Auditorium, Maastricht University Medical Centre

3rd EUROPEAN RETT SYNDROME CONFERENCE
17-19 OCTOBER 2013

Maastricht University Medical Centre, Maastricht, The Netherlands

A Report on Proceedings by Bill Callaghan, President, Rett Syndrome Association of Australia Inc.

3rd European Rett Syndrome Conference
Maastricht, The Netherlands, 17-19 October 2013

Introduction

Nearly 400 people attended the 3rd European Rett Syndrome Conference held in Maastricht during October 2013, the theme of which was "Research Update and Preventive Management". Members of the audience came from 24 countries, 8 of which were outside Europe, while the presenters hailed from 16 countries, 5 of which were non-European. It was the first occasion that RSAA had been represented at a conference organised for the European Rett syndrome community.

3rd European Rett syndrome conference in 5 years

Previous European Rett syndrome conferences have been held in Milan (2009) and Edinburgh (2010). When and where a conference is to be held is determined by who is prepared to manage such. For the event in Maastricht, there were 3 major support groups, namely,

the ***Gouverneur Kremers Centrum*** which is a knowledge centre on intellectual disability involving the Academic Hospital Maastricht and Maastricht University;

Stichting Terre - Rett Syndroom Fonds (the Dutch Rett Syndrome Foundation) which supports research and is a co-founder of the Rett Expertise Centre in Maastricht;

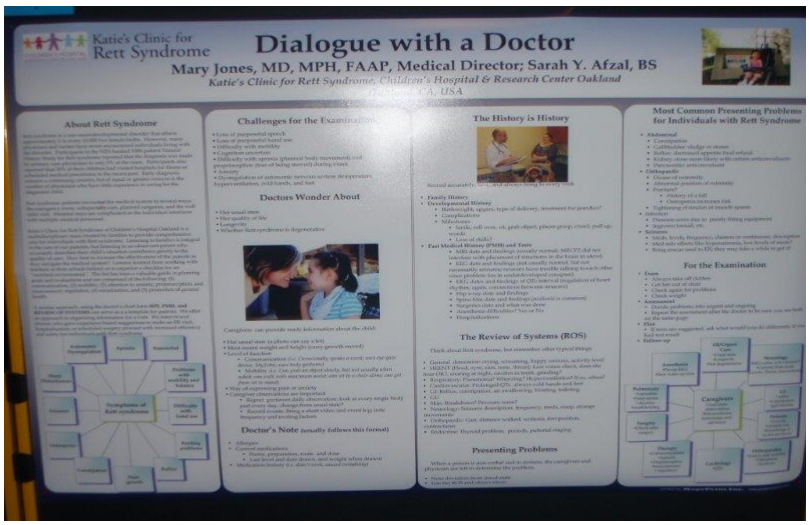
Nederlandse Rett Syndroom Vereninging (the Dutch Rett Syndrome Association) which is the official national Association in The Netherlands, for persons affected by Rett syndrome, their families and carers. It informs, promotes awareness of, and assists research into, the disorder.

Venue and programme

The Maastricht University Medical Centre (MECC) housed the conference with the cost of early registration for a parent being 175 euro. A comfortable 275 room hotel was adjacent to the Centre. A preliminary programme was available on the conference website http://www.europeanrettsyndromeconferencemaastricht.eu/ at least 3 months prior to the commencement date. As at December 2013, a pdf version of the final programme (153 pages) could still be accessed via the conference website. The only difference between the programme given to those present and that available on the website, is that the former included a list of participants. Topics presented and the timetable of sessions, were structured to appeal to 2 broad groups, the scientist/medical specialist and the parent/carer/therapist/ teacher. Sessions could be attended by members of both groups.

Facilities, displays, exhibitors

Sessions, most of which were concurrent, took place in the main auditorium or smaller meeting rooms. A spacious below ground lobby was used for food and drink service, exhibitions, publications, and poster presentations, of which there were at least 20.



Two examples of poster presentations are shown above. The one at left was prepared by staff at Katie's Clinic for Rett Syndrome, Children's Hospital and Research Centre, Oakland, California, on the topic of communicating with a doctor. Education was the main theme of the poster at right and was presented by members of the Israel Rett Centre, Karkur, Israel.

