



Media Strategy
Case study from ORDI – India

Prasanna Shirol
Co founder and Exe Director



**Over 7000
rare diseases
and counting**
What they need
is an equally
rare gesture



Without action, there most certainly is no hope



- In the year **2013**, ORDI was launched to address the unmet needs of the Rare Disease patients in India.
- ORDI serves to be the **collective voice** and acts as an advocate on behalf of Rare Disease patients throughout India.
- ORDI serves as an **umbrella organization** for Rare Disease patients and other stakeholders pan India.

Vision:

A Better Life for people with Rare Diseases.

Mission:

ORDI's mission is to be the strong united voice for all rare diseases in India, to reduce inequalities and ensure that people living with rare diseases have access to the same resources as any other population





ORDI's Multidimensional Approach Towards the Rare Disease Community

6+ years, 6000+ Calls, 6000+ Patients
100+ Volunteers and Million supporters



Advocacy Awareness Patient Support Clinical Trials R&D



RD Helpline



R D Camps



Patient support Program



COERD @IGICH - CHG



CME /Conference



PAG Members



Int Associations



Advocacy



Medical Awareness



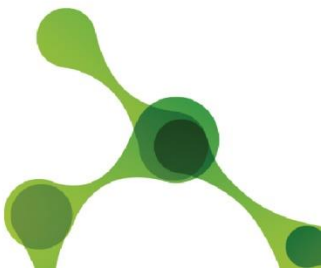
Inspiring Stories



Mass Awareness

Why Media ?

- **To communicate** or to reach out to **mass** about our **activity / cause / problem**
- To draw the **attention of policymakers** when an **appeal by individuals/groups is unheard.**
- To draw attention of the stakeholders- Researchers, Doctors, Public, and to gather their support.
- To Identify and channelize **similar Patients, Supporters, Volunteers**; basically **anyone who can be helpful to us**, or those **who can benefit from our help.**
- To create a **large network of Supporters for the cause**- For the Implementation of Policy, all that matters is numbers and we **are too negligible in number.**



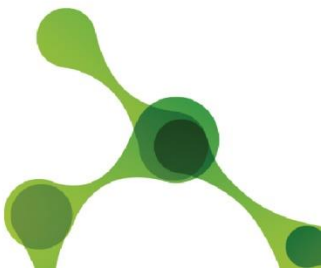
Challenges in India for media Planning

- 1.36 Billion Population (18% of world / 1/6th of world Population)
- 2nd most populous country
- 22 official languages (19500 Mother tongues)
- 28 states and 8 union territory (Each state having a population (some individual or combined countries)
- 1.18 Lakhs - No of registered news paper in India
- 926 T V Channels (National and Local)
- 60-80% literacy level – In Local Languages



Initial Media Strategy – before 2015

- Media interaction only during **major events** , **Luck based** interaction and **inconsistence**.
- Media Interaction based on the **personal contact** or referred by hospital/doctor , From Our own network of patients and family
- **No formal Media Agency** was appointed.
- Media person would ask- "**What is New?** " **each time**; only sensational/emotional news was entertained - **This did not meet our objectives**.
- Cost of appointing a PR agency or arranging Press meet was high and no dedicated funds for the same.
- No comprehensive strategy



New Strategy – 2015 onwards – Race for 7

I
Patient
Story
Appeal
Advocacy



Race for 7



WE
Stakeholder
Involvement
Patients, Caregivers.
Patients Celebrity
Policymakers
Society Involvement



1-year-old fights off rogue gene

Samarth Chavan was diagnosed with Pompe, a rare metabolic disorder. Timely treatment with enzyme replacement therapy ensured the disease was arrested every 15 days.

Little Samarth Chavan, just a year old, is a fighter. At first glance, you wouldn't think the cheerful and adorable boy has been diagnosed with Pompe disease, a rare metabolic disorder that has no cure. But the alertness of his parents and doctors ensured that the condition was detected early and he received timely treatment.

Samarth's father, Suresh Chavan, who runs a small garment store in Bilgaon, says "When he was born, he did not cry immediately. Though he cried later, he would often get fever and cough and seemed tired and uncomfortable all the time. Apart from continuous crying, he wasn't reaching his milestones such as turning over or trying to sit. That's when we took him to a doctor."

Thankfully, the doctor recognized that there was a problem and referred him to cardiologist Dr P Suresh who then, directed them to a geneticist. "If each patient are not provided treatment on time, there is further progression of the disease along with other complications," said Dr S J Patil.

consultant, clinical genetics, Centre for Molecular and Metabolic Diagnostics and Research, Narayana Healthcare Health City, who is treating Samarth. "Consistently among parents is also known to be a risk factor for LSDs, though it should not be made out to be main cause," adds Dr Patil.

LSDs can lead to progressive physical and/or mental deterioration over time. Some LSDs may be "mild" in form and others more severe. Some patients live to adulthood, but others with severe symptoms may die in their teens or earlier.

In India, around 500 babies are affected by treatable LSDs. Though a small number, they can be saved if they are given access to necessary treatment on time.

"We did an enzyme estimation and a battery of other tests and diagnosed the condition. Samarth is receiving Enzyme Replacement Therapy (ERT) and he has to 1 injection every 15 days, and we take this life-long, unless other advanced treatment comes in the future."

