

Välkommen till en eftermiddag om psykologisk behandling och forskning
vid sällsynta tillstånd med intellektuell funktionsnedsättning
med fokus på Williams syndrom

Tid: Torsdagen **den 2/6 kl 16.00-18.00.**

Plats: Karolinska Universitetssjukhuset, Solna, Eugeniavägen 3, Hiss A, sal Jan Lindsten, eller online. För digitalt deltagande använder vi videoplattformen teams och du kan ansluta via din mobiltelefon, surfplatta eller dator.

Pris: Kostnadsfritt.

Innehåll: Personer med Williams syndrom har en ökad risk för ångestproblematik, men kunskapen om psykologisk och psykiatrisk behandling av ångest och andra psykiatriska tillstånd vid Williams syndrom är begränsad. Under denna eftermiddag kommer en av de främsta experterna i världen gällande just ångestbehandling vid Williams syndrom och intellektuella funktionsnedsättningar, professor Deborah Riby vid Durham University, att berätta om hennes erfarenheter och forskning från Storbritannien. Vidare kommer en uppdatering ges av pågående forskning gällande Williams syndrom vid Karolinska institutet från forskargruppen Sällsynta diagnoser.

Anmälan görs via hemsidan för Centrum för sällsynta diagnoser under temadagar och krävs för att få den länk som behövs för att logga in till seminariet. **Sista dag för anmälan är den 26/5.**

Program:

16.00-16.15	Introduktion	Ann Nordgren (professor, klinisk genetiker)
16.15-17.15	Anxiety in Williams Syndrome: The important of awareness and support	Deborah Riby (professor, psykolog)
17.15-17.35	Mingel och fika	
17.35-18.00	Pågående forskning om Williams syndrom – UNIKA-studien	Charlotte Willfors (med dr, psykolog) Johan Lundin Kleberg (docent, psykolog)

Observera att större delen av föreläsningarna kommer ges på engelska.

Anxiety in Williams Syndrome: The important of awareness and support

Individuals with Williams syndrome are at a heightened risk of experiencing anxiety, representing a significant mental health challenge. Prof Riby will talk about a series of studies and accumulating evidence of heightened anxiety levels associated with Williams syndrome, the experience and impact of anxiety, and how they have tried to raise awareness of this mental health challenge in our work at the Centre for Neurodiversity & Development in the UK. She will draw on studies that have shown longitudinal elements of heightened anxiety, associations between anxiety and other elements of the Williams Syndrome phenotype, cross-condition links to other neurodevelopmental conditions, and potential mechanisms underlying heightened anxiety. Finally, she will present new data from her research group's recent international research project that studied anxiety and broader family well-being in Williams Syndrome, involving over 250 families from 24 countries. She will highlight the importance of involving the whole family to understand familial well-being that can inform necessary support, and emerging findings of the importance of raising awareness and acceptance of disability and Williams syndrome in supporting familial well-being.



Deborah Riby is a Professor of Developmental Psychology and Director of the Centre for Neurodiversity & Development at Durham University, UK. Her research largely focuses on the neurodevelopmental conditions of Williams Syndrome (WS) and Autism and her interests span cognition, behaviour, and mental health; specifically social cognition, social behaviour and anxiety. She is interested in the 'whole' individual and especially the interplay between these different elements of functioning and their underlying mechanisms. Her work takes a multi-methods approach involving a range of quantitative and qualitative methodologies suited to each research question. Research projects have

both delved deeply into one neurodevelopmental condition and taking cross-syndrome approaches to understand syndrome-specific signatures versus broader elements of neurodiversity. Debbie is especially keen to ensure her research has real world relevance and to translating research into practice. Debbie is also national Chair of the Developmental Psychology Section of the British Psychological Society and a member of the Professional Advisory Panel of the Williams Syndrome Foundation UK charity. As well as conducting her research on neurodevelopmental conditions, Debbie is the Director of the ESRC-funded North East and Northern Ireland Doctoral Training Partnership training social science doctoral researchers across 7 UK institutions.

Website: <https://www.durham.ac.uk/research/institutes-and-centres/neurodiversity-development/>

Website: <https://www.durham.ac.uk/staff/deborah-riby/>

Om du har frågor kring seminariet, kontakta Charlotte Willfors på email: charlotte.willfors@ki.se.