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Facilities, exhibitors and displays (cont.)
Several European Rett syndrome Associations had resource material on Rett syndrome available for distribution or purchase. Of note, was a Dutch version of the 2nd edition of 'The Rett Syndrome Handbook' by Kathy Hunter.

Exhibitors included Tobii which is a Swedish company formed in Stockholm in 2001. It offers a range of augmentative alternative communication devices which include eye tracking/eye control, text to speech conversion, communication boards, and accessories such as switches, mounts and head mice. As this company's products were often referred to in those sessions on communication, it was fitting that it was an exhibitor. As was the case at the World Congress on Rett Syndrome held in New Orleans last year, it was a popular exhibit. There always seemed to be an adequate availability of product information, plus 2 Tobii representatives were there throughout the day to answer queries.

Another innovative exhibition at the conference was the Omivista interactive projection system which is technology that creates dynamic images on a floor which will respond to any movement over its surface. One such image is shown at right. The white box-like equipment in the background, houses the computer from which the image is generated.

Omi which created this technology, is an English company which was formed in 2005. It specialises in the design, development and supply of gesture-controlled interactive technology for the education, health, special needs, and leisure sectors. The projection device on display at the conference was not cheap as it had an asking price of 10,000 euro. More information on this and other products available from Omi, can be found on their website at http://om-interactive.com/interactive_projection.html

Liaison
Aside from being able to meet other parents of Rett syndrome children, being present at the European Rett Syndrome Conference meant that there was an opportunity to further increase awareness of both RSAA and Rett syndrome in Australia, at an international level. These were both achieved, in part, by the references to the Association given by Professor Helen Leonard in her keynote speech on the final day, and informal discussions that I had with representatives from sister Associations in Austria, France, Germany, Hungary, Ireland, The Netherlands, Russia, Sweden, the United States, the United Kingdom and The Netherlands.

Presentations
As was referred to earlier, the oral presentations at the conference were split into 2 broad groups, those which were deemed to be of particular interest to the scientist and medical professional, and those that would appeal to a family, carer, teacher or therapist.

Snippets from selected scientific presentations
Muscle cell abnormalities present in a Rett mouse
Mitochondria are structures within a cell that provide it with energy. They act like a digestive system in that they take in nutrients and break them down, thereby creating the power necessary for the cell to function.

Wendy Gold (Australia) reported on work conducted at the New South Wales Centre for Rett Syndrome Research in Sydney, which found mitochondrial abnormalities in skeletal muscle samples from the Rett mouse. Such abnormalities, it was suggested, may well be contributing to what goes wrong in Rett syndrome.

Wendy Gold during her presentation in Maastricht on research done at the NSW Centre for Rett Syndrome Research, Sydney

The brain stem
To hear Alzheimer's disease, Parkinson's disease, schizophrenia, autism and Rett syndrome, all referred to in the one presentation, was surprising. Professor Harry Steinbusch (The Netherlands) stated that there were common problems in most, if not all, of these disorders, as regards emotion, anxiety, sleep, memory, breathing and movement, and for which a dysfunctional brain stem may be responsible. He suggested that future research of all these conditions should focus on the brain stem. Another presenter, Peter Julu (England), stated that there is now sufficient evidence to warrant regular monitoring of brain stem function in the life time management of an individual with Rett syndrome.

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Presentations

Snippets from selected scientific presentations (cont.)

The brain

Astrocytes are the most abundant cell in the human brain where they play a critical role in dampening the excitability of nerve cells. Vishnu Cuddapah (USA) was able to determine that astrocytes in the Rett mouse brain did not function as they should due to the influence of a faulty *MECP2* gene. This discovery led him to suggest that dysfunctional astrocytes may explain why 80% of Rett syndrome females experience seizures.

Blood pressure

The results of an investigation of heart rate and blood pressure in 21 females with Rett syndrome and 14 healthy females, were presented by Gunilla Larsson (Sweden). Measurements centred on two activities, having to stand for 3 minutes and rising from a sitting position. It was found that there was no difference in blood pressure recovery times between the two groups, but blood pressure did drop for some of the Rett syndrome girls while standing and they required physical support for a short time to remain vertical.

