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The hemangioma came into our lives the second week of our son's life. It all began when a red line suddenly appeared under his left nostril and a few red spots on his left hand. The phenomenon grew rapidly. Within a month, his hand became like a boxing glove from swelling (his fingers, because of the swelling, were bleeding and were running pus), while the left side under his nostril down to his mouth had a huge deformable tumor that blocked his nostrils completely and was also frequently bleeding. Not to mention that his dimple and left lip were gone. The shock was immense, the tears were running dry day and night, the sense of complete despair was permanent. Today, after almost 5 years and numerous visits to doctors all over Greece and abroad (not in person but through friends doctors working abroad, who had the record of our case and could reach the experts instead of us for an initial exploratory meeting) I would like to communicate to the parents who deal with the same problem as we did the following messages:

1) PARENTS, KEEP CALM:

Cry all you want, alone or in company of friends. But in front of your child being a rock is the only way. Children, intuitive as they are, understand everything. Many of them suffer because of the hemangioma effects, no need to sense your despair as well. You must never forget that you are their primary source of strength. You must also collect your pieces each time you visit a doctor. If your mind is not clear, how will you understand what the doctors are saying to you so that you will:

- a) do your personal research and
- b) make the right decision?



2) RIGHT CHOICE OF DOCTOR:

We started off with the doctors since he was 39 days old. We never counted the cost, as long as they were, theoretically speaking, the experts on the subject. Don't get impressed by the titles and the studies. We visited 20 doctors and they suggested 20 different ways of dealing with our problem. What matters is the experience and the morals of the doctor. We met doctors who clearly wanted to turn our child into a guinea pig, others who saw us as another case among many and suggested treatments mismatching the age of the patient and the possible severe permanent effects, others who wanted to play smart and refused to answer our questions saying that they are the doctors and not us. Don't get fooled. You have every right and mostly every obligation to evaluate what they are saying to you and to ask for clarifications. You cannot trust the treatment of your child to arrogant people. Always ask for photographic material as a sample of their work. You have to ask for the possible effects that might arise as a result of the suggested treatment. If you don't feel confident, ask for alternatives or time to consider it and start immediately a research on what is suggested or look for another doctor.

3) PERSONAL EXPERIENCE:

Whatever the suggested treatment, no matter how good the doctor appears to be, you are obliged to double-check what they tell you. The internet might come very useful, mostly if you visit foreign websites because there, apart the fact that there are special institutions and research centers specializing in the hemangioma, doctors that handle them post articles and mostly specimens of their work (with the "Before" and the "After") on their personal websites. You will also find many research papers and research reports of doctors on particular methods of treating the hemangioma but also information on various medication that can be suggested (you must be extremely cautious regarding that matter because some medication might cause neurotoxicity or spastic hemiplegia!!!)

4) PATIENCE AND IMPASSIVITY:

Treating an hemangioma demands more time than we us parents would like. In some cases, it requires one or two surgeries, in others a long lasting treatment with medication, in others a combination of the two. Patience. Hard as it may seem, stop paying attention to other people's gaze and words. Make up your minds. We are Greeks, with no social education and sensitivity.



Stay calm, strong and prepared to protect and keep away from the child any weird look or rude behavior. What matters is that the child doesn't see the pity in your eyes. You are the one he gets his reassurance from, if he sees that you are ashamed he will be ashamed of himself too. And when he reaches an age where you can communicate, give him an explanation to his problem that he will be able to handle. Consult on that matter your doctor, your pediatrician or his teachers.

5) DO NOT FEEL GUILTY:

There is no point to it, because the cause of the hemangioma has not yet been found. So why blame yourselves? You get nothing out of this attitude and you might also poison your relationship as a couple.

