

About VOGM Support Network

VOGM Support Network is a 501c3 nonprofit organization dedicated to supporting families facing a VOGM diagnosis. As parents who have experienced the emotional toll firsthand, we provide vital resources, emotional guidance, and financial assistance to travel for life-saving treatment. Our mission extends beyond direct support—we aim to raise awareness among medical providers and the community. We can make a lasting impact, connecting families with specialists worldwide and offering hope in the face of adversity. Together, we can transform pain into hope and help families navigate their VOGM journey with strength. Join us in creating a brighter future for VOGM families.

Connecting Patients to VOGM Specialists

Logistical and Emotional Support

**Travel Support
Access to Care**

We want to give a HUGE thank you to Dr. Berenstein for his dedication to VOGM patients for over 35 years. He pioneered the glue embolization process with a stick of crazy glue! Additionally, congratulations Dr. Fifi for taking over the Mount Sinai's program! Dr. Berenstein and Dr. Fifi have treated and cured the founders' children along with hundreds of VOGM children throughout their careers. Thank you, Dr. Fifi, for inviting us to the SNIS 20th Annual Meeting!



Dr. Alejandro Berenstein



Dr. Johanna Fifi

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Our Website
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Follow Us
@vogmsupportnetwork



Vein of Galen Malformation (VOGM/VGAM)





High Volume Centers

With VOGM being so rare, most IRs only see a few cases throughout their career. Because of the high mortality rate, it is important to consult with a high volume specialist and refer patients to the VOGM centers who perform embolizations weekly. Specialists may even recommend delivering at their facilities because approximately 40% of children need their embolization shortly after birth. Our nonprofit provides connections, logistics, and financial support to families who wish to travel for treatment. Our knowledge comes from the shared experiences of ourselves and over 1,000 families in our community from around the world.

HOW YOU CAN HELP YOUR PATIENT:

VOGM affects 1 in 58,000 children, of which 50% are diagnosed in utero and 25% within the first week of life. With so many diagnosed in utero or shortly after birth, there is time to transfer the mother or baby to a high volume VOGM center for the best chance of a favorable outcome.

We have a growing list of specialists in multiple countries and can help families get to these specialists before or after birth. Two specialists, Dr. Orbach and Dr. Rodesch, have performed in utero embolizations to help avoid intervention at birth, which is significantly riskier than intervention even a few months later. Please refer patients to our nonprofit so that we can help them connect with a specialist and provide support along their journey.

USA:

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Australia: Dr. Bhatia and Dr. Lord
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See full list of international specialists on our website:
Vogm.org/resources

In Utero Intervention



Dr. Darren Orbach

More than half of VOGM babies are born in heart failure, and it is fatal for approximately 40 percent of these babies. In utero intervention is the way of the future because it can prevent some of these fatalities. Dr. Darren Orbach, at Boston Children's, recently performed the first successful in utero intervention in the US. Please connect any family who receives an in utero diagnosis to Dr. Orbach's team to see if they are eligible for this ground breaking trial.

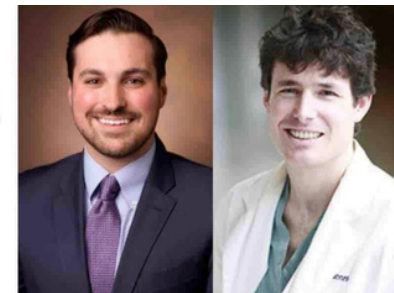
VOGM Research

"The Vein of Galen malformation Genetics Research Consortium (VOGM-GRC) is a multi-institutional, international consortium of pediatric neurosurgeons, neuro IRs, neurologists, neurointensivists, geneticists, and molecular biologists. Our aim is to use orthogonal approaches to understand the genetic basis of VOGM."



Vein of Galen Malformation
Genetics Research Consortium

vogm-genetics.com



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