Drugs and other potential treatments

Walter Kaufmann (USA) pointed out that previous drug trials in Rett syndrome have not resulted in benefits for those suffering from the condition. That situation might change, however, given the promising results to date in the trial of Insulin Growth Factor-1(IGF-1) at the Boston Children's Hospital. Phase 1 of the trial has been completed which means IGF-1 is safe to use and will be well-tolerated by those Rett syndrome girls who receive the drug in phase 2. During phase 1, modest improvements were noted in breath holding and sociability, and the girls appeared less anxious. Phase 2, which will take 12 months, was scheduled to begin in November 2013. During the first 20 weeks, half the girls will receive IGF-1 and half a placebo followed by a break of 10 weeks before the next stage begins. This, too, lasts for 20 weeks during which those girls who were given IGF-1 the first time round, will now receive the placebo, and those receiving the placebo initially, will be given IGF-1. Those who actually administer the drug will not know whether it is IGF-1 or the placebo.

IGF-1 treatment in Rett syndrome was also the topic of the session presented by Giorgio Pini (Italy). He found that there was significant improvement in both repetitive hand movement and attention span, in those girls to whom he had given IGF-1.

News of a preliminary study into the treatment of girls with Rett syndrome aged 2-15 years with dextromethorphan (a cough suppressant drug) was provided by Sakkubai Naidu (USA) who advised that a number of girls showed improvement in alertness, social interaction and receptive language, when receiving this drug. As no side effects were observed, treatment with dextromethorphan is continuing.

Levels of glutamate, the principal excitatory neurotransmitter in the brain, have been found to be abnormal in the brain of young females with Rett syndrome. Michael Johnston (USA) suggested there should be an investigation into those treatments which can reduce the impact of high levels of glutamate by selectively blocking glutamate receptors.

Additional treatment strategies were suggested by Monica Coenraads (USA) who founded both 'The Rett Syndrome Research Trust' and the former 'Rett Syndrome Research Foundation'. Under her leadership, a total of US$31 million has been raised by these organisations to assist Rett syndrome and *MECP2* gene research. Her talk referred to a number of genetic approaches that could be used to achieve a cure in Rett syndrome. The underlying problem in the condition is a genetic one so this is what needs fixing. This may involve repairing an *MECP2* gene mutation by gene correction and/or using gene therapy to deliver a healthy copy of the *MECP2* gene; activating the silent yet healthy *MECP2* gene sitting on the inactive X chromosome; or finding a way, perhaps through modifier genes, to enable them do the job that a faultless *MECP2* gene is supposed to do.

MECP2 Duplication syndrome

A number of sessions and poster presentations were devoted to two conditions which have a connection, in one way or another, with Rett syndrome. As its name suggests, *MECP2* Duplication syndrome involves the *MECP2* gene, the main gene at fault in Rett syndrome. However, unlike Rett syndrome, it is caused by duplication of that part of the X chromosome (Xq28) which houses the *MECP2* gene. The condition, which has been diagnosed mostly in boys, is characterised by low muscle tone; delays in sitting, crawling, and walking; intellectual disability; recurrent respiratory infections; epilepsy; constipation and/or reflux; limited or absent speech; autistic behavior; progressive spasticity; repetitive non-purposeful hand movements and teeth grinding. All may also be seen in Rett syndrome.

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Presentations

Snippets from selected scientific presentations (cont.)

Mutations in the CDKL5 gene

The other condition with a Rett syndrome connection is the "CDKL5 disorder". It was identified as a unique disease in 2012 and is caused by mutations in the CDKL5 gene which also sits on the X chromosome, the majority of cases of which are female. The condition usually presents with epileptic seizures in the first few weeks or months of life followed by severe neurodevelopmental delay. A number of children, who have been diagnosed with the CDKL5 disorder, were previously thought to have a variation of Rett syndrome.

