

**Human Development Institute  
Fund For Excellence**

**Final Project Report/Summary**

Date of report: February, 2017

Primary Investigator Name: Stephanie Meredith/Harold Kleinert  
Primary Investigator email:

Title of Project: HDI National Center for Prenatal and Postnatal Resources

Project Start date: September 2015

Project End date: September 2016

Total FFE Project Budget: \$10,000

Brief summary of the goals of this project:

The purpose of this project was to complete the production of a booklet on Turner Syndrome for parents and prospective parents who receive a prenatal diagnosis of this condition. We received a grant (July 1, 2015 – June 30, 2016) from the Joseph P. Kennedy Jr. Foundation to create the text of this booklet in collaboration with our National Center Medical Advisory Committee.

The HDI Fund for Excellence provided supplemental funding to our Kennedy Foundation grant so that we could create the accompanying photography for the booklet. Studies have indicated that culturally diverse photography that portrays individuals with their families in the ordinary activities of daily life enables prospective families to see beyond a diagnosis, to what it might mean for someone in their own family living with that condition (Levis et al., 2012). Photography that captures individuals across the life span also enables prospective families to envision possible positive futures, at a time when the initial diagnosis often generates paralyzing fear, and a sense of profound isolation.

**Brief summary of the outcomes/achievements resulting from this project**

This project was significant in expanding our library at the National Center for Prenatal and Postnatal Resources to be more inclusive of additional conditions beyond Down syndrome. This expansion of our library positions us to request more funding from cross-disability initiatives and to define our program as the definitive library for clinicians and families seeking accurate, up-to-date, and balanced information following the diagnosis of various genetic conditions that can cause disability.

This project was also key in assembling a “Genetic Conditions Consensus Group” that includes representatives of “The American Academy of Pediatrics,” “The National

Society of Genetic Counselors,” “The American College of Genetics and Genomics,” “The American College of Obstetricians and Gynecologists,” and the “Association of University Centers on Disabilities.” The formation of this group for the evaluation of this Turner syndrome project has been critical in establishing the credibility of this resource and further expanding the Consensus Group role in evaluating and lending significant credibility to our additional Jacobsen syndrome resource funded by the Kennedy Foundation and the update to our Down syndrome booklet.

Furthermore, the photography in this material, which has been legitimized by the approval of this resource by the Genetic Conditions Consensus Group, demonstrates the importance of portraying people with disabilities as authentic members of an inclusive society, across the lifespan and among many cultures, for new and expectant parents at the first point on the life course. This is critical in a field where people with disabilities have been historically portrayed as nudes with black bars over their eyes, dehumanized drawings, or karyotypes. We accomplished this outcome through HDI funding from the Fund for Excellence by travelling to three different locations (Atlanta, Cincinnati, and Florida) to get photos of a range of people with Turner syndrome at their jobs, schools, playgrounds, etc., and the different locations allowed us to find people of different ages and ethnicities.

**Did any products (e.g., materials, manuscripts, technology) result from this project?**

We created a web app, “Understanding a Turner Syndrome Diagnosis” at [understandingturnersyndrome.org](http://understandingturnersyndrome.org) as part of our Lettercase program at [lettercase.org](http://lettercase.org) and a bi-fold with a summary of the information in the web app. The resource has already been recommended in the recent American College of Genetic and Genomics Statement; “Noninvasive prenatal screening for fetal aneuploidy, 2016 update: a position statement of the American College of Medical Genetics and Genomics” ([http://www.acmg.net/docs/NIPS\\_AOP.pdf](http://www.acmg.net/docs/NIPS_AOP.pdf)).

We have also used internal funding from donations to pay for the Spanish translation of this resource. Moreover, we negotiated that the photography for this project be available for HDI in general and have used the photography in articles on the HDI website and also in proposed materials for the employment partnership grant.

**Has, or will, additional funding (e.g., external grants) be sought to sustain the project?**

We are currently selling a bi-fold printed version of this resource in our bookstore, and we currently earn about \$40,000 per year for all products sold in the bookstore. In addition, we are seeking funding from the national Turner syndrome organizations to print several thousand copies of the entire book wherein some books are distributed at no charge to clinicians and expectant parents and some books are sold through our bookstore in bulk. In addition, the Joseph P. Kennedy Jr., Foundation, which provided the other half of the funding for this project, was so pleased with the results that they have offered us two additional \$10,000 grants.

**Has or will the project be continuing beyond the period of Fund For Excellence funding?**

The availability of this resource will continue indefinitely because the products are self-sustaining through book sales once created.