The Association of Parents and Friends of People with RETT Syndrome "Angels on Earth" is a non profit organisation, which aims to undertake every activity that will help people with RETT Syndrome and their parents. The association was created in 2011. The main goals of the association include: a) support and information for the families of people with Rett syndrome, b) involvement of people with Rett syndrome and their families in socialisation activities, c) strengthening research dedicated on finding a cure, d) public information and awareness-raising and e) assertion of the rights of people with Rett syndrome.

Support and information for the families

The association, in the context of its activities to inform and support the families of people with Rett syndrome, as well as to inform healthcare professionals and therapists, held two events about Rett syndrome in Greece. The first event was held in Thessaloniki in 2016 and the second in Athens, in 2017. These two events discussed various issues around two major pillars regarding the management of the Syndrome's symptoms and ways to improve the quality of life of people with Rett syndrome: medical monitoring and management and therapeutic management of the symptoms. The Angels on Earth Association bought a Cough Assist machine in order to support people with Rett syndrome in cases of emergency. The machine was presented to the parents along with a training demonstration.

In addition to this, the association organises physiotherapy, hydrotherapy and iMuse music therapy sessions in order to inform the families of people with Rett syndrome.

Our Association constantly updates and supports families about issues regarding the rights of the patients, latest developments in legislation, benefits etc. Information is provided through the Angels on Earth website, Facebook page, YouTube channel as well as on a more personalised level, through private messages and on the phone. Last but not least, basic necessity items are provided to the most economically vulnerable families.

Events for the families

Every year, the association organises socialisation events for children and their families where they have the opportunity to get to know each other. Those events are held in places where children can have fun, learn and participate in various activities with their families (theatre, cinema, music hall, zoo, visit to the Acropolis, theme parks etc.). What is more, the association participates in races, such as the Athens and Thessaloniki Marathons and the annual Fotini Papadonikolaki swimming events, where children with Rett syndrome participate.

Awareness-raising events

The association organises various information and awareness-raising events on Rett syndrome. These events take place every October, on the occasion of the Rett syndrome awareness month, the International Day of People with Disability and the World Rare Disease Day. Those events include awareness-raising about the syndrome, interactive events for schools, plays such as the Shadow Theatre play entitled "Karagkiozis and Aggelitsa", visits of the Angels on Earth to State representatives and the Parliament, visits to hospitals etc. Every year, the association participates in health conferences and fora where the syndrome is presented, along with the problems we are faced with in Greece and proposals are submitted for their solution.

Assertion of the rights of people with Rett syndrome

In Greece of today, it is very important to fight in order to claim the rights of people with Rett syndrome and maintain the necessary benefits and treatments. Another achievement of the association has been the State decision regarding the monitoring of people with rare

diseases and reduced physical growth, such as Rett syndrome, by pediatric Hospitals, which are more specialised on those syndromes.
Our visits to the Parliament (at the Committee of Social Affairs of People with Disabilities) have marked another important achievement. We met with Mr. Manios, the chair of the Committee as well as with representatives of all political parties, Ms. Fotiou, the Minister for Labour and Social Affairs and the Parliament committee attempting to establish the pharmaceutical policy framework, claiming the allowances and benefits that will cover the needs of our children.
What is more, thanks to our Association, physicians groups were put together in various hospitals of Athens and Thessaloniki in order to monitor people with Rett syndrome on the basis of the latest protocols that have been successful in hospitals abroad. With the association's support and collaboration, child neurology clinics at the Children's hospital of Penteli and Ippokration hospital of Thessaloniki are expected to be designated as "Reference Centers for Rett Syndrome".
The association Angels on Earth would like to thank the hospitals for their contribution in the monitoring of our children and this is why we provide voluntary work to the hospitals (polishing services, painting, linen items provision etc).

Our efforts continue with requests such as the compulsory prenatal screening for Rett syndrome, the establishment of specialised day care centers for our children as well as support and care for the mothers who have to look after their child on a 24/7 basis. We also request the creation of an official registry of cases in Greece.