TREATMENT EXPENSIVE
The treatment is expensive as families in India cannot afford can cost anything from Rs 7-10 lakh per year for the injection and in most of complications. Samarth's parent main aim is that their son receives timely care at the future health. As of now, he needs to receive an injection in days. Fortunately, the injection sponsored by the Lysosomal Disorders Support Society, He is happy that he is responding to treatment," says Suresh.

PSG Hospitals organise marathon to create awareness on rare diseases

PSG Hospitals organise marathon to create awareness on rare diseases
By SimpliCity News Team
Mar 03, 2019 05:59 PM
Coimbatore : To create awareness on 7000 rare diseases, PSG Hospitals organised a marathon on Sunday. Formula 1 Racer, Narain Karthikeyan flagged off the marathon which was jointly organised by PSG Hospitals and ORDI (Organisation for rare diseases of India).



New Strategy – 2015 onwards – Race for 7



Media Types
Traditional Media – Print, TV, FM Channels
New Digital Media – Online Publication, Blogs, City Updates etc.
Social media - FB, Twitter, Instagram etc.
Whatsapp Group – Self, Team, Volunteers, Sponsors, PAG etc.

Diseases Awareness Day creative – Every Day

Created 107 diseases in last 9 months for Social Media



Digeorge Syndrome Awareness Day NOVEMBER 22, 2020

Also known as 22q11.2 deletion syndrome.

Care for rare. Bring smiles

Digeorge Syndrome Awareness Day NOVEMBER 22, 2020



- DiGeorge syndrome is a rare congenital disease that affects an infant's immune system and that is due to a large deletion from chromosome 22.
- The symptoms can vary, they often include congenital heart problems, specific facial features, frequent infections, developmental delay, learning problems and cleft palate.



- The occurrence rate of this syndrome worldwide, is estimated as one in 4000 births. However, the features vary widely. As a result, under-diagnosis and misdiagnosis are likely to occur.

Care for rare. Bring smiles

- For more info: <https://www.mayoclinic.org/diseases-conditions/digeorge-syndrome/symptoms-causes/syc> or <https://www.jpgmonline.com/article.or>

Awareness drive Before Event – Social Media creative/banners

f in v



f in v



DO YOU KNOW?

Approximately 7,000 rare disorders are known to exist and new ones are discovered each year.



www.ordindia.org +91 8892 555 000 www.racefor7.com

DO YOU KNOW?

Average period for the diagnosis of a Rare Disease is 7 years.



www.ordindia.org +91 8892 555 000 www.racefor7.com

f in v



DO YOU KNOW?

95% of Rare Diseases Lack an FDA Approved Treatment



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“Do you know series” During “race for 7” season– Social Media drive through creative/banners

f in v



f in v



DO YOU KNOW?

India approximately 70 millions suffer from Rare Disease



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DO YOU KNOW?

30 % of rare disorder inflicted infants don't get to celebrate their 5th birthday!!



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f in v



DO YOU KNOW?

One in 10 Americans is living with a rare disorders



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Patients participation – Social Media drive through creative/banners- Campaign



ANTONY

PRIMARY IMMUNO DEFICIENCY (PID)

A RD PATIENT WITH AN IMPRESSIVE FLAIR FOR ARTS; HE HAD TO FIGHT MANY SERIOUS RECURRENT INFECTIONS. BUT NOW, MANY THANKS TO GOVT OF KARNATAKA FOR HIS ONGOING TREATMENT, ANTONY'S HANDS ARE FULL WITH MANY AWARDS FOR REMARKABLE PAINTINGS.



AROUBA

Cystic Fibrosis

RARE DISEASES & CHEERFUL INSPIRATION!!

No! It's not an oxymoron.



DEBOSMITA GHOSH

Spinal Muscular Atrophy

I AM RARE, BUT DEFINITELY BRAVE

Come run/walk with me and make others aware of RARE
Match your pace with mine, for together we can move mountains

Patients participation – Social Media drive through creative/banners- Campaign



Nishanth MN Deshik
Duchenne Muscular Dystrophy (DMD)

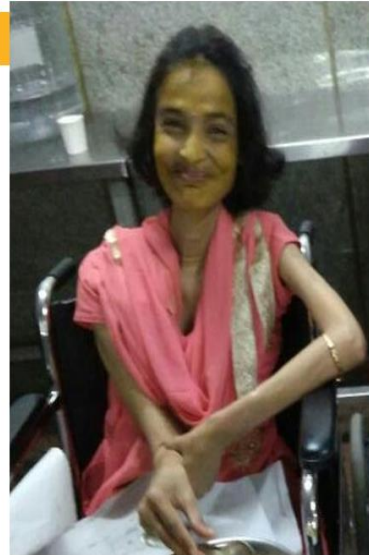


A MERRY, MUSIC LOVING MOVIE BUFF
HIS MOUTH WORDLESS YET,
HIS EYES WILL LIT UP YOUR LIVES
JOIN HANDS WITH MANY MORE SUNSHINE

COME JOIN US

Date: 8th March 2020

Venue: Balarama gate, Mysore palace



NIVEDITHA

Duchenne Muscular Dystrophy
(DMD)

