

How can you help?

- ★ *Become a member: This will strengthen this cause at national and International levels*
- ★ *Donate for the care and welfare of these Silent Rett Angels*
- ★ *Encourage others to join and to form help groups with the parents and professionals as partners*
- ★ *Participate or help in organizing Awareness symposiums, trainings and other programs*
- ★ *Initiate and develop facilities in your own region to educate people about this disorder*
- ★ *Sponsor a child's treatment, therapist's training or a school's infrastructure/facilities*

We invite you all (who love and care these Silent Angels) to become members and give your support and help, so that these Angels can have an improved quality of life. Please come and join us to strengthen this network for these Angels. Your contribution in terms of your support and help will help in strengthening this network and in building up a strong and active national body



“October is Rett Syndrome Awareness”

Whom to Contact:

For membership and additional information:

Indian Rett Syndrome Foundation

12/1, Sector-1, Pushp Vihar,
New Delhi-110017

E-mail: info.rett@yahoo.com

Website: www.rett Syndrome.in
www.irsf.in

Blog: www.rett Syndrome India.blogspot.com

Phone: +91-9412208521, +91-9313651603
+91-9999343421, +91-9868207228,

For genetic testing and evaluation of Rett syndrome:

Dr. Madhulika Kabra

Addl. Prof & office-in-charge
Genetics Unit, Dept. of Pediatrics,
Old O.T Building, First floor,
All India Institute of Medical Sciences,
Ansari Nagar, New Delhi-110029

Ph# +91-11-26594585

E-mail: madhulikakabra@hotmail.com
info.rett@yahoo.com

“Let us help together to make people aware of Rett syndrome and put a smile on these beautiful Silent Angel's faces and let them have a brighter lives like us”

Indian Rett Syndrome Foundation (IRSF)

“TAKING LEAD FOR THE CARE OF SILENT ANGELS”

“CARE TODAY FOR A BETTER TOMORROW”



(Regd. No. 531)



About IRSF

The **Indian Rett Syndrome Foundation (IRSF)** is a national association of parents, families, Doctors, health professionals and care takers of children with Rett syndrome (also known as Silent Angels) and was established in Delhi on 27th January 2010.

The Mission of IRSF is:

- ★ *To counsel & educate families & doctors on the management of Rett syndrome.*
- ★ *To unite and help parents, families, caregivers, friends, people with Rett and professionals by creating a strong, supportive community by sharing information, news and research about Rett syndrome, so that they can understand and can work together to make a bright future for these children.*
- ★ *To help in improving the quality of life with all those affected with Rett syndrome by proving support, information, services and practical help required by the families living in India*
- ★ *To raise public and professional awareness and understanding of Rett Syndrome by collecting and providing correct information describing diagnosis, causes, therapies, research and other aspects of this disorder , training for scientific and health care personnel and distribution of educational material about Rett syndrome to families, Doctors and the general public.*



About Rett Syndrome

- ★ A developmental disorder of brain that begins to show its effects in infancy or early childhood and it becomes apparent between ages of 6-18 months.
- ★ Affects one in every 10,000 to 15,000 live female births, occurring in all racial and ethnic groups worldwide.
- ★ Caused by mutation/defect in MECP2 gene in 95% cases of typical Rett syndrome
- ★ Leading cause of severe impairment that primarily affects girls, who are known as “**Silent Angels**”.
- ★ Most of these Angels do not talk, walk and use their hands for any purposeful activities



- ★ Every 5 hours a girl is born with Rett syndrome and most of the people do not know about this
- ★ Just imagine the symptoms of autism, cerebral palsy, Parkinson's, Epilepsy and anxiety disorder all in one Little Angel

Things To Remember:

“Rett syndrome is nobody's fault”

“Never feel ashamed of your Child”

“Your child is a Special Child”

“Your child will never improve if you will feel ashamed

“You are not alone”: Together we are better

Symptoms of Rett Syndrome

The diagnosis of Rett syndrome is made on the basis of established clinical criteria.. Your child may have Rett syndrome if she/he has all or majority of these features:

- ★ Development may be normal or mildly delayed during first 6-18 monthss
- ★ Loss of purposeful hand use by repetitive hand movements like hand tapping, mouthing, washing,, wringing, clapping
- ★ Slowed head growth, Severe impairment of expressive language
- ★ Shakiness of upper torso, Breathing problems, digestion and swallowing problems
- ★ Ability to walk is either impaired or lost
- ★ Sleep problems, Spinal curvature, rigid muscles, joint contractures,Seizures, Abnormal EEG pattern, Teeth grinding,Cold small hands and feet

Management of Rett Syndrome

Children with Rett syndrome need 24X7 assistance and care. There are therapies/treatments which are required for the long term care of children with Rett Syndrome and have been found to improve the life of these Angels. This includes:

- ★ Physiotherapy, Occupational therapy, Speech therapy, Hydrotherapy, Hippotherapy, Music therapy etc.
- ★ Medication for problems like seizures, breathing problems, hyperactivity etc.
- ★ Special Diets for digestion and seizure problems