Snippets from selected presentations for parents and professionals

Aging

Presently, information is scarce on women with Rett syndrome so it was refreshing to hear about some of them in the talk given by Eric Smeets (The Netherlands). He co-authored an article published in 2013 in which the age group of the oldest women was 30+ years. Information about them was provided by their parents at two points in time, 2007 (for 18 women) and 2012 (for 11 women). Small numbers, but observations included improved health, increased agitation, more alertness, less seizure activity and gross but slow motor deterioration. During his talk, he referred to 3 women in particular:

> Marie Anne was born in 1941 and her general health was described as good. Periodically since 1977, she has had episodes of screaming; lengthy inactivity and daytime sleep; and muscle spasms. Her health prior to 1977 was not referred to;
>
> Marie Claire was born in 1946 and her general health was also described as good. Periodically, since 1987, she has experienced lengthy inactivity and daytime sleep; episodes of crying complete with tears; and outbursts of anger which including hitting others. Her health prior to 1987 was not described;
>
> Martine was born in 1962 and her general health too was described as good. Since 1999, she has been prone to agitation; experienced periods of non-eating; her muscle spasms have increased; falls have been frequent; and she often opposed being involved in activity. Aside from the fact that she did not suffer epilepsy, other aspects of her health were not referred to.

The aging process in Rett syndrome was the topic of a presentation given by Alison Anderson (Australia) and included data on 423 females aged 18 years and over, of whom 50 were older than 35 years. While the health status, living arrangements, etc., of the latter group were not specifically addressed, it is worth noting that information is now becoming available about Rett syndrome women who are aged in their late 30s and older.

Alison Anderson in the middle of one of the two presentations that she delivered at the conference

A recent finding from the Australian Rett Syndrome Study is that 75% of the Study's Rett population will be alive at 25 years of age.

Immediately following Alison's address on aging, Stephanie Fehr, who is also a member of the Australian Rett Syndrome Study team, presented a session on treatment regimens for epilepsy in children and adults with the CDKL5 gene disorder. As stated above, it was only last year that this condition was recognised as a a separate disease and did not belong under the Rett syndrome umbrella.

Even so, affected individuals have many of the symptoms seen in Rett syndrome such as apraxia, breathing abnormalities, teeth grinding, feeding difficulties, sleep problems, seizures (onset during first 1 to 10 weeks of life), repetitive non-purposeful hand movements, reflux, constipation, scoliosis, low muscle tone and impaired mobility. Stephanie described patterns of epilepsy, therapies utilised and their outcomes, that she had extracted from the newly established International CDKL5 Disorder Database.

At left: Stephanie Fehr during her presentation on the 'CDKL5 Disorder'

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Presentations

Snippets from selected presentations for parents and professionals (cont.)

Communication

Much greater attention is being given to the topic of communication in Rett syndrome at conferences these days than was the case several years ago. Ten (15%) of the sessions at this conference focussed either totally, or in part, on this topic as did at least 4 of the poster presentations.

Peter Marschik (Austria) spoke about communication in 1 and 2 year old Rett syndrome children, pointing out that their language development wasn't what was expected for children of that age. Even so, in an analysis of 8 hours of audio-video recordings of 6 Rett girls aged between 9 and 12 months, Peter and his fellow researchers concluded that all the girls had at least one method of communication, be it body movement, facial expression, eye movement, vocalisation or gesture, which they used to either direct attention to themselves or respond when being spoken to. None of the girls could indicate choice or a need for something.

Augmentative and alternative communication (AAC) refers to all forms of communication other than speech. According to Judy Wine (Israel), a speech and language therapist, AAC must provide a means for the Rett syndrome child or adult to express herself in any environment whenever she has a message to communicate. Aided communication strategies can include her eye gaze in conjunction with communication charts made up of objects, pictures and/or the written word (provided she can read); switches; voice output devices; and computers. One critical point in using such devices is determining what means of access is going to prove most effective for the child or adult. It is also important that one finds out what motivates her and use such when interacting with her, keeping in mind that any interaction must allow for her slow response time.

