



Information Brochure

# 1<sup>st</sup> Conference on Rare Diseases

Theme: "Intersections with Rare Diseases – A patient-focused event."

Raising awareness and generating change

20<sup>th</sup> March 2023

AIIMS, Bhubaneswar

**Organised by:**  
**Department of Pediatrics, AIIMS, Bhubaneswar &**  
**IAP Odisha State Branch**



## Invitation

**Dear friends,**

Greetings from the 1st Conference on Rare Diseases organising team - AIIMS Bhubaneswar and the IAP Odisha State Branch!! We are honoured to host this event, so block your dates to enjoy this academic program planned on 20th March 2023 at AIIMS, Bhubaneswar.

Our event is dedicated to rare disease patients, their families, care partners, and healthcare providers. This year, our theme is: "Intersections with Rare Diseases—a Patient-Focused Event." We will raise awareness and generate a change in the diagnosis and management of rare diseases. We will also get time to hear about patients' lives with Rare Diseases directly from them.

This event will also highlight the need for legislation in enacting an Orphan Drug Act. Today, many countries have embraced this concept and enacted laws to encourage the development of orphan products, and these programs have become decades old. In India, it is still a dream. The core of the Orphan Drug Act is the concept of equity: whether the disease is common or rare, everyone deserves an early clinical suspicion and access to a diagnostic facility and treatment, especially medicines which are equitable, safe and effective. There is no doubt that Rare Disease drug development too will get a boost once this legislation is enacted. We hope that all patients with rare diseases will soon have the necessary diagnostics and therapies.

We are sure the delegates will become torchbearers in their states/colleges. Besides faculty/senior medical professionals, we request you to encourage your postgraduates to attend the same, as there are many sessions directed to them.

Discover Rare Diseases - A secret so far, but no more. Welcome!

Yours sincerely,

**Dr Joseph John**

**DrAmit Kumar Satapathy**

**Organising Secretaries, 1<sup>st</sup> Conference on Rare Diseases at AIIMS Bhubaneswar**

## Organising Committee Members

<b>Patrons</b>	Prof. Subrat Kumar Acharya, President, AIIMS, Bhubaneswar  Prof. Ashutosh Biswas, Director, AIIMS Bhubaneswar  Prof. Prashanta Raghav Mohapatra Dean, AIIMS Bhubaneswar  Prof. Dillip Parida, Medical Superintendent, AIIMS Bhubaneswar and Chairman Rare Disease Committee, AIIMS Bhubaneswar
<b>Organising Chairperson</b>	Dr Samarendra Mahapatro
<b>Organising Secretaries</b>	Dr Joseph John, Dr Amit Kumar Satapathy
<b>Treasurer</b>	Dr Bhagirathi Dwibedi
<b>Scientific Committee</b>	Dr Joseph John, Dr Tapas Kumar Som, Dr Amit Kumar Satapathy
<b>Registration Committee</b>	Dr Aditi, Mr Umakanta Lal
<b>Food and Beverage Committee</b>	Dr Krishna Mohan Gulla
<b>Venue and Stage Committee</b>	Dr Rashmi Ranjan Das, Mr Sujan Kumar Mohanty

## REGISTRATION FORM

# 1<sup>st</sup> Conference on Rare Diseases

At: AIIMS, Bhubaneswar on 20<sup>th</sup> March 2023

Date .....

IAP, Membership No ..... \*PG Student  Non-IAP Member

Name and Address: .....

City: - ..... Hospital / Institute .....

District ..... State:- ..... Pin Code: - .....

Mobile: - ..... Email Id: - .....

\*Delegate Fees Paid: Rs. ....

### Registration Fees:

Dates	Conference
Before 15 <sup>th</sup> March 2023	300
After 15 <sup>th</sup> March 2023	500
PG students - Anytime	250

\*Certificate from HOD must be attached with this form in case of PG Students.

Mode of Payment: D.D/Cheque/NEFT No. .... Date ..... Bank .....

(Signature of Delegate)

### Payment details:

D.D./Cheque should be in favour of AIIMS Bhubaneswar CME Account, payable at Bhubaneswar / at par multicurrency cheque; Name of Bank - Bank of India, Type of account - Current Plus; A/c No – 557820110000033, IFSC Code; BKID0005578. Address: Bank of India, AIIMS Bhubaneswar, At Sijua, P.O. Patrapada, Bhubaneswar - 751019

### Conference Secretariat:

Organising Secretary, 1st Conference on Rare Diseases, Department of Pediatrics, AIIMS, P.O. Dumduma, Bhubaneswar – 751019 Odisha. Email: [ped\\_joseph@aiimsbhubaneswar.edu.in](mailto:ped_joseph@aiimsbhubaneswar.edu.in)

### Program details

	Topic	Resource person
2:00 PM – 2:30 PM	Inauguration, Address by ED and dignitaries	All dignitaries
2:30 PM – 3:00 PM	Overview and Burden of Rare Diseases In India	Dr Joseph John AIIMS, Bhubaneswar
3:00 PM – 3:30 PM	When and how to suspect a Rare Disease	Dr Tapas Som AIIMS, Bhubaneswar
3:30 PM - 4:00 PM	Clinical spectrum of Rare Diseases	Dr Kuldeep Singh AIIMS, Jodhpur
4:00 – 4:30 PM	Diagnostic Algorithms in Rare Diseases	Dr Ashwin Dalal CDFD, Hyderabad
4:30 PM – 4:45 PM	Government & Non-Governmental initiatives for Rare Diseases and the need for the Orphan Drug Act	Dr Amit K Satapathy AIIMS, Bhubaneswar
4:45 PM - 5:00 PM	Patient perspectives and experiences	Parents of children with Rare Diseases
5:00 PM - 5:15 PM	Valedictory Ceremony	All dignitaries