Research Symposium Programme

All times are given here in UK BST (UTC+1), to see programme in a range of time zones, please go to ssbp.org.uk
E-venues: For further information about how to access the e-venues please see page 19.

Session 1 - Thursday 14th September

Time (UK BST)		Session 1	E-Venue
08:00 - 08:30		**KEYNOTE: 1. Jo Van Herwegen** - Improving Educational Outcomes for Young People with Williams Syndrome: From Theory to Practice (and Back Again)	*Website*
08:30 - 09:00		**Free Communications** - 3 x 10 minutes **2. Jente Verbesselt** - Clinical features and developmental trajectories in school-aged children with 16p11.2 deletion **3. Catherine Franklin** - Down Syndrome Regression Disorder **4. Elizabeth Elliott** - The Face of Fetal Alcohol Spectrum Disorder in Australia	*Website*
09:00 - 09:05	**LIVE**	**Welcome from the Organising Committee**	*Zoom*
09:05 - 09:35	**LIVE**	**Q/A Discussion** (Chair: Honey Heussler) - Van Herwegen, Verbesselt, Franklin, Elliott	*Zoom*
09:35 - 09:50		**BREAK** - 15 min	
09:50 - 10:20		**KEYNOTE: 5. Dawn Adams** - Understanding Mental Health and Well-Being in the Context of Neurodiversity	*Website*
10:20 - 10:40		**Free Communications** - 2 x 10 minutes **6. Jessica Hughes** - A parent-led intervention to reduce anxiety in autistic children with severe to profound intellectual disabilities: current data from the LADDERS proof-of-concept study **7. Mirthe Klein Haneveld** - Improving guidelines for individuals with rare genetic neurodevelopmental disorders: a systematic review and critical appraisal of existing guidelines	*Website*
10:40 - 11:05	**LIVE**	**Q/A Discussion** (Chair: Jane Waite) - Adams, Hughes, Klein Haneveld	*Zoom*
11:05 - 11:20		**BREAK** - 15 min	
11:20 - 11:35		**THE PAT HOWLIN LECTURE: 8. Laura Roche** - Enhancing Expressive Communication Using AAC: A Case Study of One Boy with 22q11.2 Deletion Syndrome	*Website*
11:35 - 11:40	**LIVE**	**Q/A Discussion** (Chair: Pat Howlin) - Roche	*Zoom*
11:40 - 12:00	**LIVE**	**Q/A Discussion** (Chair: Pat Howlin) - Why is it so difficult to do intervention research involving individuals with genetic conditions?	*Zoom*

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Session 2 - Thursday 14th September (Friday 15th September in Australia)

Time (UK BST)		Session 2	E-Venue
17:00 - 17:30		**KEYNOTE:** 9. Mustafa Sahin - Collaborative Translational Studies in Rare Neurogenetic Diseases	*Website*
17:30 - 18:00		**Free Communications** - 3 x 10 minutes	*Website*
		10. Nola Chambers - Development of consensus recommendations for the identification and treatment of TSC-Associated Neuropsychiatric Disorders (TAND)	
		11. Agnies van Eeghen - Behavioural outcomes of treatment with cannabidiol oral solution in individuals with seizures associated with tuberous sclerosis complex: design of an ongoing phase 4 trial (EpiCom)	
		12. Nadja Bednarczuk - Behavioural and developmental characteristics of SYNGAP1-related intellectual disability	
18:00 - 18:05	**LIVE**	**Welcome from the Organising Committee**	*Zoom*
18:05 - 18:35	**LIVE**	**Q/A Discussion** (Chair: Anna Jansen) - Sahin, Chambers, van Eeghen, Bednarczuk	*Zoom*
18:35 - 18:50		**BREAK** - 15 min	
18:50 - 19:35		**KEYNOTE: 13. Giacomo Vivanti** - Phenotypic Overlap Between Autism, Williams Syndrome and Angelman Syndrome	*Website*
19:35 - 20:05		**Free Communications** - 3 x 10 minutes	*Website*
		14. Tally Tafla - Critical items of CBCLs in a Brazilian sample of Williams and Down syndrome individuals	
		15. Nicole Tartaglia - The eXtraordinarY Babies Study: Utilization of Early Intervention Therapies in 289 Children with a Prenatal Diagnosis of Sex Chromosome Aneuploidy (XXY, XYY, Trisomy X) and Relationship of Speech Therapy to Speech-Language Outcomes at 36 months of age	
		16. Talia Thompson - Anxiety in Turner syndrome: Engaging community to address barriers and facilitators to diagnosis and care	
20:05 - 20:15		**BREAK** - 15 min	
20:15 - 20:45	**LIVE**	**Q/A Discussion** (Chair: Randi Hagerman) - Vivanti, Tafla, Tartaglia, Thompson	*Zoom*
20:45		**Virtual Social** - Coffee and a chance to chat	*Gather*