Einat Sarat, who works with Judy Wine at the Israel Rett Centre, referred to 3 Rett syndrome girls with whom she is involved, each of whom used different methods of communication. One was a 16 year old who used multiple methods, another a 19 year old who tapped the hand of her teacher, and the other, a 25 year old who used a voice output device. It has been Einat's experience that those girls presently using AAC systems in their everyday communication, are those who have been using AAC from an early age.

Two speakers focused on the use of eye-tracking devices in their presentations. Jose Schwartzman (Brazil) told of how he had tested 30 Brazilian Rett syndrome females aged from 4 years to 30 years and found that, in general, they were able to direct their gaze not only to an object but also to the human face (particularly the eyes and mouth). Sally-Ann Garrett (Isle of Wight) spoke of how she had collated data on the use of eye gaze technology by 40 Rett syndrome girls in regard to their responses to visual and verbal stimulation that they received from a computer screen. Tobii eye tracking equipment which was used by these girls, enabled the computer to record what the person staring at the screen was looking at. Of the children and adults Sally-Ann assessed, only one did not engage with the computer screen. The rest showed a high rate of fixation on the items shown, strongly suggesting that their eye gaze was intentional.

Two one hour practical workshops, which included demonstrations of Tobii eye-tracking and other AAC devices, were held. As regards the former, it was pointed out that its effectiveness depends on a good "calibration" technique and the users becoming familiar with the equipment.

Knowledge of the extent of speech and language in Rett syndrome is lacking. This situation was improved somewhat when Anna Urbanowicz (Australia) (at right) spoke about speech and language abilities, both before and after the Rett syndrome child regressed. In what was a large sample size of over 800 females, 19% used one or more words following regression compared with 37% beforehand, 42% used babble or word approximations versus 49% in pre-regression, while 39% had no speech after regression compared with 14% beforehand. Even though there was a decline in each category after the regression, there were still 61% of the girls who could either speak, babble or vocalise.

Anna Urbanowicz delivering her presentation on CDKL5

Anna was also a contributor to the poster presentations, one of which related to feedback received from 16 Australian mothers about their Rett daughters' communication abilities. The girls were aged from 2 to 29 years. All mothers advised that they were able to understand their daughters' communication attempts most of the time. Their daughters were able to express discomfort and pleasure, protest, make requests and choices. In addition, all mothers reported that their daughters could understand some of what was being said to them.

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Snippets from selected presentations for parents and professionals

Communication (cont.)

Training the communication partner or parent to improve his or her communication effectiveness with a person affected by Rett syndrome was referred to in 2 presentations, one by Theresa Bartolotta (USA), and the other by Gerna Scholte and Hans van Balkom (both of The Netherlands). Both studies found that such training benefitted all concerned.

Suggested strategies included attributing meaning to the Rett girl's behaviour; providing sufficient wait time after asking her a question; expanding questions and comments by using AAC techniques; increasing the wait time between each offer of food or drink; maintaining eye contact; and increasing the opportunities for choice making. Parents, in particular, learned to create and (re) establish more meaningful experiences in everyday situations with their daughters. The AAC devices that they used during training, were all low-tech.

Therapies

Applied Behaviour Analysis (ABA) is a systematic approach that a therapist can use to alter a child's behaviour and includes a mixture of psychological and educational techniques tailored to the needs of an individual child. Its use in Rett syndrome may necessitate reducing both the hours involved in a particular therapy and the intensity of the interaction. It is quite possible that ABA may prove to be ineffective in modifying a particular behaviour in Rett syndrome. However, this was not the case for a 26 year old Israeli woman with the condition. Physiotherapist Meir Lotan (Israel) set out to improve the extent of her walking which was averaging 600 steps a day, which for many girls with Rett syndrome, would be a marvellous achievement. She had little inclination to walk, preferring to sit down all day. By utilising those things that really motivated her, in conjunction with ABA, he was able to increase her walking to 8,000 steps per day.

Dental care

Because dentists and dental hygenists in The Netherlands lack knowledge on how to treat girls and women with Rett syndrome, dentist Dyonne Broers produced a booklet entitled 'Dental Alerts: Attention Points for Dental Care for People with Rett Syndrome'. Her talk, which included a video of a young Rett girl receiving treatment, centred on the booklet's content.

