



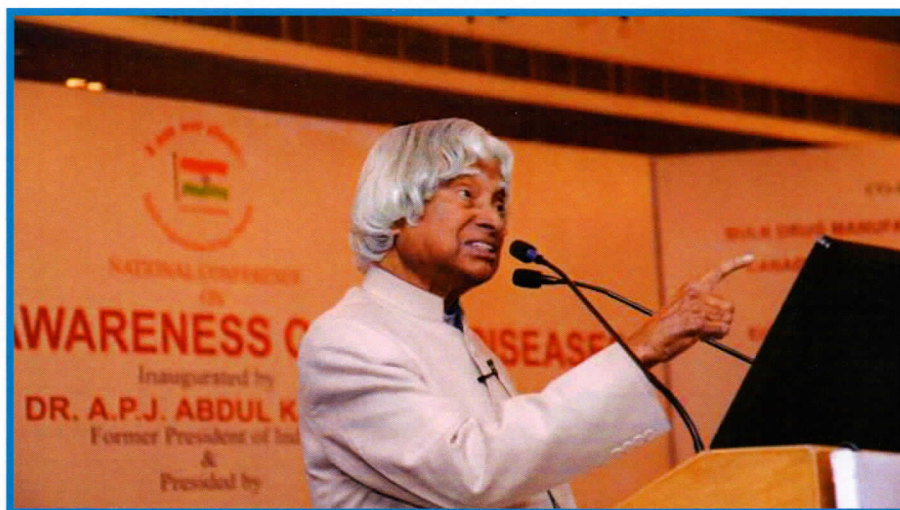
Workshop on Rare Diseases and Orphan Drugs

Theme
**Awareness on Rare Diseases
Towards Policy Initiatives
on Innovation of Orphan Drugs**

11th January 2016
11.00 AM to 4.00 PM

Casuarina Hall
India Habitat Centre
New Delhi

Organised by
Indian Organisation for Rare Diseases
in Association with
Institute of International Trade



Dr. A.P.J. Abdul Kalam's inaugural Address at the first National Conference on Raising the Awareness on Rare Diseases [Hyderabad, Mar 20 2015]

“Genetic intervention can have long term impact and change the natural history”

Friends, I am happy to participate at the inauguration of the National Conference on Raising the Awareness on Rare Diseases. My greetings to all of you. When I am with you friends, I would like to share a few thoughts on **“Alone we are rare~ together, we can make a difference!”**. Friends, I feel even when there is no effective treatment, screening for early diagnosis, followed by suitable care, can improve quality of life and life expectancy.

The most challenging problem of human civilization right now is that science is gathering knowledge faster than society is gathering the wisdom. Since the time of Hippocrates, the history of medicine has been one of ever more sophisticated phenotyping: these are the signs of diabetes- those, the symptoms of Alzheimer disease. Medicine's ability to understand and treat disease has hinged on this careful phenotyping of patients. Modern genetics now has historic opportunity to complete the symmetry of this equation by bringing genotyping to the traditionally phenotypic endeavor of clinical medicine. And while the complexity of this information is a barrier to its implementation, medical geneticists and genetic counselors are well positioned to deal with this emerging volume of information, ensuring our relevance to medical practice.

The Pharma researchers also bear the additional burden of safeguarding ethics and moral values surrounding the work done outside our country. From sequence analysis to microarrays, unprecedented amounts of medical information are being generated which will soon directly pertain to patient care. It is high time that Indian medical geneticists demonstrate to clinicians and policy makers that their activities are necessary to patient care and genetics must emerge as part of medicine's mainstream. The specificities of rare diseases, limited number of patients and scarcity of expertise, single them out as a distinctive domain where international collaboration has high added value. Knowledge must be shared and resources combined as efficiently as possible to tackle rare diseases effectively as a whole. Historically, health authorities have not systematically considered rare diseases to be a public health issue and rare diseases have not been the focus of research programs due to a lack of data. Today, however, most developed nations have launched national plans on rare disease research and management and India is not far behind. With these words, I inaugurate National Conference on Raising the Awareness on Rare Diseases and wish all its members a fulfilling scientific career in tackling rare diseases and mitigating the human suffering.

