

May 8, 2025



MEDICAL UPDATE LETTER FOR DONOR #12384 (SOREN) - 2025-05-08

Two children conceived from Donor #12384 (Soren) have been diagnosed with congenital heart findings. Additionally, one child conceived from Donor #12384 (Soren) has been diagnosed with hearing loss.

To Whom it May Concern,

We are writing to provide a medical update regarding Donor #12384 (Soren).

Congenital Heart Findings

Seattle Sperm Bank was notified that a fetus conceived from Donor #12384 (Soren) was found to have a congenital heart defect, called aortic stenosis, on prenatal ultrasound. In aortic stenosis, the main valve (aorta) that controls blood flow from the heart to the rest of the body becomes too narrow, making it harder to pump blood. The prognosis for aortic stenosis is variable and depends on the severity of the narrowing. Many people with mild or moderate aortic stenosis can live for years without problems, but severe cases—especially if untreated—can lead to serious complications.

Extensive genetic testing was performed, but no specific cause for the heart defect was identified.

Another child conceived (from a different egg source) using Donor #12384 (Soren) was diagnosed with a heart finding called bicuspid aortic valve (BAV). In BAV, the valve that controls blood flow from the heart has two flaps instead of the usual three. This can make the valve wear out or become narrow over time. Some people never have problems, while others may need regular check-ups or treatment later in life, such as surgery to repair or replace the valve. This child has not undergone genetic testing.

We contacted the donor to review this information and to obtain updated personal and family history. The donor reports no personal or family history of heart defects.

Congenital heart defects affect 1 out of 100 children in the United States. Bicuspid aortic valve is especially common; some estimates indicate a prevalence of up to 2%, with many affected individuals being asymptomatic throughout their lifetime and unaware of the condition.

Congenital heart findings can be isolated or may be associated with other features or genetic syndromes. Most isolated heart findings have a multifactorial cause, meaning that multiple genetic and non-genetic factors play a role.

The chance of heart findings in other children conceived from the donor are increased above the rate in the general population. Specific risk numbers are difficult to provide and also depend on the egg source's genetic contribution.

Hearing Loss

A child conceived from Donor #12384 (Soren) has sensorineural hearing loss reportedly due to variants in the *STRC* gene. Sensorineural hearing loss happens when there is a problem with the inner ear or the nerve that sends sound signals to the brain. The *STRC* gene is associated with nonsyndromic hearing loss that is typically mild to moderate and non-progressive. The hearing loss may be present before a child learns to speak (prelingual) or begin after a child learns to speak (postlingual). Of note, we were not able to obtain a copy of the

May 8, 2025

child's *STRC* genetic testing results for review and the donor has not undergone genetic testing for *STRC*.

Hearing loss due to *STRC* follows an autosomal recessive inheritance pattern. If both the egg source and the sperm source are carriers of an autosomal recessive condition, there is a 25% chance that a child/embryo will inherit both variants and be affected with the condition. The carrier frequency for variants in the *STRC* is 1-2%. Based on the report of an affected child, **the donor is most likely a carrier of *STRC* -related hearing loss.** However, because the donor has not been tested for *STRC*, we cannot confirm his carrier status at this time.

Screening of the egg source for *STRC* variants would provide more specific information about the chance to have an affected child/embryo.

What can I do next?

We encourage you to share this letter with your child's pediatrician and/or providers involved in your fertility treatment and prenatal care.

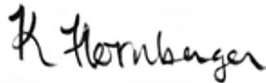
If Seattle Sperm Bank receives additional medical information that would impact the risk for birth defects in children of this donor, we will notify you by sending a follow-up letter. Please notify Seattle Sperm Bank of births and pregnancies beyond the first trimester using SSB's birth reporting webpage and notify the genetics team if your child has received any medical diagnoses.

Do not hesitate to reach out if questions arise or if clarification would be helpful. You are welcome to schedule a phone consultation with one of Seattle Sperm Bank's certified genetic counselors if you would like to discuss this information over the phone.

In partnership,



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