



**Rubinstein-Taybi Syndrome
International Conference
2016**

20th–22nd May 2016

***Conference Programme
and Information***



LOTTERY FUNDED



Contact Information



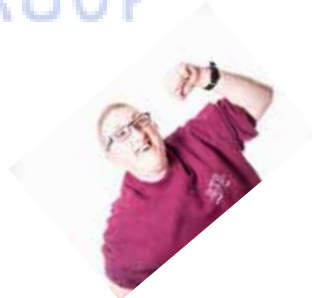
Conference Contacts:

RTS Support Group Committee and Organising Committee Members:

Siobhan Lund	Chair
Maxine Aldred	Vice Chair
Dawn Elliker	Treasurer
Barbara Baron	Secretary
Mags Ruck	Membership Secretary
Charlotte Baron	Merchandising
John Peat	Fundraising Lead
Andrea Simpson	Social Media

Telephone Numbers during Conference:

Maxine Aldred	07936 365815
James Williams	07787 228925
Anthony Cleckner	07587 034542



A Warm Welcome



Welcome!

On behalf of the RTS UK Support Group and the organising committee, I would like to welcome you to Birmingham and this International Conference on Rubinstein-Taybi Syndrome. This will be the 4th International Conference.

We were inspired by the 3rd RTS World Conference which was held in Holland in 2011 with great success. Knowledge of RTS is improving with continuing research and this weekend will give clinicians an opportunity to share the steadily emerging aspects.

There will be workshops with experts in their field for practical suggestions on improving the lives of those with RTS. There will also be opportunities to meet, connect with and learn from other families, who have travelled from all over the world. In addition, we will host a forum on Sunday which we hope will stimulate exchange and discussion between families on experiences.

I hope that you will find time to reflect on the successful (sometimes small) milestones that these children reach, despite the struggles that they face.

I would like to take this opportunity to thank the RTS UK Committee who we have to remember are all volunteers dedicating time and energy to support our RTS families. A big thank you also to our speakers and professional experts giving their valuable time to support our Conference.

We are delighted to welcome you to this event and we hope that you will enjoy the programme.

Siobhán Lund
Chair
RTS Support Group – UK

Programme

Friday, 20th May

Time	Activity	Room
15.00	Conference registration and information desk opens	Main reception area
15.00	Consultations and research commence and will run through to Sunday	To be advised on the day
18.00 – 20.00	Welcome and buffet evening meal	Westminster Suite
Evening	Informal evening – no events	Westminster Suite/hotel bar

Saturday, 21st May

Time	Activity	Room
07.30	Breakfast open	Boulevard Restaurant
08.15	Conference registration and information desk opens	Main reception area
08.30	Crèche opens for morning session. Entertainer will be doing show at 10.00 and 14.00	Oxford and Cambridge
08.30	Unsupervised play area open. Entertainer will be doing show at 11.00 and 15.00	Hampton and Henley
09.00	Conference opens	Kings Suite – Sandringham
09.15	Welcome from RTS Support Group Chair	Kings Suite – Sandringham
09.30	Dr Adam Shaw ME FRCP RTS: Overview and medical management This presentation will cover the range of health problems associated with RTS from birth through adulthood, illustrating what to expect, what to look out for, and what to tell doctors who have never heard of RTS.	Kings Suite – Sandringham
10.15	Refreshments	Kings Suite – Balmoral

Saturday, 21st May

Time	Activity	Room
10.45	Keynote Speaker: Professor Raoul CM Hennekam MD PhD, Professor of Paediatrics This presentation will cover: RTS is most frequently caused by changes in the gene CREBBP and sometimes in changes in the gene EP300. Gradually we start to understand the resemblances and differences in children and adults who have a change in either of these genes. We are still unable to find an abnormality in ~30% of all with RTS.	Kings Suite – Sandringham
11.45	Professor Chris Oliver BSc, MPhil, PhD, CPsychol This presentation will cover: Behaviour in Rubinstein-Taybi Syndrome: What we know and where we are going.	Kings Suite – Sandringham
12.15	Q & A Panel – chaired by Siobhan Lund, RTS Support Group Chair: Professor Raoul CM Hennekam MD PhD, Professor of Paediatrics Dr Adam Shaw ME FRCP Professor Chris Oliver BSc, MPhil, PhD, CPsychol	Kings Suite – Sandringham
12.45	Lunch	Kings Suite
13.45	Crèche reopens for afternoon session.	Oxford and Cambridge



