In the past 18 months, the sensitivity and selectivity of non-invasive prenatal screening (NIPS) tests for Down syndrome and other trisomy conditions has been reported as nearly 99%, and no less than four new tests have been introduced since October 2011 (Palomaki et al., 2012). Likewise, the number of pregnant women using these tests has also risen dramatically.

Levis et al. study published in 2013 showed many Hispanic and African American women who are pregnant or planning to become pregnant “said they only saw or knew of Caucasian persons with Down syndrome and requested culturally diverse educational materials about the condition.”

Hispanic population actually has the highest prevalence of Down syndrome at birth (Shin et al., 2009) while at the same time the lowest life expectancy of all demographics affected by Down syndrome (Friedman 2001). Experts often attribute this disparity to inadequate access to healthcare and support services.

The National Center for Prenatal and Postnatal Down Syndrome Resources at the Human Development Institute offers three different evidence-based and medically reviewed programs to address the growing needs of diverse audiences learning about a prenatal diagnosis of Down syndrome: Lettercase, Brighter Tomorrows, and Down Syndrome Pregnancy.

Most participants in the Levis study recommended including photographs of persons with Down syndrome of all ages and from different racial-ethnic backgrounds in educational materials. Other participants from culturally diverse backgrounds recommended family stories, internet accessibility, medical practitioner support, videos, pamphlets and brochures, social media interaction, and Hispanic participant specifically suggested fotonovelas (illustrated pamphlets) about Down syndrome.

Providing resources about Down syndrome to an increasingly diverse audience of expectant parents to improve long-term health disparities

The National Center for Prenatal and Postnatal Down Syndrome Resources