



# PEDIATRIC VASCULAR SURGERY

Malformation Becomes Inspiration

*Every day, Aaliyah Juarbe would endure chronic, excruciating leg pain and taunts from children who didn't understand her illness.*



*Shown: For years, Aaliyah Juarbe, 18, of North Plainfield, suffered from leg pain that was misdiagnosed and unsuccessfully treated. Relief finally came in the form of the Vascular Anomalies and Malformations Program (VAMP) at The Bristol-Myers Squibb Children's Hospital at Robert Wood Johnson University Hospital. Because VAMP follows an evidence-based algorithm that incorporates patient history, clinical findings and imaging to determine a diagnosis, Ms. Juarbe quickly received an accurate one as well as successful treatment.*

So the aspiring writer would channel the lyrics to one of her favorite songs by The Script, "Hall of Fame:"

"You can go the distance

You can run the mile

You can walk straight through  
hell with a smile."

Ms. Juarbe has experienced swelling, inflammation and pain in her lower right leg and foot since birth. The pain prevented her from participating in many activities that most children her age enjoy.

At age 4, her doctors wrongly diagnosed her with Klippel-Trénaunay Syndrome, a rare congenital medical condition in which blood vessels and/or lymph vessels fail to form properly, as well as varicose veins. They felt there was little they could do surgically to alleviate her discomfort, so they prescribed rest, elevating the leg, Tylenol and compression stockings.

"I couldn't participate in contact sports and I always felt the pain no matter what I tried to do," the 18-year-old North Plainfield resident said. "I didn't want to be near people or around anyone."

Ms. Juarbe's doctors tried to remove some of the varicose veins, but the surgery provided little, if any relief. Almost five years following the surgery, doctors ordered a vascular imaging test known as an MR Venograph, but it incorrectly revealed no significant issues.

She didn't find relief until she was referred to her current doctor Naiem Nassiri, MD, RPVI,



*Shown left: Naiem Nassiri, MD, RPVI, Instructor of Surgery at Rutgers Robert Wood Johnson Medical School is founder and Medical Director of the Vascular Anomalies and Malformations Program (VAMP) a joint initiative with Rutgers Robert Wood Johnson Medical School and The Bristol-Myers Squibb Children's Hospital at Robert Wood Johnson University Hospital.*

Instructor of Surgery at Rutgers Robert Wood Johnson Medical School and the founder and Medical Director of the Vascular Anomalies and Malformations Program (VAMP) at The Bristol-Myers Squibb Children's Hospital at Robert Wood Johnson University Hospital New Brunswick.

VAMP is a collaboration between RWJ New Brunswick and Rutgers Robert Wood Johnson Medical School and consists of a highly specialized, multi-disciplinary team who have formed the premier regional referral center in New Jersey for management of all vascular anomalies, including hemangiomas and malformations.

"The MR Venograph failed to clearly show the problem," Dr. Nassiri explained.

Dr. Nassiri ordered a contrast-enhanced magnetic resonance imaging series to get a

clear, high-resolution image of slow-flow blood within Ms. Juarbe's lower right leg veins. The test revealed diffusely scattered foci of what are known as slow-flow venous malformations. Essentially, clumps of abnormal veins developed over time in Ms. Juarbe's lower right leg.

"As someone grows older, blood pools in these abnormal vein structures causing pain and swelling," Dr. Nassiri said.

He recommended a series of procedures known as direct-stick embolization. Performed in stages, the procedure involves inserting a small catheter directly through the skin inside the abnormal blood vessel to record a picture of the malformation. A material is injected to inflame the malformed vein, form a clot and a scar to close it off. Blood flow is then re-directed through normal veins, relieving the patient's pain.

The procedure is performed during several 45-minute sessions. In most cases, patients can return home the same day.

"I was a little nervous at first, I don't like needles," Ms. Juarbe admitted. "But I knew Monica Hirsch, RN, the Clinical Nurse Coordinator for VAMP, for a long time and she highly recommended Dr. Nassiri."

The initial procedures reduced Ms. Juarbe's pain to the point where she could participate in marching band. With the support of good friends, Ms. Juarbe was able to enjoy marching band during her senior year.

"The vast majority of the patients we see with this condition have either been misdiagnosed or not diagnosed at all," Dr. Nassiri explained. "Once the correct diagnosis is made and they see that something can be done to relieve their pain, their lives are changed!"

Ms. Juarbe is doing much better now and is attending Raritan Valley Community College, where she is pursuing her interest in writing. She regularly writes poetry and has completed a book that she hopes to have published. As she places the pain and taunts from her peers in the past, she has some advice for other kids who face challenges like theirs.

"Find something that inspires you, that keeps you moving forward," Ms. Juarbe said.

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