My God Bless.

Dr. APJ Abdulkalam

For more information...visit www.i-ord.org



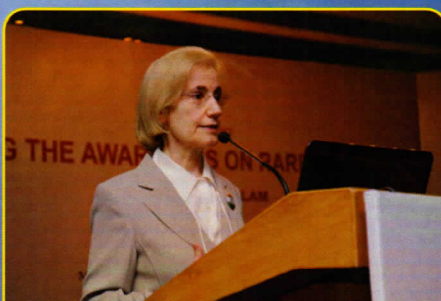
Program Schedule



Venue : **Casuarina, India Habitat Centre**

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|-----------------|--|
| 9.30-10.30 AM | : Registration |
| 10.30- 11.30 AM | : Inauguration |
| 10.30-10.40 AM | : Inaugural welcome address
Dr. Dhanpat Ram Agarwal
Chairman, Organising Committee,
Founder Director, Institute of International Trade |
| 10.40- 10.55 AM | : The Need to understand Rare Diseases and theme of the workshop
Dr. Ramaiah Muthyala
President & CEO, Indian Organisation for Rare Diseases (i-ORD) |
| 10.55- 11.10 AM | : Keynote Address
Dr. Mohammed Ariz Ahammed
Joint Secretary to Government of India, Department of Pharmaceuticals,
Ministry of Chemicals and Fertilizers, |
| 11.10- 11.30 AM | : Inaugural Address
Dr. N. K. Ganguly
President, Jawaharlal Institute of Post Graduate Medical Education & Research
Distinguished Biotechnology Fellow Adviser, Transnational Health Science Technology
Institute, National Institute of Immunology |
| 11.30- 12.00 PM | : Coffee/Tea Break |
| 12.00- 1.30 PM | : Rare Diseases and Orphan Drugs
Javed Abidi
Director, National Center for promotion of employment for Disabled people;
Founder, Disability rights group
Mr. Manjit Singh President, LSDSS, New Delhi
Dr. Jayesh Sheth
Department of Biochemistry and Molecular Genetics,
FRIGE's Institute of Human Genetics, FRIGE House, Ahmedabad
Dr. I. C. Verma
Center for Medical genetics
Dr. Ratna Devi
President, Indian Alliance of Patient Groups,
New Delhi Question and answers |
| 1.30- 2.30 PM | : Lunch Break |
| 2.30- 2.50 PM | : Dr. (Mrs.) Rajeswari R. Moganty
Professor, Department of Biochemistry,
All India Institute of Medical Sciences, New Delhi |
| 2.50 to 3.15 PM | : Tea/Coffee break |
| 3.15 to 3.45 PM | : Panel Discussion
Moderator - Dr. Ramaiah Mutyala
Panel Members - Dr. Mohammed Ariz Ahammed, Dr. N. K. Ganguly, Dr. Jayesh Sheth
Dr. I.C. Verma, Dr. (Mrs.) Rajeswari, R. Moganty, Mr. Manjit Singh, Dr. Ratna Devi |
| 3.45 to 4.00 PM | : Concluding Remarks
Dr. D.R. Agrawal |

Glimpses of First National conference



Organizing Committee Members :

- Dr. Dhanpat Ram Agarwal, Director, Institute of International Trade & Chairman, Organizing Committee
- Dr. Ramaiah Muthyala, President & CEO, Indian Organization for Rare Diseases (i-ORD), www.i-ord.org
- Dr. P.V. Appaji, Director General, Pharmexcil and Advisor to I-ORD on Govt. policies, Hyderabad
- Sri K. V. Gopal Iyer, Spry Technologies, Delhi
- Sri G. K. B. Chowdary, Chairman, Jeedimetla Effluent treatment Ltd, Hyderabad
- Sri Sambasiva Rao, P. Director, Zen Securities Ltd, Hyderabad
- Dr. Krishnaji Rao Mutyala, Editor- News Letter, Indian Organization for Rare Diseases (i-ORD), Hyderabad