere set of walls. Never thought that one day I'd put away every cloth you wore, put away every toy you loved watching, put away everything that's supposed to be your memory and yet every corner will still scream of your presence. The silence is piercing right through my heart and tearing it apart. The void you've left is hard to fill. Never thought that the life that I'd once created would one day end up defining me. Sometimes I wonder if you were just a dream, the most beautiful one I've ever seen.

~Tahira

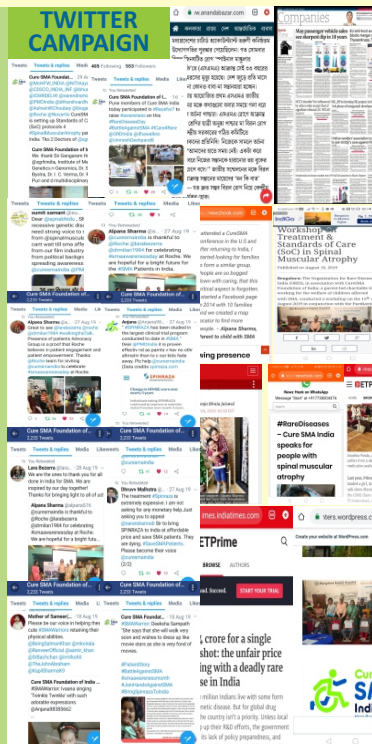
I am wearing a pair of shoes.

They aren't pretty shoes... uncomfortable shoes. Each day I wear them. Each day I wish they'd feel more comfortable. Some days my shoes hurt so badly that I do not think I can take another step. Yet, I continue to wear them and continue my journey... I get funny looks wearing these shoes. I can tell in others eyes that they are glad these are my shoes and not theirs. They never talk about my shoes.... To learn how painful my shoes are might make them uncomfortable. To truly understand these shoes one must walk in them. But, once you put them on, you can never take them off... I now realize that I am not the only one who wears these shoes. There are many pairs in this world. Some women ache daily as they try and walk in them. Some have learned how to walk in them so they don't hurt quite as much. Some have worn the shoes so long that days will go by before they think about how much they hurt. No Mom deserves to wear these shoes. Yet, because of these shoes I am a stronger woman. These shoes have given me the strength to face anything. They have made me who I am. I am a Mom who has a child(ren) with special needs. I will forever walk in these shoes. ~ Unknown

MEDIA COVERAGE

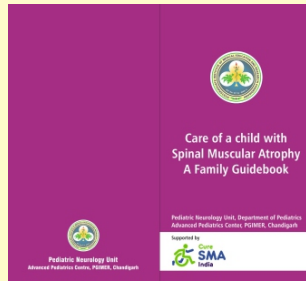


CureSMAIndia members designed and made a small memento, a Mug with CureSMAIndia logo on it, to be given away to all supportive stakeholders such as Doctors, Govt, other NGOs and civil society organisations. This was given to all the supportive and participating Doctors in multidisciplinary SMA clinics in Sir Gangaram Hospital, BLK hospital and PGI Chandigarh, during 2019.



SMA PROTOCOL : MULTIDISCIPLINARY STANDARD OF CARE

MULTI DISCIPLINARY SMA CLINICS



The Cure SMA Foundation of India in collaboration with Peerless Hospital and B.K. Roy research center, Kolkatta, West Bengal has been running a SMA Clinic for more than two years. This Clinic is being held quarterly under guidance of Dr Sanjukta De, Paediatric pulmonologist, clinical director Paediatrics, Peerless Hospital. Dr Soumyajit Basu, renowned spine surgeon, Dr Papiya Khawash (Developmental pediatrician) , Ms S Maitra (Nutritionist) and Mr Shantanu De has been supporting the clinic with their compassionate guidance. SMA is a disease that needs multi-disciplinary approach to maintain quality of life. This is first of its kind in Eastern India and second such set up in India.



SMA PROTOCOL : HEALTH, NUTRITION & SUPPLEMENTS



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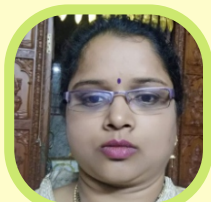
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Regional Coordinators:

Alpana Sharma (Mumbai & West India) : 09727946303
Alka Vij (Delhi - Delhi NCR & North India) : 09811362275
Archana Panda (Delhi - Delhi NCR & North India) : 09377012135
Moumita Ghosh (Kolkata & East India) : 09432888613
Satish P (South Central India) : 09849675730
Dr. Razeena (South India) : 09446341617
Srilakshmi Nalam (Hyderabad) : 09581766295
Srilakshmi Nalam (USA) : +1(646)4023414

Regional Office (West)

Alpana Sharma. C-1001, Plot Number 260, Elite Enclave, Sector-10, Kharghar

Regional Office (East)

Moumita Ghosh. Flat 1C Anilalaya Apartment 7 Dinesh Pally, Bansdronei, Kolkata 700070

Regional Office (South)

Dr. Razeena.KThambrieri (House)Neduva (P.O)ParappanangadiMalappuramKerala - 676303

Legal affairs office :

Shashi Bhushan. Vij, 14A/70 Ground Floor W.E.A, Behind Hotal Saar, Karol Bagh, Central Delhi,

Regd. Office :

Archana Panda. 501/D-23, Ireo Victory Valley, Sector -67, Gurgaon-122101 Haryana, India

✉ curesmaindia@gmail.com, info@curesmaindia.org

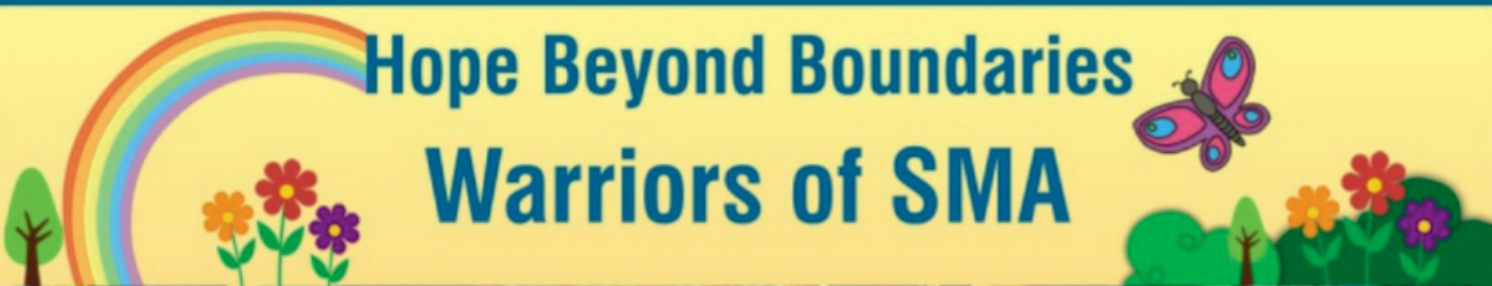
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Hope Beyond Boundaries Warriors of SMA



info@curesmaindia.org, curesmaindia@gmail.com



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501/D23, IREO VICTORY VALLEY, SECTOR -67, GURGAON-122101, HARYANA, INDIA