

**Minutes of Rett Syndrome Europe General Assembly Meeting held on 28<sup>th</sup> September 2019 in  
Tampere, Finland**

**Present:**

Stella Peckary	Austria
Alice Seror, Caroline Lietaer	France
Ella Helander, Kirsi Peltonen	Finland
Wilfried Asthalter	Germany
Gvantsa Kvantaliani	Georgia
Szili Danijela	Hungary
Laura Kanapieniene	Lithuania
Marielle van der Berg	Netherlands
Anatoly Savchenkov	Russia
Pedro Rocha	Spain
Paula Bolzani Prunes	Catalonia (Spain)
Anna Davidsson Karnevi	Sweden
Daut Tatari	Turkey
Hilde Friis	Norway
Yvonne Milne, Becky Jenner	UK

**Observers:**

Claudia Petzold	Germany
Gerhard Peckary	Austria
Tinatin Sarishvili, Guram Rtskhiladze	Georgia
Claude Buda	Australia
Chris Milne (minutes)	UK

The meeting opened at 1715.

- **Welcome**

The President (CL) opened the meeting by welcoming all country representatives and thanking the Finland association for their excellent hospitality and organisation. She announced that the next conference will be held in 2021 in the UK jointly organised by Rett UK and Reverse Rett.

- **GA meeting minutes 2018**

These were approved by all member countries.

- **Activity report 2018-19**

The President referred to the Activity report for 2018-19 and highlighted the following:

- Special thanks to Laura NK for her assistance to the Board
- The Aims of RSE were reconfirmed
- The Rett Resource is now available in 10 languages
- RS Disorders Alliance health checklist is still a work in progress.
- Welcome to new attendee from Morocco, who are unable to be full members but very welcome to attend and deserve our support.
- Belgium Rett Centre now open
- Dr. Kvantaliani is training at Maastricht

DS reported on the Rare Disease conference in Struga, North Macedonia. DS spoke at the meeting about RS and held a workshop for Rett families.

YM stated that in her Eurordis patient advocate role, she had been asked to present a patient journey for RS, which was chosen as an exemplar for other diseases

DS confirmed that she had been re-elected for another three years to DITA

DS attended winter school and reported that it had been a good learning opportunity. The next Summer school is being held in Barcelona and next winter school would be in March 2020

Members can apply to attend any of the above schools by applying to EURORDIS.

YM reported that universal RS database funding had not been agreed and a further application will be made.

3 new associations – Ukraine, Turkey and Georgia - have been formed and a new Croatian organisation has been created.

DS reported that AFSR plans to donate 200.000 euros for gene therapy research. Terms of reference have been produced for the new research subcommittee. A pilot version was shown to the meeting which will be subject to improvement. The aim is that information will be easy to search by subject. There will also be abstracts for other countries being added.

Any member country who would like to assist should contact DS.

Rett Centre Survey is still ongoing and replies are awaited from some countries. They will be contacted and the survey will be updated during the year.

- **Financial Report**

The report was presented by the Treasurer (WA). He highlighted the reduced year-end balance.

The expenses for Anatoly (Russia) which were delayed after 17/18 are shown in 18/19.

WA showed the budgets for 2019, latest forecast for 2019 and Budget for 2020.

WA reported that the audit had been completed last week and the signed report was shown to members.

The Financial report was unanimously approved.

- **Board renewal**

CL, WA and YM retire in 2020. 5 candidates have applied for vacancies and will be observed during the year.

- **2020 General Assembly**

The next GA will be held in Portugal on the 20<sup>th</sup> and 21<sup>st</sup> November 2020.

- **Any other business**

France reported that 4 countries have CDKL5 organisations – UK, Georgia, Germany and Austria and other countries who have absorbed CDKL5 in to their associations.

The meeting closed at 1825.