TRUE LOVE IS RARE
BUT IT IS THE ONLY THING THAT GIVES US HOPE!!!
MEET US AT RACEFOR7

DATE: 23rd FEBRUARY 2020

VENUE: SPORTIAN ACADEMY OF SPORTS EXCELLENCE, NAGPUR



VIDYA

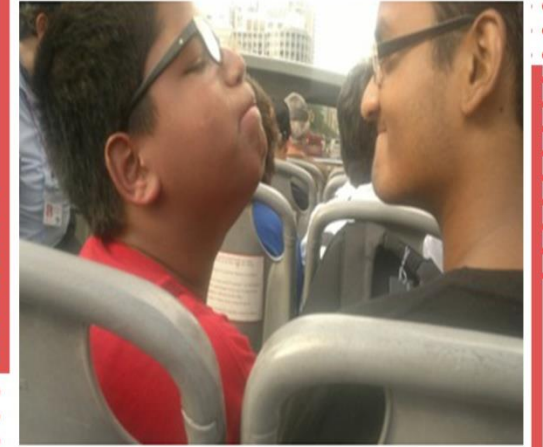
PRIMARY IMMUNO DEFICIENCY
(PID)

AN INNOCENT AND CHEERFUL RARE DISEASE
LOVES TO PLAY, KEEN TO KNOW CURRENT NEWS.
SHE IS THANKFUL TO GOVT OF KARNATAKA FOR
PROVIDING TREATMENT FOR BETTERMENT OF HER HEALTH.

Patients – Social Media drive through creative Emotional messages



VINAYAK
STURGE WEBER SYNDROME



**ANYBODY CAN LOOK AT YOU;
IT'S QUITE RARE TO FIND SOMEONE
WHO SEES THE SAME WORLD AS YOU!!!**

+91 8892 555 000

www.racefor7.com

Now Because of you,
I lead a normal life,
To be able to study
and play is much more fun



ANSH
Prader Willi Syndrome



LAKSH OM
RD - Gaucher disease



**HARDSHIPS OF MY RD
ALWAYS KEPT ME AWAY FROM SCHOOL.**

Now because of YOU, I lead a normal life;
to be able to study & play is much more fun.

www.ordindia.in

+91 8892 555 000

www.racefor7.com



VINEETH
HUNTER SYNDROME

**I AM RARE,
I DID NOT HAVE A CHOICE**

Please do not stare. Come run for me and care.
And help me spread my voice!!!!

www.ordindia.in

+91 8892 555 000

www.racefor7.com



**A RARE DISEASE WARRIOR, MULTI TALENTED CHILD
IS EAGERLY EXPECTING YOU AT THE RACEFOR7
COME JOIN US**

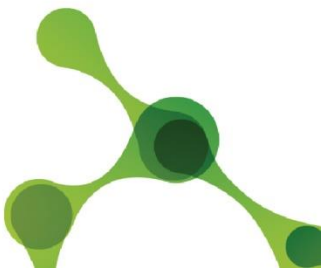
Date: 15th March 2020

Venue: Club House Road, Casuarina Avenue, Kolkata.

www.ordindia.in

+91 8892 555 000

www.r



RD patients as Celebrity, Role model , Achiever, Inspiring



Mr. Sagar Baheti
Stargardt's disease

ENTREPRENEUR, SPORTS ENTHUSIAST & THE FIRST VISUALLY IMPAIRED INDIAN TO COMPLETE THE HISTORIC BOSTON MARATHON,

ARE YOU STILL WAITING FOR INSPIRATION?
COME JOIN THEM IN THE RACEFOR7 2020



Sirisha K.V
(Recipient of National
OSTEOGENESIS IMPERFECTA
(Brittle Bone Disease)

SHE'S BRITTLE YET INDEPENDENT
STUBBORN YET DETERMINED
FOCUSED YET FRIENDLY

ARE YOU STILL WAITING FOR INSPIRATION?
COME JOIN THEM IN THE RACEFOR7 2020



ZOYEB MOHAMED ZIA.
Assistant Professor
& a Budding motivational speaker
Ataxia

THIS WARRIOR HAS EVOLVED FROM
CHALLENGING PHASES TO FACING CHALLENGES.

COME JOIN US

Date: 1st March 2020 Time: 6:30 am
Venue: Olcott School, Adayar, Chennai

RD patients Individual and Mother / Care taker



My name is **Vilas Shinde**
I have a Rare Disease- **CEREBELLAR ATAXIA**

I may have an unsteady walk,
but I am headed towards victory.

Dear Pune,
WALK WITH ME AND CREATE AN IMPACT.

**MAKE OUR VOICES HEARD!!
I CARE FOR RARE...
DO YOU?**

I am Hoping to meet you all
at the **RACEFOR7**

: Date :
16th February 2020

: Venue :
The Queen Mary Technical Institute for
Differently Abled Soldiers, Range Hills,
Park Road, Khadaki, **Pune**

For Registration log into : www.racefor7.com



DISEASE MAY BE RARE
BUT HOPE SHOULDN'T BE

Videos of all Stake Holders – Patients, Parent, Doctor Any one who supports



Organization
for Rare Diseases India

100+ Videos



Celebrity – personalised Invitation – Social Media



SHWETHA R PRASAD
Architect & Actress

I CARE FOR RARE & I will be Joining
Racefor7!!
Will you join hands with us?

