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

Description:
People who have Tuberous Sclerosis Complex (TSC) have many physical features and these are usually well recognized and treated. However, most people will 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. 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.

In this TANDem project we will:
1) make a self-complete, quantified TAND Checklist, build it into a smartphone application (‘App’) and validate it;
2) generate consensus guidelines for treatment of TAND and build those into the TAND App;
3) do a range of networking activities including building an international TAND research consortium (focusing on early career researchers to work in TAND) and public engagement events to help empower everyone with knowledge and tools about TAND.

Start date: 01/10/2019

End date: 01/10/2023

Principal Investigators:
- Prof. Dr. Petrus de Vries, University of Cape Town, South Africa;
- Prof. Dr. Anna Jansen, UZ Brussel, Belgium.
Hosting institutions:
- University of Cape Town, South Africa;
- UZ Brussel, Belgium.

Funding body(ies): Fund Dr & Mrs Charles Tournay-Dubuisson managed by the King Baudouin Foundation.