

# 4<sup>th</sup> Annual Rett Syndrome Symposium 23 October, 2011

Conference Hall, Jawaharlal Nehru Auditorium,  
AIIMS, Delhi



Indian Rett Syndrome Foundation is a non-profit charitable national trust working for families having children affected with Rett Syndrome. October is Rett syndrome Awareness month and we marked this month by holding our annual Rett Syndrome Awareness meeting cum symposium for parents, health professionals and general public. We are grateful to the staff of Genetics Division, Dept. of Pediatrics for always extending their support and participation to this cause. The event had been organized by several months of mental and physical engagement of the members of IRSF. Nearly 150 parents were informed about it this event beforehand. Many lived very far from Delhi. There were nearly a dozen volunteers who made it possible for IRSF to hold this function.

It is heartening to see that many parents made the effort to cross half the country to attend this function. Seeing so many Rett girls, lost in their own world, made us more determined to work for the cause. The parents were educated on many relevant aspects of Rett syndrome. The topics discussed were:



1. Epileptic seizures and their handling at home.
2. Gastro intestinal issues involving Rett children.
3. Occupational therapy.
4. Physiotherapy approach.
5. Eye contact and behavioural issues.
6. Rules, regulations, schemes for special children.
7. Special equipments like wheel chairs, walkers, splints, AFO etc were displayed for the learning of parents.

## Highlights of the event:

### Session I:

- Meeting was started with welcome address by Shri. Surender Singh (President, IRSF) who welcome all families, Doctors, health professionals and general public.
- Dr. Madhulika Kabra (Professor and Office-in-Charge, Genetics Unit, Dept. of Pediatrics, AIIMS) informed parents on the basic facts about Rett Syndrome
- Dr. Biswaroop Chakravarty (Senior Resident, Dept. of Pediatrics, AIIMS) presented about various neurological issues in Rett Syndrome.
- Dr. Rachna Sehgal (Senior Resident, Dept. of Pediatrics, AIIMS) presents the Domiciliary management of Seizures in Rett patients. She informed the parents about what are the basic needs which should be taken care when the child gets a seizure.
- Dr. Abdus Sami Bhat (Senior Resident, Dept. of Pediatrics, AIIMS) shared his views on gastro intestinal issues in Rett syndrome Patients and what care to be taken to manage these problems.



### Session II:

- Mrs. Mary Barua (President, Action for Autism (AFA), New Delhi) shared information on stimulation and intervention needs of special children. She shared her experiences with all parents regarding day to day training of children.
- Dr. Nidhi (AFA) recalled the governmental schemes and insurances meant for special children and their parents. This was useful for parents with limited resources.



- Mrs. Sharmila Fernando, parent to beautiful Rett angel Aaisha, shared her experiences in the trials conducted at Boston, USA as her daughter has been enrolled in the trial. She shared that she hopes that this trial will bring joy in the lives of all the families and motivated the families to keep their faith high that the treatment to the Rett monster will be coming soon. She also shared her personal experiences of being in touch with Rett parents from different parts of world and how it helps and support of being in touch with each other.



- Foundation donated Wheel chairs to the needy parents with help of donation from Shri Panchayati Akhara bada udaseen (Haridwar). We are grateful to them for lending us their support and help which could help the needy Parents. We wish to have their support in future too so that we could reach to each and every Rett family requiring help and support.

### Session III:

- Panel discussion between parents and doctor was organized in this session. The Panel included Dr. Madhulika kabra, Dr. Manju Ghosh, Mrs. Mary Barua, Dr. Rachna Sehgal, Dr. Rajni Khajuria, Dr. Abdus Sami, Dr. Nidhi and Dr. Suvasini Sharma from diverse field so that the queries of the parents can be answered. In this panel discussion parents were given opportunities to ask their queries related to the health and management of their children.



Session III followed by lunch.

- After lunch, there was panel discussion between the IRSF board members and the Parents. IRSF team included Mr. Surender Singh, Mr. Harsh Malhotra, Mr. Hemraj Rattan, Dr. Rajni Khajuria and Mr. Umesh Kumawat. Helpline numbers and board member's number were shared with the parents to be called in time of emergencies. Parents shared their success stories of their children with other parents. Nearly 20 new parents also volunteered to work for the cause of Rett Syndrome in India. Parents from different states of India could interact with each others. The parents who came forward to volunteer were explained about the duties to be shared for helping the Rett families, to raise funds for Rett families and to raise awareness about Rett syndrome in their states and local areas.



- Most parents got to share their problems, feelings, and experiences with each other. Many more parents came forward to do volunteering work. A Rett girl is being born every 10,000 live female births. Most of such girls are not even being diagnosed and remain untraced in the country. So parents from all corners of the country can effectively contribute towards sharing their experiences with doctors and the community at large. The awareness can be spread only locally.



- Rett Families who were unable to afford their visit to the Annual meet were given the to and fro fare to encourage them to attend the symposium so that they can get the benefit from the information and knowledge shared about the children in these events. Wheel chairs were distributed by Dr.Madhulika Kabra and Dr.Manju Ghosh on behalf of IRSF.



- We also thank many parents and well wishers who contributed donations to IRSF. They are our strength with whose help we could arrange the symposium. The most notable contribution was from Mr. Sanjay Gunjiyal and Dr. Mandira Gunjiyal, who are parent to beautiful Rett angel Misthi and who are always given their never ending support and help to all of us. Their help and support has always helped in the organization of the Rett syndrome awareness events. Mrs. Sharmila Fernando, parent to beautiful Rett angel Aayisha shared her experience of the trials conducted on Rett girls in Boston, USA. Parents bonded well with each other.



- We thank Mr. Samrender Sarin and Karishma Sarin who are parent to beautiful Rett Angel Aadya and also the representative of IRSF and have been able to help us in raising funds through donation on behalf of IRSF.



- We remain committed to our mission in spreading awareness of Rett syndrome in India and to reach out to the local doctors, physiotherapists, occupational therapists and the society to create awareness and sensitize them towards girls with Rett Syndrome. We urge all the parents to be in a team with IRSF to make our mission to be successful for them and their children.