Saturday, 21st May

Time	Activity	Room
14.00 – 14.30	<p>Seminars:</p> <p>Prof Didier Lacombe: Clinical Trial with HDAC inhibitor (Sodium Valproate) on RTS patients.</p> <p>Prof Chris Oliver: Challenging behaviour pertaining to RTS and strategies to deal with them.</p> <p>Vanessa Dourass, Paediatric Dietitian: Diet and compulsive eating strategy.</p> <p>Dr Carol Mason: Dental features of RTS, evidence based preventative messages for good oral health and practical tips/physical aids for oral hygiene in those with severe learning disabilities.</p> <p>Stephanie Ropic: Speech therapy. General principles and practical things you can do.</p>	<p>Kings Suite - Sandringham</p> <p>Dorset</p> <p>Lancaster</p> <p>York</p> <p>Norfolk</p>
14.45 – 15.15	<p>Dr Jo Moss: Autism Spectrum Characteristics in Rubinstein-Taybi Syndrome</p> <p>Charlotte Mawby: Gain an understanding and learn tips on toileting problems including potty training.</p> <p>Stephanie Ropic: Speech therapy. General principles and practical things you can do.</p> <p>Dr Carol Mason: Dental features of RTS, evidence based preventative messages for good oral health and practical tips/physical aids for oral hygiene in those with severe learning disabilities.</p> <p>Cecilie Bredrup, MD PhD: Keloids are proliferative fibrous growths that can cause severe itching. Individuals with Rubinstein-Taybi Syndrome have an increased risk of developing keloids. This condition and other hereditary syndromes in which keloid formation occur can be used to increase our understanding of how keloids develop, and as a next step to identify new approaches to treatment.</p>	<p>Lancaster</p> <p>Dorset</p> <p>Norfolk</p> <p>Kings Suite – Sandringham</p> <p>York</p>

Saturday, 21st May

Time	Activity	Room
15.30 – 16.00	<p>Dr Carol Mason: Dental features of RTS, evidence based preventative messages for good oral health and practical tips/physical aids for oral hygiene in those with severe learning disabilities.</p> <p>Dr Jo Moss: Autism Spectrum Characteristics in Rubinstein-Taybi Syndrome</p> <p>Vanessa Dourass, Paediatric Dietitian: Diet and compulsive eating strategy.</p> <p>Charlotte Mawby: Gain an understanding and learn tips on toileting problems including potty training.</p> <p>Cecilie Bredrup, MD PhD: Keloids are proliferative fibrous growths that can cause severe itching. Individuals with Rubinstein-Taybi Syndrome have an increased risk of developing keloids. This condition and other hereditary syndromes in which keloid formation occur can be used to increase our understanding of how keloids develop, and as a next step to identify new approaches to treatment.</p>	<p>Kings Suite – Sandringham</p> <p>Norfolk</p> <p>Lancaster</p> <p>Dorset</p> <p>York</p>
16.00	Time to relax and meet with families.	
18.00	Evening dinner – Please ensure you know your table name. Table plan situated outside The Kings Suite and also by the Information Desk	Kings Suite
19.30 – 22.00	RTS has Talent and disco	