CONCLUSION:

THERE IS A SOLUTION. MEDICINE IS EVOLVING, NEW TREATMENTS ARE DISCOVERED. GREECE HAS VERY COMPETENT DOCTORS WHO REALLY CARE AND CAN HELP. YOU NEED TO RESEARCH, TO HAVE STRENGTH AND A GOOD JUDGMENT WHEN IT'S TIME TO MAKE A DECISION.

Despoina Kaniou

I am the mother of a 17 month old girl who unfortunately had the misfortune to have a rather big hemangioma on her temple that ruined (if I may say so) all the beauty... For 17 months the whole family was in a terrible psychological state and while I was thinking that I wouldn't be able to send my child to the nursery like that I was going crazy!!!

We visited a pediatric dermatologist with my husband who told us to let the hemangioma run its course and then after many years it would go away... I had lost all hope and I was sad. One day we went to the Andreas Syggors hospital. Dr. Stefanaki who is a dermatologist there, suggested, after seeing our child, to visit Dr. Tombris, who is a specialist in the area and the best surgeon of hemangioma. When we went to his office, from the very first moment I felt that there was a solution to my problem and that I was in good hands!! There was no doubt in my mind that everything would turn out great, maybe it was the instinct of the mother who wants the best for her child! So we decided to have the surgery on October 7th 2013



The best and most important day of our life! There was tremendous anxiety until the surgery was over. On 11.30 a.m. our Annie came out of surgery and I was speechless by the result!!! She woke up immediately, ate after two hours and she was just fine when we got home (we went home the same day)... after two days we took off the gauze.. and there was our miracle!!!We couldn't believe our eyes!!! The hemangioma was gone and since then we go out without worrying that this different scar of the child might show...Our life has changed and we still cannot realize how happy we are!!! It might sound exaggerated but to me as a mother Dr. Tombris is a gift from God and a very important person in my life!!!
Dr. Tombris I pray that you are well, happy and to continue your priceless work of giving joy to children and parents!!! I love you so much!!!

Didachou Marilena

My name is George and I am 40 years old. I took the courage to write about my problem too, a facial hemangioma that appeared 13 years ago. I started off with embolism in Germany (Hamburg) and partly because of my ignorance, partly because of personal matters I didn't complete the embolisms and I returned to Greece. I continued my treatment in various hospitals in Thessaloniki. There I faced several problems, I met doctors NOT capable of dealing with my problem and instead of getting better my problem grew worse and I also dealt with racism from my environment. I got over it by myself, I think I was strong, until I met the maxillofacial surgeon Stavros Tombris and his team and I had a big surgery in Athens.I was in the operating room for 12 hours the first day in order to have the lesion removed. Four days after that I was operated for my reconstruction. This took another ten hours... and the surgery was a success! So I was given the opportunity of living a new life and having new dreams. That's why we should face life with courage.

"life is no game you should take it seriously
like the squirrel does without waiting for anything from outside or anywhere
you'll have nothing else but to live our most beautiful days are not here yet
and the most beautiful thing I would like to say to you I haven't' told you yet"
(Nazim Hickmet)

George Karapetsas



We have a little girl who is now 5 years old and who had an hemangioma on the right side of the occipital area, with Kasabach Merritt symptoms.

When we discovered the tumor she was 40 days old and until the age of 14 months everyone told us not to do anything and let it be because it was probably a simple hemangioma that would decline by itself. We visited many doctors of various specialties and titles (professors, managers etc.) in all pediatric (public and private) without being able to actually find a solution.

Only one doctor in Greece (who we discovered ourselves after research on the Internet) told us that the tumor does not behave as a true hemangioma and that we should perform a biopsy to see exactly what is that tumor and to define its treatment.

On January 2010 the child showed symptoms of disorder of coagulation factors and fall of the number of platelet (because of the tumor) in dangerous levels for the child's life (PLT=3.000). At the children's hospital they were unaware of the particular matter and they were not only unable to help us, but also to suggest a certain solution (ex. Go abroad). The solution came from a Greek doctor that I mention above and with whom we went to Berlin in a specialized centre for vascular malformations (St. Joseph Krankenhaus

<http://www.sjk.de/medizinische-zentren/zentrum-fuer-vasculaere-malformationen-bei-kindern-zvm>), where the tumor was removed successfully (at the age of 18 months).

