

AIRETT ACTIVITIES REPORT

AIrett Onlus – no profit Rett Syndrome Italian Association – was founded in 1990 and is a Rett Syndrome Europe (RSE) Member.

Its aims are to support and assist families of Rett syndrome patients, inform and raise awareness on the disease, promote and support basic, clinical, rehabilitative and technological research in order to find a definitive cure for Rett syndrome.

AIrett regularly organizes National Congresses to create chances of meeting scientists and families for a correct update on the disease and for a promotion of research on Rett syndrome. It had the honour to organize in Italy the 1st and 4th European Congress on Rett Syndrome in 2009 and 2015, respectively. In order to inform on Rett syndrome, it publishes information booklets and the magazine “Vivirett”; it also has an active website www.airett.it and a Facebook page.

AIrett created a cooperation (also by financial support) with medical centres for Rett patients in 5 hospitals (Genoa, Messina, Milan, Rome and Siena) as main national references on Rett syndrome for research, trials and high-quality care.

RECENT PROJECTS

Clinical passport It's a bracelet with a flash-drive carrying general information on the disease as well as the Rett patient clinical history, extremely useful in case of urgent care at emergency rooms.

Eye-gaze communicator Thanks to new technologies, Rett patients demonstrate how they can communicate by a device enriched by software controlled by girls eye-input.

Summer campus It's a week devoted to families, with experts following Rett girls who experience new games, funny activities, empowerment moments, and parents being free to rest.

Motor rehabilitation Prof. Lotan's expertise created a multitasking, innovative rehabilitation method to be reached for every patient after a correct education of physicians and therapists by seminars and workshops throughout the country.

Teachers education A on-line course on cognitive empowerment and AAC for teachers and educators who work every day with Rett patients.

Work is in progress for

- International Call for Research Projects in Rett Syndrome
- Rett Syndrome Innovation and Research Centre