

**Deadline for application:** August 31<sup>st</sup> 2019

**Contract duration:** Fixed term (4 years), full-time

**Minimum qualifications required:** Master of Psychology, Master of Social Sciences, Master of Medical Sciences or equivalent degree suitable to register for a PhD

**Vacancy Type:** Research Staff

**Base for the post:** Joint appointment between UZ Brussel and KU Leuven

### **Job description**

The TANDem team is seeking a highly motivated and enthusiastic PhD student to join our dynamic and international research consortium and to initiate his/her PhD research from October 2019 onwards.

**Topic:** Empowering Families through Technology: a mobile-health project to reduce the TAND identification and treatment gap (TANDem)

People who have Tuberous Sclerosis Complex (TSC) have many physical features and these are usually well recognized and treated. However, most people with TSC will also have problems with their development (like intellectual disability or autism), with mental health difficulties (like anxiety or depression) and with learning (such as in school or at work). Together, we call these TSC-Associated Neuropsychiatric Disorders or 'TAND'. Even though most people with TSC have TAND, most of them never get diagnosed or treated. A few years ago, we made up a TAND Checklist to help families and doctors look for and treat TAND. We think it has started to help, but there are still many difficulties to get good assessment and treatment for TAND. When we asked families who live with TSC what they would like us to do next in TAND research, they told us to make the TAND Checklist on a smartphone or iPad so that it would be very easy to use, and asked that we 'quantify' the TAND Checklist so that we can see not only IF somebody is affected but can measure HOW MUCH they are affected. Most importantly, families asked if we could build into the smartphone app a 'TAND Toolkit' that would give them tips and information about what they can do next to help their family members.

The need for interventions or treatments for TAND is the number 1 request from families and doctors all over the world. One of the problems with intervention for TAND is the fact that we actually don't have any interventions that have been scientifically evaluated for the prevention or treatment of TAND. When no evidence-based treatments are available, the first step is to bring together a group of family and professional experts and to make consensus clinical guidelines for treatment. While doing such a process we can also plan what future research will be needed to help us make the evidence to guide us in future.

The PhD student, in close collaboration with the TANDem project coordinator and team of supervisors will assist with

1. The development and validation of a self-complete, quantified TAND Checklist (TAND-SQ), which will be used to develop a Smartphone Application ('App')
2. The generation of consensus clinical guidelines for identification and treatment of TAND, and incorporation of these consensus guidelines into the Smartphone App
3. Active participation in the global TAND Consortium through networking, capacity-building and public engagement activities that will create a transformative 'impact loop' for ongoing improvements in TAND over time

The PhD student will prepare scientific publications related to the research project, which will serve as a basis for a doctoral thesis to be completed by the end of the project.

### **Profile of the candidate**

- strong interest in rare diseases, patient empowerment, multi-stakeholder participatory research
- highly motivated
- positive attitude
- team player
- prepared to travel
- fluent English (spoken and written)

### **How to apply**

Send your motivational letter and CV via email to Prof. Petrus de Vries ([petrus.devries@uct.ac.za](mailto:petrus.devries@uct.ac.za)) and Prof. Anna Jansen ([anna.jansen@uzbrussel.be](mailto:anna.jansen@uzbrussel.be)) by August 31<sup>st</sup> at the latest.