Session 3 - Friday 15th September

Time (UK BST)		Session 2	E-Venue
08:00 - 08:45	**LIVE**	**Poster Session A** Presentation of posters, plus poster browsing time. (Chair: Johan Lundin Kleberg)	*Gather*
08:45 - 09:00		**BREAK** - 15 min	
09:00 - 09:30		**KEYNOTE: 17. Bruno Falissard** - Did We Take the Right Train in Promoting the Concept of 'Neurodevelopmental Disorders'?	*Website*
09:30 - 10:00		**Free Communications** - 3 x 10 minutes **18. Honey Heussler** - An Open-Label Trial Assessing Short- and Long-Term Tolerability and Efficacy of ZYN002 (Cannabidiol) Administered as a Transdermal Gel to Children and Adolescents with 22q11.2 Deletion Syndrome (INSPIRE) **19. Nadia van Silfhout** - PROM4RARE: Giving a voice to individuals with rare genetic neurodevelopmental disorders **20. Lauren Shelley** - Associations between executive functioning, intolerance of uncertainty and behaviours that challenge in SATB2-associated syndrome	*Website*
10:00 - 10:30	**LIVE**	**Q/A Discussion** (Chair: Honey Heussler) - Falissard, Heussler, van Silfhout, Shelley	*Zoom*
10:30 - 10:45		**BREAK** - 15 min	
10:45 - 11:00	**LIVE**	**A Presentation Introducing SSBP 2024 - Indonesia**	*Zoom*
11:00 - 12:00	**LIVE**	**SSBP AGM**	*Zoom*
12:00		**Virtual Social** - Coffee and a chance to chat	*Gather*

Session 4 - Friday 15th September (Saturday 16th September in Australia)

Time (UK BST)		Session 2	E-Venue
17:00 - 17:45	**LIVE**	**Poster Session B** Presentation of posters, plus poster browsing time (Chair: Randi Hagerman)	*Gather*
17:45 - 18:00		**BREAK** - 15 min	
18:00 - 18:15	**LIVE**	**THE LECLEZIO-DE VRIES LECTURE:** 21. Jeanne Wolstencroft - Autism Picture Tool: Children and young people's views on consent	*Website*
18:15 - 18:20	**LIVE**	**Q/A Discussion** (Chair: Petrus de Vries) - Wolstencroft	*Zoom*
18:20 - 18:50	**LIVE**	**Panel Discussion** (Chair: Petrus de Vries) - Towards socially responsive and participatory research around the globe	*Zoom*
18:50 - 19:05		**BREAK** - 15 min	
19:05 - 19:35		**KEYNOTE:** 22. Walter Kaufmann - Development of Targeted Treatments for Rett Syndrome	*Website*
19:35 - 20:15		**Free Communications** - 4 x 10 minutes 23. Randi Hagerman - Open Label Trial of Sulforaphane in FXTAS 24. Dejan Budimirovic - High frequency of neuropsychiatric disorders and a need for treatment in patients with FXAND linked to FMR1 gene premutation carriers 25. Federica Alice Maria Montanaro - Fragile X Syndrome and FMR1 premutation: results from a survey on associated conditions and treatment priorities in Italy 26. Kayla Smith - The Relationship between Autism Characteristics, Intolerance of Uncertainty, and Anxiety in Fragile X Syndrome	*Website*
20:15 - 20:20		**SHORT BREAK** - 5 min	
20:20 - 20:55	**LIVE**	**Q/A Discussion** (Chair: Randi Hagerman) - Kaufmann, Hagerman, Budimirovic, Montanaro, Smith	*Zoom*
20:55 - 21:00		**Thanks and Goodbyes**	*Zoom*

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