MEDICAL UPDATE LETTER FOR DONOR #10603 (DWAYNE ) - 2025-09-10

A child conceived with donor #10603 (Dwayne) was diagnosed with multiple birth defects.

To Whom it May Concern,

We are writing to provide a medical update regarding Donor #10603 (Dwayne ).

Updated Medical Information:

Seattle Sperm Bank was recently notified that a child conceived using donations from donor #10603 (Dwayne) was diagnosed prenatally with a complex heart defect (hypoplastic right ventricle, hypoplastic pulmonic valve, and hypoplastic tricuspid valve), brain malformations (absent corpus callosum and absent cavum septum pellucidum), absent gallbladder, and hydrops. The child passed away after birth.

Extensive genetic testing was completed and was inconclusive. No clear explanation for the child's symptoms was identified, but a variant of uncertain significance called c.2510C>A (p.Pro837Gln) was found in the *MED13* gene. The mother of the child tested negative for this variant. Donor 10603 (Dwayne) has not been evaluated for this variant.

Heart Defects:

The combination of a hypoplastic right ventricle, hypoplastic pulmonic valve, and a hypoplastic tricuspid valve is commonly referred to as hypoplastic right heart syndrome (HRHS). HRHS is a rare heart defect that occurs when the right side of the heart doesn't form typically. HRHS can vary in severity, but children born with hypoplastic right heart syndrome often require multiple surgeries.

Brain malformations:

The corpus callosum is a band of tissue connecting the left and right sides of the brain. Its function is to relay information between the two sides of the brain. Agenesis of the corpus callosum (ACC) is the term used when this band of tissue is missing. The cavum septum pellucidum (CSP) is a small, fluid-filled space situated above the corpus callosum. It is typically present during fetal development and persists during the newborn period before fusing and disappearing later in infancy. Children with absent CSP prenatally and ACC often experience neurodevelopmental differences that can range from mild to severe.

Absent Gallbladder:

The gallbladder is a small organ located beneath the liver that is responsible for storing and releasing bile into the digestive tract to help break down food. Absent gallbladder, also known as gallbladder agenesis, is a rare condition where the gallbladder never develops and is therefore missing at birth. It is most often isolated and sporadic, but there have been rare reports of it running in families or being present alongside other birth defects.

Hydrops:

Hydrops is the term used to describe severe edema (swelling) in an unborn or newborn baby. Hydrops can be categorized as either immune or non-immune depending on the cause. Immune hydrops occurs when there is a blood-type incompatibility between a pregnant person and the fetus (Rh incompatibility). Non-immune hydrops is the term used when the hydrops occurs due to some other condition affecting the baby, such as heart conditions, genetic disease, urinary tract issues, or maternal diseases/infections. Treatment and prognosis depend on the underlying cause of the hydrops.

Interpretation:

Birth defects are common, affecting 3-5% of babies in the United States. Most birth defects occur sporadically, without a family history, and are not related to an underlying genetic syndrome. However, the combination of

multiple birth defects in a child may suggest a shared underlying cause, such as a genetic syndrome or environmental exposure. The genetic testing completed for the child mentioned above identified a variant of uncertain significance in the MED13 gene which may potentially be the explanation for their symptoms. This means that the child has a change (or variant) in this gene that is not commonly seen in the general population. At this time, it is not clear whether this change is the cause of the child's birth defects or whether it is a completely harmless change, unrelated to the birth defects. Seattle Sperm Bank contacted the laboratory to ask whether testing the donor for this variant could provide useful information. The lab advised that donor testing would likely not clarify the significance of the result. For this reason, donor testing has not been pursued. Seattle Sperm Bank contacted the donor to review this information and to obtain an updated personal and family history. The donor reported no personal or family history of related health conditions. In addition, no other children conceived with this donor have been reported to have similar medical concerns.

Based on the information available at this time, children conceived using sperm from donor #10603 (Dwayne) may have an increased risk for the birth defects reviewed in this letter. Because the cause of the birth defects in the affected child is not definitively known, an exact risk estimate cannot be provided.

Please share this letter with your doctors and/or child's pediatrician. If Seattle Sperm Bank receives additional new medical information that would impact the risk for health conditions in children of this donor, we will notify you by sending a follow-up letter. Please notify Seattle Sperm Bank of births and or pregnancies beyond the first trimester using SSB's birth reporting webpage and notify the genetics team if your child has been diagnosed with any birth defects or neurological differences.
Please reach out if any questions arise or if clarification would be helpful.

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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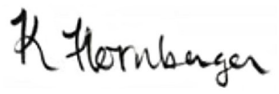

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