



**Down Syndrome Association of Memphis & the Mid-South**  
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## **NEWS RELEASE**

### **FOR IMMEDIATE RELEASE**

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### **New Down Syndrome Test Hits Market**

*Prenatal blood test to detect Down syndrome raises concerns*

*MEMPHIS, TN* - October 20, 2011 – The Down Syndrome Association of Memphis & the Mid-South (DSAM) is increasing its medical outreach strategy in light of the release of a non-invasive pre-natal test for Trisomy 21, the most common genetic cause for Down syndrome. San Diego-based Sequenom is a biotechnology company that made the test available in 20 cities earlier this week. At least two other companies are preparing to roll out similar tests in the next two years.

The test is a highly sensitive screening test; for a diagnosis, invasive tests that have a risk of miscarriage are still required. The new test has sparked major discussion within the Down syndrome community. Nationwide, parent support groups such as DSAM that advocate on behalf of individuals with Down syndrome, are expressing concerns regarding information provided to expectant parents.

Dr. Brian G. Skotko, a Children's Hospital Boston physician specializing in Down syndrome, points out that these tests could encourage more people to end their pregnancies, causing a decline in the numbers of people with Down syndrome and leading to diminished support for all people with Down syndrome. Behind that concern is the issue of whether expectant parents, told that their child is likely to have Down syndrome, and facing a daunting decision, have all the necessary information to make the best choice for their family.

"This news creates a sense of urgency at a time when DSAM is working on many levels to promote the acceptance and inclusion of all individuals with Down syndrome," says DSAM Executive Director Alyson Edwards.

"We are committed to expanding our efforts to educate the public that people with Down syndrome can lead meaningful, fulfilling lives. Expectant couples who receive a positive diagnosis from this new test must be able to make informed decisions based on accurate and up-to-date information."

The test developers recognize that educational materials are needed for patients to make informed decisions. Guidelines issued this summer on delivering a diagnosis require medical professionals to provide accurate written materials about Down syndrome and to refer the

patients to their local parent support organization. DSAM has written materials to provide to patients and trained staff and volunteers to support these expectant parents receiving a prenatal diagnosis.

The National Down Syndrome Society has released [a position statement on prenatal tests](#), identifying necessary measures for the responsible administration of the new prenatal tests. These measures include requiring that for a test to be called a "Down syndrome test," all forms of Down syndrome must be evaluated. Also, the decision whether to have a test performed must be that of the pregnant woman and her significant other, and the decision should remain strictly confidential.

Despite the challenges of living with Down syndrome, parents, siblings, even people with Down syndrome overwhelmingly report that they are enriched by the experience. Earlier this month, Dr. Skotko, along with Susan Levine of Family Resource Associates, published a study in the [October issue of the American Journal of Medical Genetics](#) that proved this. According to the study:

- 79 percent of parents or guardians felt their outlook on life was more positive because of their child. Only 5 percent felt embarrassed by their child.
- 94 percent of siblings age 9 and older expressed feelings of pride about their sibling. 88 percent said they felt they were better people because of their sibling with Down syndrome. Only 4 percent said they would "trade their sibling in" for another.
- 99 percent of people with Down syndrome said they were happy with their lives. 97 percent liked who they are and 96 percent liked how they look. Only 4 percent expressed sadness about their life.

When talking about life with Down syndrome, it is also critical to note that medical advances in recent decades have led to a dramatic increase in life expectancy. Today, people with Down syndrome live, on average, to 60 years old, with many living into their seventies.

DSAM continues to educate the community about Down syndrome through speaking presentations delivered at community group functions, medical offices and schools. Spreading Down syndrome awareness is critical to the organization's mission to support and empower individuals with Down syndrome and their families.

For more information regarding Down syndrome or this article, contact DSAM at 901-547-7588 or go online to [www.dsamemphis.org](http://www.dsamemphis.org).

## **About DSAM**

The Down Syndrome Association of Memphis & the Mid-South is a 501(c)3 whose mission is to support and empower people with Down syndrome and their families. DSAM envisions a Mid-South that accepts, promotes and embraces individuals with developmental disabilities in all aspects of life.

For additional information about DSAM, visit [www.dsamemphis.org](http://www.dsamemphis.org).

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