

Rett Syndrome Europe meets in Copenhagen

RSE held its general assembly on 26/10/2018 to present the activity report and to discuss future plans. This year's GA meeting took place in Copenhagen, Denmark. Our friends from Landesforeningen Rett Syndroms hosted the meeting and kindly arranged the organisation of the two days. To make it more interesting, two visits to a special school and a Rett Centre were organized for the participants.

We started the day with visiting [Kirkebaekskolen](http://www.kirkebaekskolen.dk) special school (www.kirkebaekskolen.dk) which is unofficially called a Rett school as it has 12 students with Rett syndrome (over 68 students in total, all with very complex special needs). We spent around two hours in the school and got a chance to see the environment, talk with the specialists and students as well.



The first thing that anyone can notice in this school is how amazingly well it is equipped, starting with the whole project of the building, which was created thinking about the special needs of the students, and finishing with the enormous amount of all possible technical equipment. It seems that they have thought of everything: a bright and spacious building of only one floor that doesn't have a single step; every classroom has its own direct exit to the garden that surrounds the building; a warm hydrotherapy pool inside the school; visual support for students in every possible way; modern wheelchairs, standing frames and other mobility equipment; therapy rooms full of activities; computers; eye gaze communicators which belong to the students. Speech therapists work with the students individually a special learning program.

The school is funded by the government, it's clear that the children and their special needs comes first in Denmark. But even the best equipment would be nothing without the specialists that work there. This school has 1 adult per 2 children ratio in their personnel. There are 9 physio therapists and 8 occupational therapists. During the second part of our visit to this school we got a chance to sit down and talk about the specifics of their everyday work with Rett children.



Apart from other educational activities, Rett children every week get one hour of group work with PT as well as going to the hydrotherapy pool. On top of that each child also gets one hour of individual work with PT and one hour with OT a week. These individual work hours may be raised to 4 hours a week if a child had a surgery (to manage scoliosis or hip problems etc.). School performs tests and evaluations of children's abilities, invite doctors every year to provide consultations on site, provide recommendations and adjustments of aids for families, work closely with orthopedists who also arrive to the school to provide and adjust corsets, orthopedic shoes, orthoses for hands, arms or feet for the children. We've also learned about the ways PT tries to manage scoliosis, the great work OT does on evaluating oral motor skills of Rett children and much more. Although most of the children have complex health difficulties, the school does not have nurses as part of the staff team. If a child has a specific medical need, staff are specially trained to deal with it.

The schooltime is from 9 – 15 or 17 and includes lunch. Children only bring snacks from home.

The question was raised about what happens to the Rett people when they reach school leaving age. The school is able to keep them on for a few years, you can apply for 3 more years but access to all the services of OT, physio, etc is restricted. This is a problem we have in a many countries.

Kirkebaekskolen school has left a very good impression not only because of amazing technical equipment, but more importantly because of the knowledgeable and dedicated personnel who do everything in their power (and beyond) to make the lives of children with RS and their families easier.

Full of positive impressions we moved to **the Kennedy Centre** to talk about a small, yet very important **Centre for Rett Syndrome**, which is a part of a hospital and is financed by the government. Here we listened to the presentations about the activity of Danish RS association and the research conducted at Centre for Rett Syndrome. This Centre follows Rett patients (120 in total) lifelong once a year with a complex evaluation. They also provide counselling and support for families and professionals. After the visit to the Centre for RS, schools or other care institutions contact the Centre for RS to organize a local visit and discuss the findings, future work methods and directions as well as follow up. Special attention is given to life-changing situations (like diagnosis, changing from kindergarten to school, turning 18, etc.). The Centre also performs research that emerges from the clinic and practice.



Such a Centre for RS is undoubtedly important because it concentrates deep and complex knowledge. This is later disseminated to the families and targeted specialists who work directly with a specific patient daily, thus maintaining the quality of services and life.

With a kindly envy to our Danish friends for their wonderful system, we move on to the GA and reports of the RSE activity. **GA was attended by representatives from 15 European countries:** Austria, Finland, Denmark, Spain(+ Catalonia), Italy, UK, Lithuania, Poland, France, Portugal, Russia, Finland, Sweden, Germany and Hungary. We had also as observers Anne-Marie Bisgaard (Rett Center Denmark), Helena Wandin (Rett Center Sweden), Dr Semino Martina (Airett Italy)

The RSE board is full of energy and worked very hard this year. The Activity report was presented by Caroline Lietaer, president of RSE. You can find the **Activity Report**: <http://www.rettsyndrome.eu/association-rse/minutes-etc>



The Rett Resource project has been successfully online for a few months now. With the help and close cooperation of volunteers, namely Laura Kanapieniene, Tim Addison, Tim Lang, Laura Luisaityte and Andreas Meissner.... RSE provides some articles already in Croatian, Dutch and Lithuanian

There was also a proposal by Danijela Szili to create **RSE Subcommittees**. This is an option, as set down in our statutes. This proposal prompted interesting discussions. We were very happy to hear all the comments and suggestions. The proposal was accepted in principle but there is a need to adapt it in accordance with the members' wishes. The outcome will be presented at the next GA meeting. A number of RSE members volunteered to help with various projects and tasks during the next year. Daniela Szili will be the contact person for all proposals and volunteers for other tasks of RSE

A new project for this year will be the **mapping of the Rett Centres or Centres in Europe**, where there is great expertise in Rett syndrome. This project was launched at the GA and will be coordinated by Laura Kanapiepiene together with the RSE Board. An online questionnaire will be sent out to the relevant Centres.

The scheduled Rett database videoconference with Dr. Alessandra Renieri unfortunately couldn't take place due to technical problems.

The Italian Association **Airett (Dr Semino Martina)** presented their ongoing project "Amelie" aimed at developing a new software for eye-tracking technology which is created for Rett people. It takes in to consideration their specific problems, with the aim of enhancing their learning and communication skills.

In the evening, at the end of the day's Rett business, **Iben and Soren Hjarsø**, parents of Friderikke, who has Rett syndrome, generously invited all those who had attended the GA to their home, which is close to Copenhagen. We were spoiled with a fabulous candlelit dinner of Danish dishes, beer and wine. Discussions centered on family stories, continuing improvements

of the communication of our girls, the different types of schools in European countries and the huge gap between school and day care centres for older Rett people. As we all spoke English – naturally with an individual accent of the native language – the evening had a very familiar and cosy “hyggeligt” atmosphere.

The next day, Rett mum **Louise Lund** led a private tour for us, through the ancient city of Copenhagen, telling some interesting historical anecdotes.

Finally, it was time to bid our farewells, but with the promise of meeting again next year in Tampere, Finland.

We would once again like to take the opportunity to say **Thank You to the Danish Rett Syndrome Association and the Danish Rett Centre** for the warmly hosting and fantastic organisation of this important European Rett event.

Report written by Laura Kanapieniene, Caroline Lietaer, Stella Peckary and Yvonne Milne

We would like to announce that **our next European conference will take place on 27. – 28.9.2019** in Tampere, Finland : <https://www.rett2019tampere.fi/>

RETT FINLAND

RETTIN OIREYHTYMÄN
6. EUROOPAN-KONFERENSSI
27.-28.9.2019, Tampere

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