

International HHT Guidelines Education Series

Epistaxis / Nosebleed Management Webinar

June 12, 2021

Question	Answer(s) Provided by Dr. Piccirillo unless otherwise stated
Do you have any advice about using a nasal moisturizing spray containing hyaluronic acid such as Hyalogic or Hysan?	None, specifically about hyaluronic acid. In my experience, no one moisturizing spray is better than the other.
A week after my first Pfizer vaccine, I had an unstoppable nose bleed where I ended up in the hospital. Can the vaccine cause such an occurrence?	I have not heard that nasal bleeding is side effect of vaccine.
What are some prophylactic treatments I can do at home to prevent major nosebleeds at home?	Moisturizers as Dr. Gossage mentioned. No one type is better than the other
Do you think surgical buttons are of benefit and would you use them to aid in the crusting and bleeding of septal perforation?	Yes, they can be. Some patients like them, some don't. If crusting and bleeding enough of a concern, then yes, consideration of button is reasonable.
Although I have had nose bleeds since I was a child, they were far between, maybe one every two/three weeks and minor. Lately, in the past couple of years (now 62yrs) I find an increase in numbers, every couple of days, the intensity remains the same. Do HHT nose bleeds increase with age and/or seasons (does temp have an impact - winter vs summer, pollen season...)??	Not sure about the impact of age, but do believe that allergies make bleeding worse.
My doctor said Vaseline can end up in the lungs.	Yes, that is a concern, but I have never seen it happen in any of my patients.
What about the downside of breathing into our lungs the baseline or Aquafor. How big a risk is this? It is a petroleum product.	I don't think it is a big risk, but we do have to explain the possibility. I have never seen it to be a problem in my patients. Maybe more a "theoretical" concern than a practical concern.
How Does Doxycycline Work in reducing nosebleeds?	In addition, to its antibiotic effect, it also has antiangiogenic effects.

My cardiologist recommends low dose aspirin. Is it safe to take every day with nosebleeds? My nose bleeds range from mild to severe. the severe bleeds don't come very often.	Well, as a general rule, not a good idea for HHT patient with nosebleeds to use ASA. However, for each individual patient it is a very individual risk:benefit discussion. if the cardiologist thinks your risk of cardiac disease is enough then maybe worth the risk of nosebleeds.
Folic acid helps?	Don't think so. :(
Are there any negative side effects of Tranexamic Acid for someone with Pulmonary Arterial Hypertension?	live answered
For how long would one try the tranexamic acid?	live answered
Does a septal perforation have a propensity to bleed? Several ENTs have said my nasal perforation disturbs the normal air flow and so dries the tissues, making them more susceptible to bleeding. Thank you.	Yes, septal perforation leads to disturbance of airflow. I normally see bleeding around the margins of the perforation. However, as a result of the perforation there is actually less nasal surface area to bleed.
Dr Gossage-- Why is anti-angiogenesis recommendation strong at 82% when surgery was not strong at 94%?	live answered
Are anti-angiogenesis drugs contraindicated in patients with type 2 diabetes, when the blood sugars are well controlled, due to wound healing concerns?	live answered
Are there any topical antiangiogenic drugs that might help directly applying to the nose?	live answered
I didn't notice any mention of cauterization using silver nitrate? Is this still being considered?	I do not use silver nitrate cautery for HHT epistaxis.
Does nasal closure stop bleeds from posterior bleeding sites?	No and they can become a real challenge
What is the best ways to help a 12 year old reduce nosebleeds?	Moisterizers, ensure allergies are under good control (to decrease blood flow to nose and sneezing), and refrain from "picking" nose.

<p>My ENT PA posed my using a modified Young procedure in which I stuff my nose with cotton overnight, and first putting tacrolimus ointment on the cotton and spraying my nose with rose geranium oil. This was a huge game changer for controlling severe nose bleeding in combination with regular Avastin infusions. Could such a modified Young procedure be a first step before actual surgery?</p>	<p>Yes, excellent idea and glad you had a good response. Several of my patients use the cotton overnight and do not want to proceed to Young's. They are happy with cotton overnight.</p>
<p>What is your experience with either Doxycycline or Tamoxifen?</p>	<p>Yes, my patients have had a very good response to doxycycline. No experience with tamoxifen.</p>
<p>Since I started using Folic acid on the recommendation of another HHT sufferer, I have had fewer, less severe nosebleeds.</p>	<p>Excellent. Thank you for sharing.</p>
<p>What is the best method of applying moisture treatment such as vaseline or saline gel without causing bleeding?</p>	<p>No one "best" way. Gentle application.</p>
<p>I also had an unstoppable bleed after COVID vaccine one. Put on tranexamic acid before second vaccine.</p>	<p>Interesting. Hmmm. Two HHT patients with similar complaints.</p>
<p>I see Aquaphor contains petrolatum. I have been told that this can be carcinogenic. What is your opinion?</p>	<p>Doubt it is truly carcinogenic.</p>
<p>Will this presentation be available to be shared with others?</p>	<p>(Nicole) Yes, this webinar is being recorded and will be available on the Cure HHT website both under webinars and under the Resource Library tabs.</p>
<p>In UK we have been told Vaseline can affect the lungs. Do you not find this is a problem? I stopped using Vaseline despite the fact it was working due to advice about inhalation into lungs.</p>	<p>This question was addressed but there are no concerns by these physicians.</p>
<p>How long can a patient safely be on Avastin? I have been on this drug very successfully for several years now. I have had most of the other procedures including 2 septodermoplasty, several lasers, and currently have a septal perforation.</p>	<p>live answered</p>