REGISTER SOON

<https://registration.racefor7.com>

23rd February 2020
6:30 am

BENGALURU

VENUE

St. Joseph's Indian High School,
Besides Mallya Hospital,
Bengaluru.



YOGATMA SRIHARI
MD, GSS project consultants pvt limited
Managing Trustee
Gss Yogic Research Foundation

Voice of Rare has to be heard
in every small part of India
Join hands with us in the Racefor7
I care For Rare! Do You??

7 km walk/run across 20 Indian cities.

Choose your nearest city

REGISTER SOON

<https://registration.racefor7.com>

8th March 2020
6:30 am

MYSORE

VENUE

Balarama gate, Mysore palace



REGISTER SOON

<https://registration.racefor7.com>

1st March 2020
6:30 am

MUMBAI

VENUE
St Antony's Homes Co operative Society,
OLPS School ground , Chembur,
Mumbai.

Policy maker's Invitation – Social Media drive through creative/banners



TEJASVI SURYA Member of Parliament

Racefor7, Mega Awareness Campaign
Is an initiative to amplify
The voices of
Millions of People with Rare Genetic Diseases!!!
I will be joining Racefor7
How about you??



G. M. SIDDESHWARA Member of the Lok Sabha

Rare disease community is not so Rare after all.
It is our moral responsibility to support these patients
by creating awareness.
I will be joining Racefor7 because I care for Rare
I am hoping you would join as well!!



DR. K. SUDHAKAR Minister of Medical Education of Karnataka

Racefor7 is an initiative to amplify
The voices of
Millions of People with Rare Genetic Diseases!!!
I will be joining Racefor7 because I care for Rare
I am hoping you would join as well!!



7 km walk/run across 20 Indian cities.

Choose your nearest city

REGISTER SOON

<https://registration.racefor7.com>

**23rd February 2020
6:30 am**

BENGALURU

VENUE
St. Joseph's Indian High School,
Besides Mallya Hospital,
Bengaluru.

REGISTER SOON

<https://registration.racefor7.com>

**29th February 2020
6:30 am**

DAVANGERE

VENUE
Karnataka Hemophilia Society,
Ring Road,
S Nijalingappa Layout,
Davangere.

REGISTER SOON

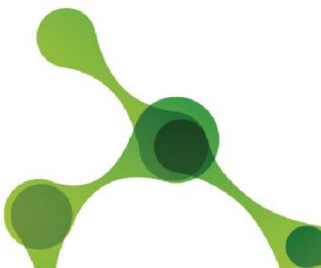
<https://registration.racefor7.com>

**23rd February 2020
6:30 am**

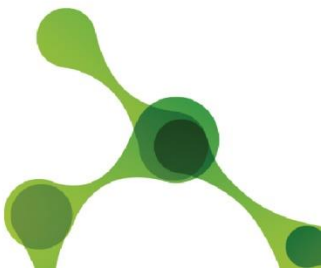
BENGALURU

VENUE
St. Joseph's Indian High School,
Besides Mallya Hospital,
Bengaluru.

- Race for 7 **Budget** included in **PR agency Cost**.
- Plan for a **Press Meet / Conference** – This is in Press clubs in **each state/ City**
- Media **invite to all media** house for 100% registered and listed with Press club. **2-3 day in advance**.
- **Press release** is prepared to be given during the Press meet, Also to be sent to all media through email even if they don't attend. They get the information. 50:50 chances of writing
- Press release shall include **who shall address and their quote** – ORDI, Doctors, Sponsor and Patients.



- During the address ORDI – why Race for 7, Doctor – Medical Challenges and need of Awareness, Sponsor – CSR supporting the cause, Patients and Families – Inviting the public to support.
- After briefing **Q & A, Personal interview of the Key persons, Patients and Families**
- Display a large poster for the event as backdrop and information leaflets about event and Rare Diseases.
- While addressing cover both **event and Need for Rare Diseases.**



Pre Event Press meet

Show case few **large event standees** at the venue...

Briefing Team - Genetic experts, ORDI Director, Patient & sponsor sharing the dais

Let the background of the dais be covered with a **wide backdrop**

mentioning the event..... Releasing the Event Poster



Pre Event -Press meet Scenario



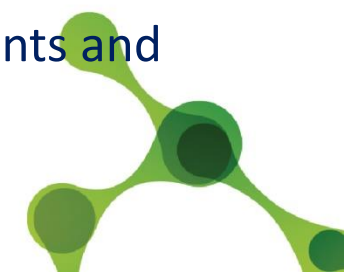
No of reporter and Videos

Pre Event - Press meet Scenario



Show case a **group photo** displaying the **large poster** of the event. This is to be published in all media..

