

Hydrops Fetalis

ucsfhealth.org/hydrops



Our multidisciplinary team is at the forefront of fetal diagnosis and therapy, utilizing cutting-edge genomic sequencing and in utero interventions. We focus on addressing genetic diseases that contribute to various causes of non-immune hydrops fetalis (NIHF) and single fetal effusions.



NIHF is a serious condition that affects up to **1 in 1,700** pregnancies.



We can identify a genetic disease underlying NIHF and single fetal effusions using exome or genome sequencing in **1 out of 3 pregnancies** that had normal results of standard testing.



We have sequenced **close to 300** fetuses with hydrops fetalis.

EXCELLENCE IN HYDROPS CARE AT UCSF

UCSF is the premier center for the diagnosis and management of pregnancies with hydrops fetalis. We have decades of experience in prenatal and neonatal care for NIHF and offer cutting-edge genomic testing, fetal imaging, comprehensive prenatal and neonatal care, and access to novel in utero treatments. Our approach to care is multidisciplinary, with internationally recognized experts in maternal-fetal medicine, genetics, radiology, pediatric surgery, neonatal medicine, bioinformatics, bioethics, pediatric cardiology, social work, palliative care and many other subspecialties working together to provide the most comprehensive and individualized care for each patient. Standard testing identifies a genetic explanation for NIHF in up to 25 percent of cases; our detailed evaluations find the cause in an additional one-third of cases that remain unsolved by standard tests.

WHAT IS HYDROPS FETALIS?

Hydrops fetalis is a condition in pregnancy marked by abnormal collections of fluid in the fetus. It carries significant risks of stillbirth during the pregnancy, as well as early delivery, serious illness, and death for the newborn. There is also significant risk of mirror syndrome, or preeclampsia, for the pregnant individual when hydrops is diagnosed.

Hydrops can develop at any point in pregnancy and can result from immune causes such as blood type incompatibilities or non-immune causes such as genetic abnormalities, birth defects or viral infections. While most cases of hydrops today are non-immune hydrops fetalis, our multidisciplinary team provides expert care for all types of the condition.

Identifying the cause of the hydrops is a critical step toward optimizing prenatal clinical care, identifying opportunities for in utero interventions, and better preparing for the complex needs of the newborn.

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INFORMATION / REFERRALS

- **San Francisco:** Phone: (800) 793-3887 (800-RX-FETUS) | Fax: (415) 502-0660
- **Oakland:** Phone: (510) 428-3156 | Fax: (415) 502-0660
- **Email:** hydrops@ucsf.edu



WHY REFER TO UCSF?

- **Expert care:** Our multidisciplinary team works closely and collaboratively to improve the diagnosis, treatment and outcomes for hundreds of pregnancies affected by hydrops.
- **Personalized genomics:** The UCSF Genomic Medicine Laboratory has extensive experience with genes involved in the development of hydrops and works closely with our clinical team and an expert panel to report the most accurate results of genome sequencing for each pregnancy. We further provide personalized genetic counseling to discuss the testing and how the results may affect current and future pregnancies.
- **Detailed prenatal imaging:** Our internationally recognized experts in maternal-fetal medicine, radiology and pediatric cardiology use advanced imaging tools to identify clues that may reveal the reason for hydrops.
- **State-of-the-art fetal procedures:** The Fetal Treatment Center at UCSF offers a full range of clinically indicated fetal procedures for hydrops, including fetal shunts, laser therapy and in utero transfusions, performed by experienced clinicians.
- **Novel fetal therapies:** The Fetal Treatment Center is home to clinical trials for novel fetal therapies designed to improve the in utero and post-delivery outcomes for pregnancies affected with hydrops fetalis.
Clinical trials include:
 - Genome sequencing for non-immune hydrops fetalis (NCT05528796)
 - Enzyme replacement therapy (Clinical Trial: NCT04532047) for a group of genetic diseases referred to as inborn errors of metabolism
- **Comprehensive perinatal care:** Our team prepares individualized, comprehensive perinatal care plans for each patient. These plans may include imaging surveillance during pregnancy, fetal interventions, special considerations for delivery, subspecialists needed at delivery, neonatal treatments and more.
- **Mental health and emotional support:** Patients have access to social work and palliative care providers who are specially trained to care for families with difficult pregnancies and perinatal loss.

OUR TEAM

- Teresa Sparks, MD, MAS**
Perinatologist and clinical geneticist
Co-Director, Hydrops Center of Excellence
- Mary Norton, MD**
Perinatologist and clinical geneticist
Co-Medical Director, Fetal Treatment Center
- Rebecca Freeman, MS, LCGC**
Genetic counselor
- Juan Gonzalez-Velez, MD, PhD**
Perinatologist
Chief, Division of Maternal-Fetal Medicine
- Kyle Heraty, MS, LCGC**
Genetic counselor
- Billie Lianoglou, MS, LCGC**
Genetic counselor
- Tippi MacKenzie, MD**
Fetal and pediatric surgeon
- Sarah Russell, MS, LCGC**
Genetic counselor
- Janice Scudmore, NP**
Nurse practitioner
Manager, Fetal Treatment Center
- Katie Tick, MPH**
Clinical research coordinator
- Jessica Van Ziffle, PhD**
Director, Genomic Medicine Laboratory

LOCATIONS

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UCSF Benioff Children's Hospital Oakland

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Oakland, CA 94609

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