Sunday, 22nd May

Time	Activity	Room
09.00	Information desk opens	Main reception area
09.00	Unsupervised play area open	Henley and Hampton
09.30	Crèche opens	Oxford and Cambridge
10.15 – 10.45	<p>Seminars:</p> <p>Prof Chris Oliver: Challenging behaviour pertaining to RTS and strategies to deal with them</p> <p>Cecilie Bredrup, MD PhD: Keloids are proliferative fibrous growths that can cause severe itching. Individuals with Rubinstein-Taybi Syndrome have an increased risk of developing keloids. This condition and other hereditary syndromes in which keloid formation occur can be used to increase our understanding of how keloids develop, and as a next step to identify new approaches to treatment.</p> <p>Dr Jane Waite: Autism Spectrum Characteristics in Rubinstein-Taybi Syndrome</p> <p>Vanessa Dourass, Paediatric Dietitian: Diet and compulsive eating strategy.</p>	<p>Dorset</p> <p>York</p> <p>Norfolk</p> <p>Lancaster</p>
11.00	Refreshments available in Kings Suite	
11.15 – 12.30	Open family discussion	Kings Suite – Sandringham
12.30 – 12.45	Close of Conference – Siobhan Lund, RTS Support Group UK Chair	Kings Suite – Sandringham
13.00	Lunch	Kings Suite

Introduction to our Professionals



Dr RCM Hennekam

Raoul Hennekam received his speciality training in Paediatrics and in Clinical Genetics at Utrecht University. He was appointed Professor of Paediatrics and Clinical Genetics in 2002 at the AMC University of Amsterdam. During 2005-2010 he worked in London at The Institute of Child Health and Great Ormond Street Hospital as Professor of Clinical Genetics and Dymorphology. He is presently working as Professor of Paediatrics and Translational Genetics in Amsterdam.

Main scientific interests include intellectual disabilities, autism, connective tissue disorders, and (molecular) dysmorphology. He is a member of: the Dutch Health Council; EUCERD; European Research Council; Editor of American Journal of Medical Genetics and of the European Journal of Medical Genetics; author of 500 papers in peer-reviewed journals (H-index 64) and 24 chapters in international texts; co-chair of the international Morphology Nomenclature Committee; and senior editor of 'Gorlin's Syndromes of the Head and Neck'.



Dr Adam Shaw

Adam Shaw, a Consultant in Clinical Genetics at Guy's & St Thomas' NHS Foundation Trust in London, qualified in Medicine in 1996, and then trained in both Adult and Paediatric Medicine, before entering research to study genetic syndromes. He has had a special interest in RTS for 10 years, and ran a specialist RTS research clinic between 2007 and 2010. Dr Shaw continues to see children and adults with RTS on a regular basis and advise families and other health professionals.



Prof. Chris Oliver, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham, Birmingham, UK.

Chris Oliver is Professor of Neurodevelopmental Disorders at the University of Birmingham and director of the Cerebra Centre for Neurodevelopmental Disorders. He trained as a clinical psychologist at Edinburgh University before completing a PhD on self-injurious behaviour in people with intellectual disability at the Institute of Psychiatry, London. He is currently researching early intervention, behaviour disorders in people with severe intellectual disability and autism spectrum disorder, behavioural phenotypes in genetic syndromes and neuropsychological and behavioural assessment for people with severe intellectual disability. He has published over 100 peer reviewed articles in scientific journals, is Editor in Chief for the Journal of Intellectual Disability Research and serves on a number of scientific advisory committees for syndrome support groups. Sadly, he supports Luton Town Football Club.



Dr Jo Moss BSc, PhD

I am a research fellow at the Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham (www.cndd.bham.ac.uk) and an honorary senior research associate at the Institute of Cognitive Neuroscience, UCL.

My principal research interests include the study of behavioural phenotypes in genetic syndromes associated with intellectual disability. Specifically, I am interested in understanding the nature and developmental trajectory of autism spectrum disorder and related characteristics in genetic syndromes. I am also interested in understanding sociability and social functioning more broadly in this population and aspects of social-cognition which underpin these abilities.



Jane Waite, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham, Birmingham, UK.

Jane Waite is a Postdoctoral Research Fellow at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham. Jane completed her PhD in the behavioural phenotype of Rubinstein-Taybi syndrome before training as a Clinical Psychologist. In September 2013 she returned to the University of Birmingham to work on a project aimed at improving knowledge exchange between families and professionals. She researches repetitive behaviour, challenging behaviour and emotional difficulties in genetic syndromes.



Charlotte Mawby: RGN. RSCN. Independent Paediatric Continence Nurse

Charlotte has over 30 years experience of caring for children in a variety of settings.

