



INFORMATION PACKET

We believe in the strength of families and the power of community. This packet is designed to provide you with valuable information, resources, and unwavering support from our VOGM Support Network.

Together, we can navigate this journey and find strength in each other.



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YOU ARE NOT ALONE

We understand that receiving this diagnosis can be overwhelming and frightening, but please know that you are not alone. Our global community of over 1600 families is here to support you. Our nonprofit is dedicated to guiding you every step of the way, helping you access the top specialists for your child's life-saving treatment.

OUR MISSION

Is to spread awareness, provide up-to-date information, and connect families with top VOGM Specialists around the world. We support VOGM families financially and emotionally no matter where they are in their journey. With the support and information provided, we hope to make a difficult time a little easier.

WHERE TO FIND US

Search or scan to join our community



**Vein of Galen Malformation
Support Network, Inc**



@vogmsupportnetwork

FACEBOOK



INSTAGRAM



This 501c3 non-profit was started by a few parents who connected through the VOGM Facebook groups. We saw a need for accurate information and emotional and financial support to help VOGM families get their child to a top specialist, especially those new to the diagnosis. We created this non-profit as a way to alleviate some of the pain and helplessness we felt during our journeys.



ABOUT VOGM

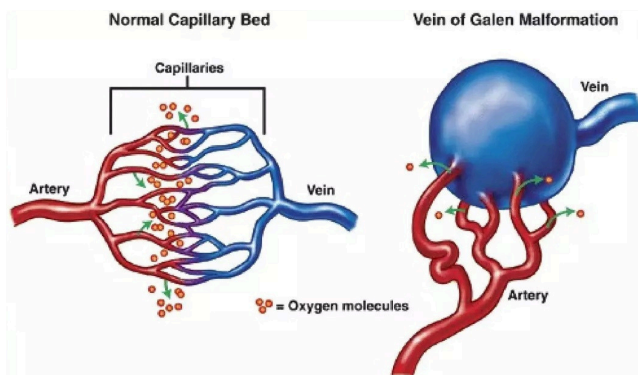
A Vein of Galen Malformation is a rare condition that occurs between weeks 8-11 weeks of pregnancy, causing abnormal connections between brain blood vessels. Specifically, it involves the arteries that carry blood to the brain and the deep veins that drain it back to the heart. This drainage happens in the Vein of Galen, located at the brain's base. To maintain proper blood supply for brain development, the heart must work harder to meet this increased demand.

CAUSES

Research is ongoing to better understand Vein of Galen Malformation. While genetic and environmental factors are believed to play a role, it is important to know that it is not caused by anything you did or did not do during pregnancy. There are currently research studies that families can participate in, contact us for more information

HOW COMMON IS IT AND WHO DOES IT AFFECT?

The Vein of Galen Malformation affects approximately 1 in 15,000 children annually. Each year, about 200 children in the US are diagnosed with this condition. It affects boys 2-3 times more often than girls and occurs across all races. VOGM accounts for 30% of pediatric arteriovenous malformations (AVMs).



WHAT ARE THE SIGNS AND SYMPTOMS

More than half of babies with Vein of Galen Malformation (VOGM) are diagnosed in utero, typically at or after 32 weeks, though detection can occur as early as 19 weeks. Diagnosis often reveals enlarged hearts and the vogm in the brain, particularly visible with color doppler imaging. Symptoms vary widely and can be subtle, making early detection challenging. Approximately two-thirds of VOGM babies develop high-output heart failure at birth, half of cases requiring immediate intervention or medication. However, some may show no symptoms initially and are diagnosed later through routine cranial or heart ultrasounds.

In some cases, symptoms might be first noticed by a parent or pediatrician during a routine check-up. The most common secondary condition is heart failure at birth. The increased workload on the heart can lead to enlargement and, if untreated, may result in heart failure.

If heart failure doesn't occur at birth, children may experience a significant increase in head circumference, not in line with previous growth rates (eg. a spike in percentile on the growth chart) usually between 2-12 months . Other signs parents might observe include a large head, full/hard Fontanelle (soft spot), prominent facial veins down the face, and dark circles under the eyes. "Sundowning" of the eyes where the pupil of the child's eyes may start to drop below the lower eyelid. - all of these symptoms are symptoms of hydrocephalus, which is excess fluid that builds in the brain as a result of the growing VOGM disrupting the brains ability to regulate the fluid levels and Embolization for the VOGM is needed to resolve (hydrocephalus intervention such as ETV or Shunting can usually be avoided if VOGM is addressed).

NEWBORN PRESENTATION OF VOGM

Newborns with Vein of Galen Malformation often have multiple arteries attached to it, causing up to 25 percent of their blood volume to pass through these arteries and leading to high pressure in the heart.

Clinical signs of this condition can include rapid breathing (tachypnea), fast heart rate (tachycardia), failure to thrive, a blue tinge around the lips (cyanosis), and lethargy or tiredness. The bruit (wooshing heart beat sound like an ultrasound heartbeat) can be heard through the fontanel (soft spot at the top of the head) with a stethoscope or sometimes with just the ear on the head.