The medical and nursing services offered were incredible.

The cost of the whole procedure was relatively low regarding the Greek pricing policy.

The child recovered from the surgery immediately.

We stayed at the hospital for 7 days 3 of which were after the surgery. The progress on the child's health was so rapid that we even took a 3-day vacation to Berlin after leaving the hospital.

Today, 3,5 years after the child is free of the disease. Be careful because there are doctors (public and private) with big titles who present themselves as experts and in reality they cannot help. The expertise in Greece on the field is limited.

The doctor who found a solution to our problem is Stavros Tombris and he is by far the most expert in matters of vascular malformations. He is working together with the American Professor Milton Waner who is one of the top in the world.

Anyone who might need any further information, we are willing to help.

GIANNIS SAVVAFIDIS-ATHENA THEODOROPOULOU



On February 2008 I had the first symptom (oral bleeding) from a disease that honestly I had never heard before. After quite a research I went to Dr. Tombris office who told me that I have an arteriovenous malformation! At first it all seemed terrible; the calmness of Dr. Tombris made me feel better though.

After analyzing the "response" plan to the problem I realized that what I had was certainly rare and complicated but it can be dealt with. It needed some effort from both of us though. We started off with an embolism (a procedure of isolating the damaged vanes) and we continued with the surgery of removing them and reconstructing the removed part. Today no one can see the slightest difference. A surgical scar (very difficult to see) is what reminds me of my adventure and my memories! I am not saying it was all easy and that I didn't have some difficult times, physically and emotionally. Thanks to my family, my friends and my doctor it was all manageable and curable.

That was what kept me going, without hesitation, in the right plan that we had made.

Demosthenes Rachianiotis

My name is George Siokis and I was born in Thessaloniki in 1977. Since my birth I had a bluish lesion on my upper lip. The diagnosis of the doctors that had examined me up until the age of 33 was of a hemangioma. More importantly, the fact that I could get rid of it very easily and painlessly. Luckily none of them had persuaded me and I didn't let them experiment with my problem. Three year ago I was in Athens by chance and having heard the best about Dr. Tombris, my doctor, I made an appointment for a consultation, as I have done many times during the previous years of my life.

So I have learned, in the age of 33, that the lesion that I had was not a hemangioma but a venous malformation. I also learned that it could be successfully treated, but both the treatment and the recovery would not be as easy as I was told. Above all, having it done, would have been my choice.

The result is that my doctor is my savior.

I remember him every day that I look at myself and I am grateful to him.

The recovery as difficult indeed, but I was courageous because I trusted the medical team that undertook my treatment.

George Siokis



Respected Sir,

Thanks for your valued opinion and advice. I remain obliged to you and if opportunity arises, I would like to do my best to repay it. With lots of patient you are having every day, you will forget me naturally some day, but I won't.

If you happen to be in India, I would be pleased to welcome you as my valued guest.

With kind regards.

Ankita

Dear Dr. Tombris

I would like to thank you very much for seeing my sister's little boy with the facial hemangioma and for the valuable advice that you gave to his parents.

They felt a great joy after their visit to your office, because they found an exceptional doctor but above all a fine human being.

T...E...

On behalf of the Vascular Birthmarks Foundation, I would like to thank you for giving your time and talent to the families attending the 2008 conference in New York City. Your dedication and support for the Vascular Birthmarks Foundation and the families we serve is invaluable. The families are astonished by your willingness to volunteer your time, talent and information. This was a chance of a lifetime for the families and they will never forget their experience.

I would like to personally thank you for being flexible as we converted the conference into a one day event and by helping it run so smoothly....

Best Regards,

Corinne Barinaga

VBF Administrative Director/Family Services