Media Strategy
Case study from ORDI – India

Prasanna Shirol
Co founder and Exe Director
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.

Without action, there most certainly is no hope
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 of 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 **inconsistency**.

• 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

WE
Stakeholder Involvement
Patients, Caregivers.
Policymakers
Society Involvement

PSG Hospitals organise marathon to create awareness on rare diseases

PSG Hospitals organise a marathon to create awareness on rare diseases
By NearCity News Team
Mar 03, 2019 05:59 PM

Celebrations: 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 Disease of India).
New Strategy – 2015 onwards – Race for 7

Pre event
- Policy Makers

Event
- Students
- Volunteers
- Testimonials
- Patients Celebrity
- Celebrity

Post event
- 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.

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

+91-8892555000
https://ordindia.in/contact.us

Care for rare. Bring smiles

+91-8892555000
https://ordindia.in/contact.us
Awareness drive Before Event – Social Media creative/banners

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

ANTONY

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!!

Not 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

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

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

Niveditha
Duchenne Muscular Dystrophy (DMD)

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 PROVING TREATMENT FOR BETTERMENT OF HER HEALTH.
Patients – Social Media drive through creative Emotional messages

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

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
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, Khadak, Pune

For Registration log into: www.racefor7.com

RD patients Individual and Mother/Care taker
Videos of all Stake Holders – Patients, Parent, Doctor Any one who supports 100+ Videos
Celebrity – personalised Invitation – Social Media

It may be rare, but we need to be aware

Join the unique event Race for 7
Seven km walk/run showing your solidarity to Rare Diseases

SHWETHA R PRASAD
Architect & Actress
I CARE FOR RARE & I will be Joining Racefor7!!!
Will you join hands with us?

https://registration.racefor7.com
1st March 2020
6:30 am
Mumbai
VENUE
St Antony’s Homes Co operative Society,
OLPS School ground, Chembur,
Mumbai.

YOGATMA SRIHARI
MD, GSS project consultants Pvt limited
Managing Trustee
Gos Yogi 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

https://registration.racefor7.com
8th March 2020
6:30 am
MYSORE
VENUE
Balarama gate, Mysore palace

https://registration.racefor7.com
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

https://registration.racefor7.com
29th February 2020
6:30 am
DAVANGERE
VENUE
Karnataka Hemophilia Society,
Ring Road,
S Njalingappa Layout,
Davangere.

https://registration.racefor7.com
23rd February 2020
6:30 am
BENGALURU
VENUE
St. Joseph's Indian High School,
Besides Mallya Hospital,
Bengaluru.
Pre Event

• 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.
Pre Event - Contd

• 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
Pre Event (News articles)… Drives Registration

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 5th 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 call to scale up efforts 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 Indian cities. Racefor7 is held in February to commemorate World Rare Disease Day which falls on the first 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 raises perceptions of what it means to be ‘rare’ so that one is left behind in achieving greater equity.

Keith about Rare Diseases:
- 500 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

Sakshi

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.

‘Racefor7’ was flagged off by Johny Tom Verghese, director for the Welfare of the Differently Abled, and S. Suresh, founder and managing trustee of Patil Care Research Foundation.

The participants ran 7 km, representing the 7000 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.

Racefor7 began as an awareness walk in Bengaluru in February 2016, and has grown into a campaign held across 20 cities in the country.

Need for policy

According to Prasanna Shiroi, 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.”

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.

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

The Hindu
Racefor7: Rare disease patients, caregivers to hold multi-city march

Chennai: Patients suffering from rare diseases and their caregivers will participate in Racefor7, a multi-city run/walk to raise awareness for rare disease patients in India. The initiative aims to bring attention to the fact that it takes an average of seven years to diagnose a rare disease due to lack of awareness and diagnostics available. Besides, most treatments, even when available, is either not accessible in India or beyond the reach of an average Indian patient, claimed health care experts here.

Patients and caregivers go through a very challenging time coupled with the lack of public access to patients who suffer from physical disabilities. Racefor7, symbolically representing 7,000 rare diseases and the average of seven years it takes to diagnose a rare disease, is first of its kind event for rare diseases in the world with 7,000 people running/walking seven kilometers on February 29, marking World Rare Disease Day.

The run aims to draw attention towards the need for government support in creating a comprehensive Rare Diseases Policy for India as well as the need of other stakeholders to create a more supportive and inclusive environment for the rare disease community.

Dr. Sujatha Jagadeesh, Geneticist and Metabolic Disorder specialist, Mediscan said, “Diagnosis of a metabolic disorder itself can take a long time and by then the patients would have gone through an immense amount of suffering. Arriving at a precise diagnosis needs expertise and testing is expensive. After diagnosis, children would need modification in diet, continuous monitoring and expensive treatments by a multidisciplinary team. For this, the government must support these Children. A public-private partnership model would be ideal to share the expertise and mobilize funds for the same.”

Racefor7, symbolically representing 7,000 rare diseases, is first of its kind event for rare diseases in the world with 7,000 people participating in it.

Andhra Jyothi
### News Paper Impact

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

Assembly of all the stakeholders 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 stakeholders
- 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
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 – Impact

Post event print media articles in different media with different regional languages
A non-competitive run was organized by the Organisation 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, Da-vanagere, Delhi, Hyderabad, Indore, Jaipur, Kochi, Kolkata, Mangaluru, Mumbai, Mysuru, Nagpur, Puducherry, Pune, Thiruvananthapuram, Vadodara and Vellore.
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 support, I have undergone treatments. Now I use my skills to collect many awards for my paintings.

ANTONY
Primary Immune Deficiency

Dear, Employees' State Insurance (ESI)
Thank You

I am Cheeful, 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
Gauher 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
Gauher disease

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 Immune Deficiency

Dear, Employees' State Insurance (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
Gauher disease

Ground Breakers
Thank You

Thank you Ground Breakers & Sash Stogniy for being the voice of millions of rare disease patients

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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**.
Let's 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!