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# How cavernous hemangioma went undiagnosed and lessons learned

CLINICAL CASE REPORT

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**SUMMARY**
A barely noticeable lump on the bottom medial part of my right eyelid went undiagnosed after two exploratory surgeries. Additional exploratory surgeries were recommended in subsequent consults with different ophthalmologists without anyone suggesting diagnostic tools (eg, MRI). An MRI ultimately confirmed a common condition called an orbital cavernous hemangioma. Patients can contribute to their patient experience by doing research, being informed, asking questions, and getting a second, even third, opinion, if necessary.

**Key Words**
Patient care; MRI; diagnostic tools; ophthalmologist; orbital cavernous hemangioma

## INTRODUCTION

In July 2013, I had a routine eye exam and I asked the ophthalmologist about a barely noticeable lump on the bottom medial part of my right eyelid. I was referred to an oculoplastic and reconstructive surgeon who informed me that I had a "Benign neoplasm of the orbit". The surgeon performed two separate exploratory surgeries on my eye. The surgeon also stated that without removing the orbital lesion and sending it to a pathologist, it was not possible to know for certain what the lump was. I declined having a third surgical procedure. Subsequently, between 2014 and 2016 the orbital lesion grew larger. I consulted with three other ophthalmologists and each wanted to do exploratory surgery.

## SUMMARY

After the first two exploratory surgeries yielded an inconclusive diagnosis, I was reluctant to undergo further surgeries. The ophthalmologists I was referred to proposed performing exploratory surgical procedures, since they felt doing so was the only way to know definitively what the condition was. I undertook my own research to learn more about what my condition could be, as well as how it could be diagnosed and treated. Even though I inquired about diagnostic testing (CT scan, MRI, radiological scan), I was told that they could not be used on the orbit. Fortunately, in February 2017, I consulted with another ophthalmologist who suspected I had either a cavernous hemangioma or a schwannoma.[1] She ordered an MRI, and I was diagnosed as having a cavernous hemangioma.[2] She monitored the growth without surgery until the lesion started to put a lot of pressure on my eyeball and caused minor proptosis. In October 2018, I had surgery and the lesion was removed successfully. The lesion was more than 4cm long when it was removed.

## LESSONS LEARNED

The experience taught me the importance of being my own advocate. As patients, we need to do our own research so that we can understand our diagnoses, ask informed questions, and not merely accept the "doctor as expert."

In my experience, a surgeon's initial instinct is to perform a surgical procedure (eg, a biopsy) to provide a diagnosis. In my case, I believe they overlooked diagnostic technologies such as the CT scan and MRI, which would have led to an accurate assessment earlier on. According to the American Association of Neurological Surgeons, "Magnetic resonance imaging (MRI), with and without contrast and with gradient echo sequences, remains the best means of diagnosing cavernous malformations."[3]

During my courses of treatment, I learned no two physicians follow the same protocol, which in my case, contributed to one of the most common orbital lesions going undiagnosed.

I have also learned that before undergoing a surgical procedure, it is wise to get a second or even a third consult. Doing so in my case led to the correct diagnosis. Getting a second opinion is useful, even if it confirms the initial diagnosis. If the second opinion is different, it can help a patient delve deeper into their condition and get answers.

## EXPERT INSIGHT

A quick review of the literature revealed that orbital cavernous hemangiomas (sometimes known as cavernous venous malformation of the orbit) are one of the most common benign vascular lesion in adults in the developed world. There are clear diagnostic and treatment guidelines available with recommendations ranging from physical examination and observation through to orbital imaging and surgery, depending on the size and position of the malformation.

From the patient insight, it would appear that six medical practitioners within the same discipline managed the same condition differently. However, although there were some anomalies and treatment was not always optimal, it could be said that part or all of the correct diagnostic guidelines were followed by each practitioner at each presentation. [1]

The major lesson that we should learn from of this patient's journey is not whether treatment guidelines were implemented appropriately nor the number of opinions that should be sought to ensure a correct diagnosis (although both are important). This story reminds us that patients have a right to be informed about their condition, the outcomes of various treatment or management choices, and be involved in the decision-making process.[2] The tragedy is that it took four years for this patient to be given the opportunity to make an informed choice about their own medical care.

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