This group will involve ORDI Directors, Genetic experts, Sponsor, patients, parents and caregivers



'రేస్ ఫర్ 7'కు విశేష స్పందన

కొలుకుపేట ప్రమాణ స్మారక సుస్థలమున అన్నివేషాల్లో రేస్ రేక్ డీజర్ (డబ్లీవ్) ఆధ్వర్యంలో రేస్ ఫర్ 7 పేరుతో ఆరువైపుల వ్యాధులపై అవగాహన మారథాన్ అధికారం ఉద్యమం మనంగా జరిగింది. రెక్కో ఆట దీనినిపై ముఖ్య వైద్యుల వారు అనుభవం, సేవల కోసం పాఠశాల వ్యాధులకు చేసే జుంక్ ఫైజర్ వ్యాధి వన సురక్ష పాఠశాల రేస్ ఫర్ 7ను జేచా అనే ప్రారంభించారు. రెక్కో జైంట్ నగర్లో జరిగిన ఈ కార్యక్రమంలో అధికార వ్యాధిగ్రస్తులు, వైద్యులు, ఉద్యోగులు పెద్ద సంఖ్యలో పాల్గొన్నారు. మైక్రోసాఫ్ట్ సీన్స్ మ్యా వైజర్ వ్యాధి సురక్ష జానల్ వ్యాధి సుఖార జానల్ సీక్యూర్లో ఈ రేస్ జరిగింది.



రేస్ ఫర్ 7 పాల్గొన్న ముఖ్య వికలాంగులు

వరల్డ్ రేక్ డీజర్ దీని ఉద్యమించుకు ఈ కార్యక్రమం రేస్ ఫర్ 7ను నిర్వహించి 350 మంది మంది రేక్ డీజర్ సీన్స్ మ్యా అనుభవ వ్యాధులు, వ్యాధిగ్రస్తుల వద్ద అవగాహన వారు పెట్టడం జరిగింది. ప్రపంచ వ్యాప్తంగా జరిగిన రేక్ డీజర్.

Sakshi

ORDI Organizes Racefor7 to Raise Awareness and Advocacy for Rare Diseases

Chennai, February 28: The Organization for Rare Diseases India (ORDI), a not for profit organization committed to addressing the challenges of rare disease patients and their families, today announced the fifth edition of Racefor7, a multi-city run/walk to raise awareness for rare disease patients in India. Racefor7, symbolically representing 7000 rare diseases and the average of 7 years it takes to diagnose a rare disease, is a one of its kind event for rare diseases in the world with 7000 people running or walking 7 kilometers. The fifth edition will be on a much larger scale than before with events scheduled in 20 India cities. Racefor7 is held in February to commemorate World Rare Disease Day which falls on the last day of the month. This year's rare disease theme is Reframe Rare for Rare Disease Day with the message that 'Rare is many, rare is strong and rare is proud!' The campaign message reframes perceptions of what it means to be 'rare' so that no one is left behind in achieving greater equity.

- Facts about Rare Diseases:
- 350 million patients globally of which 70 million rare disease patients are in India
 - India has the world's third highest rare disease population, more than the whole population of Thailand
 - There are an estimated 7000 known rare diseases. Only 450 are recorded in India
 - Average of 7 years to diagnose a rare disease
 - Less than 5% of rare disease have available treatment, most unaffordable

A race to raise awareness about rare diseases

Children, wheelchair users take part

SPECIAL CORRESPONDENT CHENNAI
Scores of people, including children and wheelchair users, took part in a one-of-its-kind race to create awareness about rare diseases.

has grown into a campaign held across 20 cities in the country.

Need for policy
According to Prasanna Shiroli, founder-director of Organisation for Rare Diseases India (ORDI) and father of a rare-disease patient, 50% of all rare disease patients are children. "We also need a supportive rare disease policy and institutions like corporates, schools and colleges to create a more inclusive environment for rare disease patients."

'Racefor7' was flagged off by Johny Tom Varghese, director for the Welfare of the Differently Abled, and S. Suresh, founder and managing trustee of Fetal Care Research Foundation.

The participants ran 7 km, representing the 7,000 rare diseases.

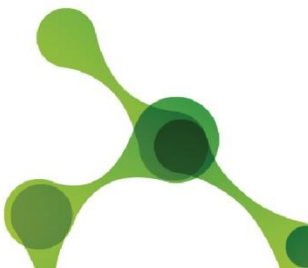
February 28 is observed as World Rare Disease Day. The theme for Rare Disease Day this year is 'Reframe Rare for Rare Disease Day'. The message was 'Rare is many, rare is strong and rare is proud!'

Dr. Suresh said that FCRF and Mediscan were working in the field of rare diseases for the past two decades and over 350 children had been provided treatment.

Racefor7 began as an awareness walk in Bengaluru in February 2016, and

ORDI also launched a helpline for rare diseases (+91 8892 555 000) on the occasion.

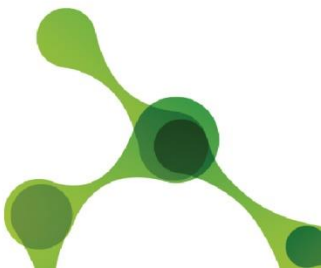
Pre event print media articles in different media with different regional languages



News Paper Impact

			2020 Events Print media penetration	
News Paper Circulation	Volume	%ge	Circulation	Population Covered
Hindi	52416667	37	26208333	131041667
English	34000000	24	27200000	136000000
Marathi	12750000	9	6375000	31875000
Telugu	8500000	6	5950000	29750000
Tamil	8500000	6	5950000	29750000
Kannada	7083333	5	6375000	31875000
Gajarathi	5666667	4	3966667	19833333
Malayalam	4250000	3	2125000	10625000
Oriya	2833333	2	0	0
Bengali	1416667	1	708333	3541667
Others	4207500	3	0	0
	141624167	100	84858333	424291667

**Covered Population of
42 Crores (420 Million)
This only Print media**



Event Day..