She worked for 5 years as a Senior Paediatric Continence Nurse Specialist. Assessing children in the community covering specialist training sessions. She spent 8 years as Clinical Nurse Specialist at a Special school for children with severe / profound learning difficulties.

Was on the working and advisory groups:

NICE 'Advisory group' Commissioning guide – (Implementing NICE guidance) Paediatric Continence Services

NICE 'Guideline development Group' for Nocturnal Enuresis: the management of bedwetting.

NICE 'Implementation planning meeting' for Constipation in children & young people.

Presented Nationally: NICE guidance, Nocturnal Enuresis, Toilet training:

ERIC Conference, Promocon @ Kids South, R.C.N. Continence Care Conference: British Association Paediatric Urology: Continence UK Conference.

Cecilie Bredrup, MD PhD

Cecilie Bredrup, MD PhD, is a paediatric ophthalmologist working in Bergen, Norway. She has an interest in hereditary conditions that affect the eyes alone or in combination with other organs. Currently her focus is on hereditary syndromes in which keloid formation occur.



Carol Mason BDS(Hons) FDSRCS(Eng) FHEA

Carol Mason is a Consultant in Paediatric Dentistry, who has worked at Great Ormond Street Hospital since 1992, first as Senior Registrar, then Honorary Consultant and as a substantive Consultant since 2003. She is the clinical lead for Paediatric Dentistry and works within a number of multi-disciplinary teams. She is also the departmental link for Learning Disability.

She provides comprehensive dental care for children with a wide range of complex medical conditions and syndromes, such as;

- Haematology problems, including bleeding disorders and leukaemia
- Oncology / tumours
- Conditions requiring transplantation (organ / bone marrow)
- Metabolic disorders
- Neurodisability, special needs and learning disability

She qualified with honours from Manchester University in 1985 and undertook general professional training at Manchester Dental School and Alder Hey Childrens Hospital in Liverpool. Following this she worked in the Community Dental Service before undertaking specialist training in Paediatric Dentistry at Guy's Hospital, Eastman Dental Institute and Great Ormond Street Hospital.

She holds the Fellowship in Dental Surgery of the Royal College of Surgeons of England and is a full member of the Higher Education Academy.

In addition to a busy clinical workload, she has been committed to postgraduate teaching and training. She was an examiner for several postgraduate qualifications for the University of London (M Clin Dent in Paediatric Dentistry), Royal College of Surgeons of England (MFDS and exit fellowship for Paediatric Dentistry) and the Bicollegiate Membership in Paediatric Dentistry, of which she was Chairman of the panel of examiners. She is currently an examiner for MJDF.

Vanessa Dourass

Vanessa Dourass qualified as a dietitian in 2010 at Coventry University. She originally started her career working in County Durham within the community, in which her role was to audit and facilitate training which focused on under nutrition, identifying those at risk and treatment pathways to prevent under nutrition. This was based in the adult sector within care homes, community hospitals and patients in their own homes.

Vanessa then moved to work within the acute trust in the Black Country experiencing a variety of specialties- oncology, gastroenterology, renal, cardiology etc. She moved quickly into paediatrics here and worked alongside a small team looking after patients from the acute hospital and the community, spending a year within this role before moving over to Birmingham Children's Hospital where she has been in post for the last year.

Vanessa currently works within the gastroenterology team and also works with the surgical patients covering the neonatal surgical wards.



Stephanie Ropic

Stephanie Ropic qualified as a speech and language therapist in 2002 at Birmingham City University. She has worked with children and young people for the past 14 years in a variety of settings including mainstream and special schools, nurseries and clinics. For 12 years Stephanie worked for the NHS and in her last position she was graded as a senior specialist. Stephanie has helped children with verbal dyspraxia, autism, learning difficulties, cleft lip and palate, Aspergers and Down's Syndrome to communicate more effectively. She decided to leave the NHS 2 years ago to set up her own company called Star Talkers, where schools and parents can access a private speech and language therapy service as much or as little as they choose. Stephanie currently works independently across schools in Birmingham and visits clients privately at their homes.