Things which may harm the teeth of, or make treatment difficult with, the girls, can include teeth grinding, reflux of stomach acid, drooling, abnormal position of the teeth, swallowing problems, an extreme gag reflex, minimal co-operation from them, issues with sedation, dental trauma resulting from falls or self-injurious behaviour, and an inability by them to indicate what the problem is, be it a toothache or something else. Techniques that were suggested to assist with treatment included placing a cushion on the dental chair; a disposable plastic mouth mirror to enable visual observation by the dentist; a silicon mouth prop; and a general anaesthetic.

Curvature of the spine

Research conducted by the Australian Rett Syndrome Study on scoliosis (curvature of the spine) was the subject of the session given by Jenny Downs (Australia) (below right). Of those Australian Rett girls under 14 years of age, 75% had scoliosis, a condition which can cause pain and discomfort, loss of motor skills, and unhealthy pressure on the lungs and other organs. This high percentage reinforces the fact that scoliosis is the most common orthopaedic complication in Rett syndrome. Over the past 17 years, 87 or 1 in 5 of those girls and women participating in the Study, underwent spinal fusion to lessen their degree of curvature.

At right: Helen Leonard (centre) and Jenny Downs (front right) conversing with health professionals and parents at the conference dinner

Families play an important role in research

As 2013 marks the 20th anniversary of the establishment of the Australian Rett Syndrome Study, it seemed fitting that its Founder and Director, Professor Helen Leonard (at right), was invited to be a speaker at the conference. She mentioned how vital it was for the researcher to listen to what the parents had to say and translate that into improved outcomes for those affected by Rett syndrome.

As a result of research conducted by the Study, there has been a considerable expansion of knowledge in the areas of early development, diagnosis, epilepsy, family well-being, feeding and growth, functional abilities, genotype/phenotype relationships, hand movements, health status, health service use, scoliosis, sleep dysfunction and survival. With the establishment of InterRett 10 years ago, the Rett syndrome

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Snippets from selected presentations for parents and professionals

Families play an important role in research (cont.)

population on which information can be collected these days has increased significantly as more and more families from various countries enrol.

Copies of the Study's recently released booklet '*Nutrition and Digestive Health'* were available at the conference and can be obtained by going to the following website http://interrett.org.au/resources/guidelines,-reports-and-books.aspx Work is continuing on another booklet which will contain guidelines for bone health.

The Danish Centre for Rett Syndrome

In 2007, the Danish Centre for Rett Syndrome was established in Copenhagen as a nationwide resource for families and professionals. At its core is a multidisciplinary team consisting of a paediatrician, physiotherapist, geneticist, social worker, nurse, psychologist, and a secretary. Of particular interest was its out-reach capability where information on the syndrome and/or patient reports are personally conveyed to teachers at special education centres, and staff at day care facilities and residential homes for the disabled.

The Rett syndrome scene in Europe

On the first morning of the conference, Rett syndrome representatives from a number of European countries and Israel gave brief descriptions of the work of the Association they represented or on Rett syndrome in their country. The speakers came from Austria, Belgium, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Hungary, Iceland, Israel, Russia, Slovakia, Sweden, the United Kingdom and The Netherlands. It was interesting to hear that:

Both the Belgian and Danish Associations celebrated their 25th anniversaries this year;
Only 2 children in Iceland (population 325,000 as at Sept 2013) have been diagnosed as having the syndrome;
Fewer Swedish families are attending gatherings than in days gone by (This is also happening in Australia);
Families in Finland attend the Swedish Rett Centre;
The help line managed by Rett UK received 1300 phone calls in the 6 month period Sept 2012-March 2103;
Some European countries do not have an Association such as Cyprus and Slovakia;
The German Association has established a working group to see how it can assist adults with Rett syndrome;
The next World Congress on Rett Syndrome will be held in Moscow on 13-17 May 2016;
Rett Syndrome Europe (RSE) acts as the umbrella organisation for 40 Rett syndrome Associations in Europe, more information about which can be found on its website http://www.rettsyndrome.eu/association-rse/europe/

