

Deadline for application: August 31st 2019

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

Minimum qualifications required: PhD in discipline relevant to the project

Vacancy Type: Post-doctoral Research Staff

Base for the post: UZ Brussel, Belgium *or* University of Cape Town, South Africa

Job description

The TANDem team is seeking a highly motivated and enthusiastic Post-Doctoral project coordinator to join our dynamic and international research consortium and to coordinate the TANDem research project from October 2019 for 48 months.

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 project coordinator, in close collaboration with the TANDem Principle Investigators (Prof de Vries and Prof Jansen), the TANDem PhD student, and the study team will coordinate

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. Managing 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 Post-doctoral project coordinator will lead in protocol development, submission of Ethics/IRB and all study documentation, have the opportunity to lead some scientific publications related to the research project, will co-author some scientific publications and will oversee all practical aspects of the project throughout the 4 years of the study.

Profile of the candidate

- strong interest in rare diseases, patient empowerment, multi-stakeholder participatory research
- could have an interest in health technology and technology development, but not a requirement
- highly motivated, positive attitude
- excellent at project management, coordination and logistics
- team player and excellent communicator
- 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) and Prof. Anna Jansen (anna.jansen@uzbrussel.be) by August 31st at the latest.