Sophia Mitchell

Sophia Mitchell graduated from Birmingham City University in July 2013, starting her first job soon after working within the community for Sandwell and West Birmingham NHS Trust. As part of this role Sophia has managed a large caseload of children and young people ageing from 0-19, assessing and providing intervention for their speech, language and communication needs. With a special interest in working with young people with complex needs, Sophia was soon placed in a secondary school for students with profound and multiple learning difficulties. At this school, Sophia continues to work with the students, alongside their families and staff members implementing Alternative and Augmentative Communication (AAC) methods and improving the communication environment within the School. As part of this role Sophia has also participated in a number of projects supporting young people as they transition to adult services and encouraging full participation within the local community. Over the past 12 months Sophia has started working within private speech and language therapy where she has enjoyed providing weekly therapy for families, watching as her clients progress with their communication skills.



Useful Information

Check in/out: Check in 15.00 Friday, 20th May. Check out noon Sunday, 22nd May.

Please note that the RTS Support Group will not accept any charges put on your room. You are responsible for all costs.

Hotel parking: There is a charge for the hotel car park of £9 per 24hrs. The group have been given a discounted rate from £12 per 24 hrs but you will be fully responsible for paying the parking charge.

Conference Registration & Information Desk Registration and Information Desk will be open:
Fri 20th May: 15.00 – 18.30
Sat 21st May: 08.15 – 18.00
Sun 22nd May: 09.00 – 13.00

Wi-Fi: Wi-Fi is available in the public areas of the hotel. There will be a charge to use Wi-Fi in the bedrooms and instructions on charges and how to logon will be available in your room. *(The RTS Support Group will not be responsible for any costs incurred).*

Consultations: 1:1 consultations will take place throughout the conference. You will have details of your time and room in your Welcome Pack. Barbara Baron is your contact for information. The Consultation Info Desk and waiting area will be situated outside the Kings Suite. The Sussex, Kent and Boardroom have been allocated for consultations.

RTS Research: You will have registered your interest in taking part in the research being carried out by Professor Chris Oliver's team. Dr Jane Waite will be your main contact.

Photography: We will have a photographer taking photos throughout the conference. If you do not wish to be photographed, then you must make this known to Maxine Aldred, RTS Support Group. The photos will be used following conference for publicity purposes. You will be able to download photos for your own use following conference. Details will be given to you. There will be a group photo taken on Saturday, details will be announced.

Leisure Centre: The Leisure Centre is available for families attending conference and there is a hoist if required.

Crèche: Please note the crèche is available for families that DO NOT have care support via carers or extended family. We have a limit on numbers in the crèche and we must abide by the regulations. Babies under 6 months will not be allowed into the crèche. There will be a strict booking in process for the crèche, it will be correctly manned by qualified people, but it is a crèche and parents will need to fill in information sheet giving details of special requirements, medication, etc. Also you will need to leave your mobile number and details of which seminars you will be attending. If you are needed, someone will immediately come and get you. Please note that parents will not be permitted to stay with their child or go in and out of the crèche during the session for the safety of all children.

Unsupervised play area:

There will also be a play area for those with carers or extended family to support. An entertainer will be visiting and details will be available in your full programme. Please note that parents/carers will be fully responsible for their own dependents and they must be supervised at all times. The RTS Support Group will not accept any responsibility.

Friday evening meal:

This is available only for those booked on the full conference package. It will be a buffet meal and will be available from 18.00 until 20.00 in the Westminster Suite.

Breakfast:

Breakfast will be available on Saturday and Sunday from 07.30. Please note that breakfast is in the main hotel Boulevard restaurant and is for all hotel guests not just RTS families and is likely to be busy.

Other meals:

All other meals and refreshments will be available in the Kings Suite. The Saturday evening dinner will be a served meal and there will be a table plan in place.

RTS Has Talent:

It would not be an RTS Support Group Conference without a Saturday evening RTS has Talent session. This is about showing achievement – just having the confidence to come up on the stage says it all. If anyone would like to take part, singing, dancing, reciting or even just coming on stage please let us know. If you would like to book then please speak to Maxine Aldred.

Presentations:

Presentations that we are able to share (some will not be available due to copyright) will be available to attendees via a memory stick and will also be available on the RTS website after conference – www.rtsuk.org.



Special Thanks



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