Risk and resilience in coping with Tourette Syndrome or chronic tics

**Bounce Back**

Annet Heijerman, Pieter J. Hoekstra, Andrea Dietrich and the Bounce Back consortium in collaboration with international patient advocacy groups

University of Groningen, University Medical Center Groningen, Department of Child and Adolescent Psychiatry & Accare Child Study Center, Groningen, The Netherlands. a.heijerman@accare.nl

**BACKGROUND**

- Tic disorders and comorbid conditions have been associated with poorer functioning and quality of life.
- Little is known about risk and resilience factors in dealing with tic disorders in daily life.

**RESEARCH QUESTION**

“Why do some families experience more distress than others in dealing with tic disorders and what can we do about it?”

**PARTICIPANTS**

Children (N=300), adolescents (N=300) and their parents (N=600), adults (N=300):

- prior study participants (TicGenetics)
- patients recruited from participating clinics (e.g. Netherlands, Germany, UK, Hungary, Spain, USA)
- participants recruited from patient organizations across Europe & USA

**AIMS**

- identify: risk and resilience factors within the individual
- the role of parents, family, peers and society in coping with the condition
- individual’s and their parents’ strengths related to better outcomes

**SURVEY**

- online survey in multiple languages via secured link (RedCap)
- questions: risk and resilience factors, differences in coping strategies, quality of life and stigma
- max. 1 hour to fill in

**EXPECTED**

- survey available: 2nd half of 2024
- results: end of 2025
- insights into the individual, family and societal factors that are most important in coping with tic disorders in daily life
- this knowledge may help clinicians to better explore an individual’s strengths in offering personalized treatment.