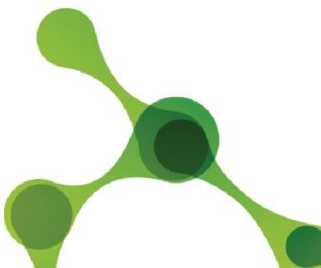
Assembly of all the stake holders and participants who have registered becomes a common voice for the community.

Participants:

- ❖ Assembly of Team members of ORDI, Volunteers
- ❖ Genetic Specialists of the place who gives a **brief on the subject** for which we have this event
- ❖ Most of the **patients/parents/caregivers** from the place who **stress for their needs** from stake holders
- ❖ One speaker from the **sponsor** for the event who **shows their social responsibility**
- ❖ Chief Guest for the event who gives his talks of wisdom for the event – **Policymaker, Celebrity, VIP**

Flow of Agenda & media engagement:

- ❖ Strictly follow the schedule and timelines for each speaker
- ❖ **Allocate a camera angle space for media persons for wide coverage**
- ❖ Set up **large dais, Arch, Standees at the venue**. This gives the size & importance of the event
- ❖ **Engage and keep the media personal till the end of the event**
- ❖ Dedicate few of the volunteers to make **live streaming of the event at all social media**

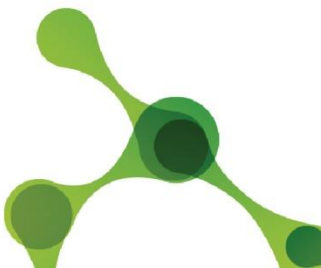


Event Day (Media Pictures for media)..



Large dais has to be completely covered by camera angles

Besides, media personnel camera man, we need to have our professional camera men where some of the good pictures can be given to media



Event Day- Pictures for media – Identify pots for media within the event



dia



Patients participation – helps for Media Attention

Only place to meet Rare diseases patients is the “Race for 7” event apart from their home and hospitals. Every roll of the wheel of wheel chair is the roll towards new beginning



Celebrity – for Flag Off – Mr Karthikeyan –Formula 1 Racer



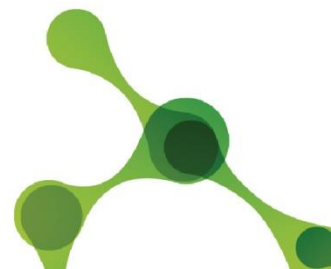
More No of Celebrities More Voices



Doctors participation- Expert Opinion counts Add value to news



Every Genetic doctor in the city conducted has participated



Interaction with- VIP / Celebrity



Youngest MP- Member of Parliament



Doctor and Health Minister of the State



Post event print
media articles in
different media
with different
regional
languages