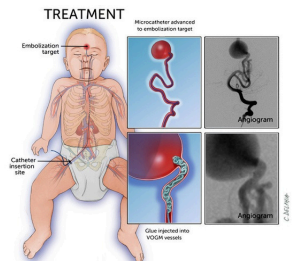
HOW IS VOGM DIAGNOSED?

Diagnosis of Vein of Galen Malformation (VOGM) varies for each baby. Research shows that 80-90% of VOGM cases are now being diagnosed in utero, 25% at birth, and 25% after the first month of life. When VOGM is suspected, three standard tests are typically used to diagnose the condition:

- **MRI (Magnetic Resonance Imaging):** This scan uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.
- **Cranial Ultrasound (CUSS):** This ultrasound scan uses sound waves to create an image of the brain through the fontanelle (the soft spot on the baby's head).
- **Echocardiogram (ECHO):** This ultrasound scan of the heart measures the extent of any strain or failure.

HOW IS IT TREATED?

The treatment your child needs depends on their condition at diagnosis and other issues. Babies may stay in a Neonatal Intensive Care Unit (NICU) or Pediatric Intensive Care Unit (PICU). A common complication is heart failure due to the extra pressure on the heart. If this occurs, treatment aims to stabilize heart function with ventilator support and drug infusions like Lasix.



The surgery for VOGM, called embolization, uses glue or coils to block abnormal blood vessels, reducing blood flow and easing the heart's workload. A neurointerventional radiologist and their specialized team perform this procedure by guiding a catheter using X-ray imaging (angiogram) through the UA line (umbilical Arterial line) if embo is done at birth, or through the femoral artery in the groin and fed to the brain. Then micro catheters are insured and the glue or coils are injected into the vessels that feed into the VOGM.

WHAT ARE THE RISKS?

Every procedure carries risks, which increase if your child is very sick or premature. The experienced neuroradiologists performing embolization strive to minimize complications.

- **Anesthesia:** General anesthesia is used, carrying a very small risk.
- **Infection:** The risk is minimal since no incisions are made.
- **Glue/Coils:** There's a small chance the glue or coils could block another vessel, potentially causing permanent effects. There is also a slight risk of bleeding in the brain post-treatment.

WHAT ABOUT RECOVERY?

Your child will be closely monitored for two to three days, with support from breathing machines and infusions gradually reduced. After leaving intensive care, your child will move to a regular pediatric unit for continued monitoring. If intervention is needed at birth NICU stays may be weeks or months until the child is stable, but with routine scheduled interventions usually a 2 night stay is needed if no complications arise your child can be sent home.



THE IMPORTANCE OF HIGH-VOLUME CENTERS

VOGM is a rare condition, with over 50% of cases requiring treatment at birth. It is important to consider all options at diagnosis and, if possible, to seek care at a high-volume specialist center, where a multidisciplinary team can plan and execute the treatment. At these centers, neurointerventional radiologists collaborate closely with neurosurgeons, cardiologists, and neurologists to form a comprehensive treatment plan, and nurses are trained to identify VOGM-specific complications. These centers have the expertise, experience, and equipment to provide the best outcomes, treating similar cases multiple times a week.

A high-volume center is a specialized medical facility that handles a large number of cases of a particular condition, such as Vein of Galen Malformation (VOGM), each year. These centers are characterized by their extensive experience and expertise in treating complex conditions, resulting in better patient outcomes. They are staffed with multidisciplinary teams, including neurointerventional radiologists, neurosurgeons, cardiologists, and neurologists, who work collaboratively to develop and implement comprehensive treatment plans. Nurses and other support staff at high-volume centers are specially trained to manage the unique complications associated with these conditions. Additionally, high-volume centers are equipped with advanced medical technology and infrastructure, enabling them to provide cutting-edge treatments and continuous, specialized care.

If diagnosed in-utero, delivering at these centers is highly recommended and our support network can help coordinate with their teams and we provide resources for free flights housing and also provide travel assistance to make this process as smooth as possible.



GETTING A SECOND OPINION

Second medical opinions for Vein of Galen Malformation (VOGM) are crucial because they ensure the accuracy of the diagnosis and provide additional treatment options from different specialists. Consulting multiple experts enhances the chances of benefiting from the latest research and advanced techniques while offering a more comprehensive assessment of risks and outcomes. This multidisciplinary perspective, involving neurointerventional radiologists, neurosurgeons, and cardiologists, provides reassurance and confidence for parents in the chosen treatment plan.

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Home to **Dr. Alejandro Berenstein**, a pioneer in embolization treatment.

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For an **in-utero diagnosis**, include Kassie and Laurie in emails.

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Mount Sinai Hospital has a high-volume VOGM specialist center led by Dr. Johanna Fifi and Dr. Tomoyoshi Shigematsu.

Boston Children's Hospital is another high-volume center. The VOGM specialist center is led by Dr. Darren Orbach, who is conducting an in-utero trial for eligible patients.



LET US HELP GUIDE YOU

Visit our website for an extensive list of resources, including free medical flights, free and discounted housing at our high-volume centers, and travel assistance to offset other travel costs provided by the VOGM Support Network

CONTACT US



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JOIN OUR FAMILIES



Vein of Galen
Support Group



In addition to our own research, much of the information in this booklet is credited to Great Ormond Street Hospital (GOSH) in London.