Opening morning of the 3rd European Rett Syndrome Conference and those who had been at the meeting for parent Associations, posed for a group photo

The organisation of the conference was driven by 2 committees, one consisting of members of the Dutch Rett Syndrome Foundation, the Dutch Rett Syndrome Association, the Belgian Rett Syndrome Association, and the Rett Expertise Centre in Maastricht; and the other, a group of scientists from The Netherlands, Sweden and Wales. Their teamwork delivered a conference which ran smoothly; saw professional and parent together under the one roof; contained presentations that were relevant to either group; and was easily accessible to anyone in Europe.

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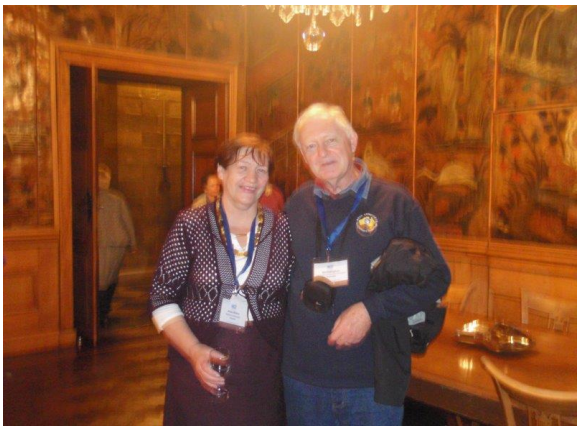
Australian representation

Besides myself, other Australians who attended the conference were Helen Leonard, Jenny Downs, Alison Anderson, Stephanie Fehr and Anna Urbanowicz, all from the Australian Rett Syndrome Study (Perth), and Wendy Gold, Sarah Williamson and John Christodoulou from the NSW Centre for Rett Syndrome Research (Sydney). Financial assistance was provided by RSAA to help two members from each group attend.

Left to right: Helen Leonard, John Christodoulou, Sarah Williamson and Wendy Gold, enjoying the conference dinner at the Grand Café, Maastricht

Never before have there been so many Australian researchers present at a Rett syndrome conference taking place outside of Australia. Each made a positive contribution to what was a most successful conference.



Above: Professor Alina Midro and RSAA President Bill Callaghan, at the welcoming reception for conference attendees held at the Maastricht City Hall

As was referred to earlier, having parent and professional in the one place where the topic of conversation is Rett syndrome, reinforced the fact that we need each other in order to get those things done that will help those affected by the disorder.

Professor Alina Midro (at left), a geneticist at the Medical University of Bialystok, Poland, has a long involvement with Rett syndrome. It began in Berlin in 1985 and continues to the present day. She has always maintained that the co-operation the scientist receives from the parents of the girls, is invaluable. She believes that a scientist attending a conference such as this one, where parents are also attending, gets a much better appreciation of the impact that Rett syndrome has, not only on an affected individual but also the family and others directly involved.

Conclusion

It is with much appreciation that I acknowledge the financial support that I received from RSAA that enabled me to attend this conference. It was an event tailored for the parent, professional and scientist, each of which was represented by at least one Australian. The European Rett syndrome community's awareness of RSAA and their knowledge of the research being done in Australia, was enhanced as a result.

I had not attended Rett syndrome conferences in Europe since 1993 and1996. Within the first half hour of being in the conference venue, just prior to the official opening, I was talking to parents whom I had not seen or been in contact with, since those conferences. When talking to them, it seemed to me that our conversations just continued on from where they left off, all those years ago.

On behalf of RSAA, I thank Rob van der Stel (Chairman, Dutch Rett Syndrome Foundation), Marielle van den Berg (Chairman, Dutch Rett Syndrome Association), Eric Smeets and Leopold Curfs (both from the Maastricht Rett Expertise Centre) and their fellow workers, for everything that they did to make this conference happen. Its success spoke volumes for how they went about things.

The conference concluded in the auditorium with a series of slides on a big screen featuring European Rett syndrome children, one of whom is shown at left.

Bill Callaghan
Rett Syndrome Association of Australia
December 2013.