The Hindu



Samvuktha Karnataka



ಬೆಂಗಳೂರು: ಅಪರೂಪದ ರೋಗ ಸಮುದಾಯಕ್ಕೆ ಬಾಗ್ಯಾಟಿ ಮೂಡಿಸಲು ಆರ್ಗನೈಸೇಶನ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್ ಫಾರಮ್ (ಒಪ್ಪಿಎಂ) ಎಂಬ ಪ್ರಾರಂಭವನ್ನು ರೇಸ್ ಫಾರ್ 7 ಅನ್ನು ಇಂದು ಬೆಂಗಳೂರಿನಲ್ಲಿ ಆಯೋಜಿಸಲಾಗಿದೆ. ಈ ತೇವಸ್ತಿ ಸೂರ್ಯ, ಸಂಸದರು ಮತ್ತು ಶ್ರೀಮತಿ ಪ್ರೀತಾ ಆರ್. ಪ್ರಸಾದ್, ನಟಿ ಮತ್ತು ಐಕಲ್ಯುವಿವಿಎ ಹಿರಿಯ ನಿರ್ದೇಶಕರಾದ ಶ್ರೀ ಪಾಲ್ ಡಾಡ್ ಅವರ ಫಾಗ್ ಆಫ್ ಕೋಡಿಟಿಯು ಮೂಲಕ ಈ ಓಟಕ್ಕೆ ಚಾಲನೆ ನೀಡಿದರು. ಮತ್ತು ನೂರಾರು ಬೆಂಗಳೂರಿಗರೊಂದಿಗೆ ಓಡಿಬಂದರು. ಅವರು ರೇಸ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್ ಓಟದಲ್ಲಿ ಭಾಗವಹಿಸಿದರು. ಏಷ್ಯದ ಅಪರೂಪದ ಕಾಯಿಲೆಗಳಿಗೆ ಸಂಬಂಧಿಸಿದ ಕೊಡುಗೆ ಘಟನೆಯಾದ ರೇಸ್ ಫಾರ್ 7, 7000 ಅವರುಗಳಿಂದ ಸಂಯೋಜಿಸಲಾಗಿದೆ. ಸಾಂಕೇತಿಕವಾಗಿ ಪ್ರತಿನಿಧಿಸುತ್ತದೆ. 7000 ಜನರು 7 ರೋಗಿಗಳಿಗೆ ಓಟದಲ್ಲಿ ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ಪತ್ತೆಹಚ್ಚಲು ಕೈನುಕೊಳ್ಳುವ ಪರಿಶ್ರಮ ವಹಿಸಲಾಗಿದೆ. ಪ್ರತಿನಿಧಿಸಿದ್ದಾರೆ. ಪ್ರಸಕ್ತ ಓರೋಲ್, ಸ್ವಾಸ್ಥಕ ನಿರ್ದೇಶಕರು. ಓಟದಲ್ಲಿ ಅಪರೂಪದ ರೋಗಿ ರೋಗಿಗಳ ತಂತ್ರಜ್ಞರಿದ್ದಾರೆ. 'ನಿನ್ನೂ ಅಪರೂಪದ ರೋಗಿಗಳಲ್ಲಿ 90% ಮಕ್ಕಳು ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ಚಾಚೂರಿನು ಅರಿವಿಲ್ಲದವರು ಇಂತಹ ಪ್ರಯತ್ನಗಳನ್ನು ತೆಗೆದುಕೊಳ್ಳುವುದು ಅನೇಕರು ತಿಳಿದಿಲ್ಲ. ಜಾಗೃತಿಯಿಂದ ಆರಂಭಿಕ ರೋಗನಿರ್ಣಯ ಮತ್ತು ತಿಳಿವಳಿಯು ಅವರ ಜೀವಿತಾವಧಿ ಮತ್ತು ಜೀವನದ ಗುಣಮಟ್ಟವನ್ನು ಹೆಚ್ಚಿಸುತ್ತದೆ. ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ಪಾಪಕವಾದ ಅರಿವಿನ ಸೂಚನೆಯಿಂದಾಗಿ ಆರಂಭಿಕ ಪತ್ತೆ ಮತ್ತು ಚಿಕಿತ್ಸೆಯು ಕೊರತೆಯು ಹೊಸದಾಗಿ. ಉಪ್ಪಿನುದು ಕಣಗಳಲ್ಲಿ ಚಿಕಿತ್ಸೆಯು ಹೆಚ್ಚುತ್ತಿದೆ ಮತ್ತು ದುಪ್ಪಾಂಶವಾಗಿದೆ. ಅಪರೂಪದ ರೋಗಿಗಳಿಗೆ ಹೆಚ್ಚು ಅಂತರ್ಗತ ವಾತಾವರಣವನ್ನು ಸೃಷ್ಟಿಸಲು ಸಮಗ್ರ ಬೆಂಬಲ ನೀಡುವ ಅಪರೂಪದ ರೋಗ ನಿರೀಕ್ಷೆ ರೋಗರೇಸ್ ಸಂಸ್ಥೆಗಳು, ಕಾಲ ಮತ್ತು ಕಾಲೇಜುಗಳ ಸಹಾಯ ತಿಳಿಸುವುದು ಎಂದು ಅವರು ಹೇಳಿದರು.

Ee Sanje

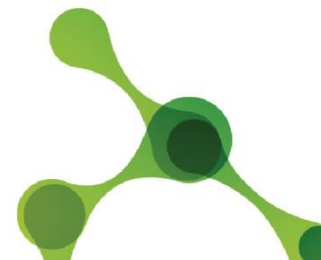


Ee Naadu



Prajavani

Vijaya Karnataka



Post Event -Impact



Organization for Rare Diseases India

CITY FIRST

FOR THE GIFT



A non-competitive run was organized by the Organization for Rare Diseases India (ORDI) as part of its 'Racefor7' initiative in Ahmedabad on Sunday. Hundreds of runners participated in this run, that ended at Decathlon, Applewoods.

The event was aimed at creating awareness about the challenges faced by rare disease patients and their families. The initiative 'Racefor7' represents 7,000 rare diseases with 7,000 people running or walking seven kilometres. Started in February, it has covered 20 cities in the country - Ahmedabad, Bengaluru, Chennai, Coimbatore, Davanagere, Delhi, Hyderabad, Indore, Jaipur, Kochi, Kolkata, Mangaluru, Mumbai, Mysuru, Nagpur, Puducherry, Pune, Thiruvananthapuram, Vadodara and Vellore.



અસાધારણ રોગો પ્રત્યે જાગૃતિ લાવવા અનોખી નોન કોમ્પિટેટિવ રેસનું આયોજન કરાયું



અસાધારણ થતા રોગોની જાગૃતિ માટે તેમજ પરિવારના આ રોગો સામેના પડકારો પ્રત્યે જાગૃતિ લાવવા માટે ઓર્ગેનાઈઝેશન ફોર રેર ડિસીઝ ઈન્ડિયા દ્વારા અનોખી નોન કોમ્પિટેટિવ રન રેસફોસ ૭ યોજવામાં આવી હતી. પ્રતિકાત્મક રીતે રેસફોસ ૭ દ્વારા ૭,૦૦૦ અસાધારણ રોગો સામે આવ્યા છે જે ઘણી મોટી વાત કહેવાય . તેથી ઓર્ગેનાઈઝેશન ફોર રેર ડિસીઝ દ્વારા લોકોમાં તેને લઈને જાગૃતતા ફેલાવવા માટે ભારતમાં ૨૦ શહેરોમાં માર્ચમાં રેસ યોજવાની છે. આ કેમ્પેઈનમાં ૭,૦૦૦ લોકો જોડાયા છે, જેઓ

એક સાથે દોડયાં અને ૭ કિલોમીટર વોક કર્યું. અમદાવાદમાં પણ રવિવારે આ મેરેથોન યોજાઈ. જાગૃતિનો અભાવ અને ડાયગ્નોસ્ટિક્સના અભાવને કારણે કોઈ અસાધારણ રોગનું નિદાન કરવામાં સરેરાશ સાત વર્ષ લાગી જાય છે તે ઉપરાંત, ઉપલબ્ધ હોય ત્યારે મોટાભાગની સારવાર ત્યાં તો ભારતમાં સુલભ હોતી નથી અથવા સરેરાશ ભારતીય દર્દીની પહોંચથી બહાર હોય છે. તેથી તે અંગે જાગૃતિ લાવવા એક વોકનું આયોજન ડિકેલોન ખાતે કરવામાં આવ્યું હતું.

