



## Third Annual Rett Syndrome Awareness Meeting (31st October, 2010)

**Indian Rett Syndrome Foundation  
New Delhi, India**

The third annual meeting of Rett syndrome was organised on **31<sup>st</sup> October, 2010** to celebrate October as “**Rett syndrome awareness month**”. This meeting was attended by around 70 Families and Doctors, Researchers, Scientists, Students, Therapist and other Healthcare Professionals.

This was the first official meeting of **Indian Rett Syndrome Foundation (IRSF)** after its birth on 27<sup>th</sup> January, 2010 and was hosted by IRSF with support of Department of Pediatrics, All India Institute of Medical Sciences (AIIMS). IRSF had its launch and inauguration before the start of this meeting. This meeting was held in Lecture theatre II, Teaching Block building, AIIMS.



Vice-President of IRSF, **Mr. Harsh Malhotra** welcomed all the guests of day and invited the guests to deliver their opening remarks on the launch of IRSF. **Mr. Surender Singh**, President of IRSF, addressed the Parents and attendees about the Mission and activities of IRSF and requested the support of other new parents to join the IRSF.



**Mrs. Poonam Natarajan**, Chairperson National Trust of India and **Maj. Gen. Ian Cardozo** (Retd.), President, Rehabilitation Council of India were the special guests of the day to launch IRSF. Other guests of the day were **Dr. V.K Paul**, Head and Professor, Department of Pediatrics, **Mrs. Mary Barua**, President, Action for Autism (AFA) and **Mrs. Shardhamani Iyer**, member of ASAR group. All were given floral welcome by the IRSF team.

This meeting was started with inauguration by lamp lighting by all the guests of the day. Inauguration was followed by the official launch of IRSF and its website ([www.rettsyndrome.in](http://www.rettsyndrome.in)).

Information booklet “Little Angels” and “Nanhe Farishte” made for the parents of Rett Syndrome Children was also released in two languages Hindi and English by the special guests of the day.



Meeting was then started with the opening remarks by Mrs. Poonam Natrajan and Maj. Gen. Ian Cardozo. Mrs. Poonam Natarajan and Maj. Gen. Ian Cardozo. Both the guests shared their life experiences and sensitized the audience with their thoughts and remarks.



**Dr. V.K Paul** (Head and Professor, Department of Pediatrics, AIIMS), **Mrs. Mary Barua** (Chairman, AFA) and Mrs. Shardhamani Iyer (Member, ASAR), have shared their thoughts with the parents and congratulated them for their efforts to form the parent foundation for Rett syndrome.



**Dr. Madhulika Kabra** (Office-in-charge and Professor, Genetics Division, Department of Pediatrics, AIIMS) shared the basic information about Rett syndrome with the parents. **Dr. Neerja Gupta** (Assistant Professor, Genetics Division, Department of Pediatrics, AIIMS) presented the information on management of various problems faced by Rett Angels and their families in daily routine.



**Dr. Savita Sapra** (Senior Psychologist, Department of Pediatrics, AIIMS) presented the information on psychological and stimulation needs of the Family and their Rett Angels. **Ms. Rajni Khajuria** (Founder Trustee, IRSF and Researcher, Genetics Division, Department of Pediatrics, AIIMS) shared the information of genetic aspects of Rett syndrome.



**Dr. Suvasini Sharma** (Senior Resident, Department of Pediatrics, AIIMS) presented information on role of ketogenic diet in control of seizures in Rett syndrome. **Mr. Manjit Singh**, Member of Lysosomal storage disorder support society (LSDSS) represented their society and shared their views and experience on being a parent of special child and motivated parents on the aspects that how being involved in parent support groups can help the families and their children's lives.



Few parents of Rett Angels also came forward to share their experience with other families. **Dr. Lilly Ganju**, who has 16 year old Angel, Pallavi has shared the journey of her Angel throughout the years and how her daughter has motivated her life to keep her going. A Nigerian Parent, **Ms. Nagozi**, who has come to attend this meeting has also shared her

experience as her daughter was very recently diagnosed with Rett Syndrome. Mrs. Mary Barua, who is also a Parent to a special Child shared her experience and motivated the families.



Various Therapists from AIIMS and other hospital showed various therapy techniques including Physiotherapy and Occupational needs to be used in daily routine of the Rett Angels with all the parents and also educated them with the need of these therapies in lives of Rett Angels.



Parents interacted with doctors regarding various issues of day to day management of their children and the other issues they had about the future of their Angels. Parents also interacted with the other parents to help them solve various issues regarding their Angels.



**Mr. Hemraj Rattan**, Treasurer, IRSF and Volunteers (**Mrs. Jyoti Malhotra, Mr. Rajeev Sharma, Dr. Shivaram, Ms. Vartika, Ms. Shalini, Mr. Panakj, Mr. Nisar, Mr. Ravi and Mr. Baijnath**) have given their best to help us in the successful organisation of the launch of IRSF. LSDSS of India's sponsored the organization of lunch and tea for the event.

Last session of meeting was ended with vote of thanks by Ms. Rajni Khajuria. She thanked all the Rett families, Doctors, Scientists, Therapists, volunteers, LSDSS, other healthcare professionals and AIIMS staff involved in the meeting arrangements and for making this meeting a successful event for the families by giving their help and support and requested for a forever support from everybody for making life beautiful.