Spreading Positivity - Thank you Messages for GOVT, ESI for Supporting Treatment



DEAR,
KARNATAKA GOVERNMENT
THANK YOU



I AM ANTONY, TIMID AND ARTISTIC; BUT ALSO DIAGNOSED WITH A RARE DISEASE PID.

WITH YOUR IMMENSE SUPORT, I HAVE UNDERGONE TREATMENTS. NOW I USE MY SKILLS TO COLLECT MANY AWARDS FOR MY PAINTINGS

ANTONY
PRIMARY IMMUNO DEFICIENCY (PID)



DEAR,
EMPLOYEES' STATE INSURANCE(ESI)
THANK YOU



I AM CHEERFUL, BUBBLY; LOVE TO SING & DANCE. MY RARE DISEASE CAUSED SEVERAL HEALTH ISSUES.

THANKS TO YOU, WITH YOUR MEDICAL TREATMENT , I AM HEALTHY & LUCKY TO HAVE A BETTER LIFE NOW.

NISARGA
Gaucher disease



DEAR,
KARNATAKA GOVERNMENT
THANK YOU



HARDSHIPS OF MY RARE DISEASE ALWAYS KEPT ME AWAY FROM SCHOOL.

NOW BECAUSE OF YOU, I LEAD A NORMAL LIFE; TO BE ABLE TO STUDY & PLAY IS MUCH MORE FUN.

Laksh Om
Gaucher disease



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DEAR,
KARNATAKA GOVERNMENT
THANK YOU



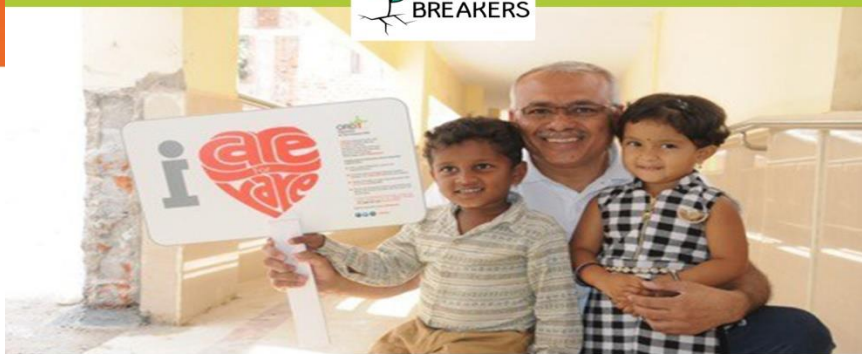
I AM VIDYA, DIAGNOSED WITH A RARE DISEASE CALLED PID.

YOUR HELP IN MEDICAL TREATMENT HAS MADE MY LIFE BETTER, HENCE I CAN NOW PLAY CHEERFULLY.....

VIDYA
PRIMARY IMMUNO DEFICIENCY (PID)



THANK YOU



THANK YOU
GROUND BREAKERS & SASHA STOGNIY
FOR BEING THE VOICE OF MILLIONS OF
RARE DISEASE PATIENTS



DEAR,
EMPLOYEES' STATE INSTURANCE(ESI)
THANK YOU



I AM A CHEERFUL LITTLE CHILD WHO LOVES NAUGHTY TRICKS. MY RARE DISEASE CAUSED SEVERAL HEALTH ISSUES AND AFFECTED MY DAILY LIFE.

THANKS TO YOU, WITH YOUR MEDICAL TREATMENT , I HAPPILY PLAY, RUN AND ENJOY LIFE NOW .

LALITH KUMAR
Gaucher disease



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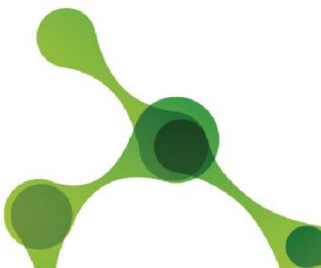
www.ordindia.in +91 8892 555 000 www.racefor7.com

Add some fun in the event for entertainment



Final Take away Message

- Media Planning is a **year long process , not a one time activity.**
- You cannot depend on one media and need to have a **multi Media strategy**
- Need some **WOW** factor for Media Persons to write.
- **VIP, Celebrities bring value to Media plan** and their follower bases helps to spread message
- **Creative Event or Activity** helps to draw the attention of the public and stake holders.
- **Media agency helps if Budget permits**



Lets us Join Hand to Host



Your
Organization
In your
City
Country





Thanks to all our Patients, Families, Care Givers, Doctors, Sponsor's, Volunteers and all Sponsors

THANK
YOU
SO
MUCH!