What about nasal embolization? How successful and for what length of time?	Interventional radiologists block the blood vessels with small metal springs by putting a Cather into the blood vessels. Not very successful as embolization blocks big vessels, yet HHT bleeding is from very small blood vessels that are not usually affected by embolization.
Will the questions and answers be available as well?	(Nicole) The question and answer period will also be recorded and available on the Cure HHT website.
Any recommendations for controlling an active Posterior bleed? When I get these and pack the nose, I end up with the blood then just pouring out my mouth.	Oh, that is a tough one. Yes, the pack has to go to the pack of nose. Rapid Rhino?
How long is laser treatment expected to last?	Varies. No set time.
Does using the SinuCleanse system help reduce nosebleeds (waterpik for nose?)?	For some of my patients yes, for some no. Give it a try.
For how long would one try the tranexamic acid?	live answered
I have read where medications such as estrogen and mupirocin may help with nosebleed management. I have been using mupirocin for a skin infection and found that my nosebleeds have substantially decreased.	live answered
I use Polysporin as a moisturizer and topical antibiotic. Is this the best to use on a regular basis?	Sure. OK.
Is Estriol ointment any better than Vaseline?	Not sure.
Does sclerotherapy alone require general anesthesia?	live answered
I am on warfarin for clots and a heart valve replacement. How much is this affecting my HHT and is there a treatment that would give me some relief?	live answered
Dr.Piccirillo. We live in SW FL - high humidity here. We use a nightly humidifier already. Our 12 does not pick her nose. What are we missing?	I don't think you are "missing" anything. The mystery of HHT. A thorough examination of the inside of the nose by an ENT may provide some insight.

What about Coblation? Could you describe that please?	(Nicole) This was included in Dr. Piccirillo's presentation. I would recommend watching the recording of this webinar when you receive the email tomorrow.
Are the AVMs located in the sinuses too, or just the nasal passages?	Maybe - more likely they are in nose and not sinus.
Can you give more details about recommended packing materials?	Rapid Rhino
What is the best way to reach Dr. Piccirillo for an appointment?	(314) 747-5558 Ask for Tara, my medical assistant.
Please discuss the effect of Doxycycline on nosebleeds.	We have seen a very good response among our ~50-75 HHT patients on the medication.
Does Estriol .01% in Poloxamer Spray Compound a nasal spray help to prevent nosebleeds?	As Dr. Gossage says - no one treatment better than the other.
How does stress, lack of sleep and caffeine influence nosebleeds?	Not sure, but my educated guess is that it will make them worse.
Example of "low pressure pneumatic packing", where do you buy it?	I have not heard of that. I recommend Rapid Rhino. If you can't but from the internet, then ask your health care provider for prescription.
What are your thoughts on trial using Pomalidomide. I am on this drug due to Multiple Myeloma and seems to be helping my severe bleeds.	I am not aware of any information on this.
What exactly does Doxycycline do for HHT symptoms and how long can it be taken without losing its effects or causing long term side effects?	Decrease bleeding. Not aware that it loses its effectiveness.
I had sphenopalatine artery embolization and it gave me 10 years of greatly reduced nosebleeds. Then I had a repeat and going on 5 years of relief. Is anyone else doing that? It changed my life after having all other procedures and therapy except Avastin.	Yes, that is a well-known treatment.
Is there a major risk of blood clots with Avastin?	live answered

<p>Will the Q's & A's be available on the HHT website for later viewing?</p>	<p>(Nicole) The Q&As are part of the recording so you will be able to view it again.</p> <p>We will reproduce the answers that have been typed into the Q&A box and make them available on the recording post in the Cure HHT Resource Library.</p>
<p>There is a Research Clinical Trial (RCT) being set up right now with Pomalidomide for nosebleeds. HHT treatment center at UNC is recruiting patients for it.</p> <p>The "PATH study" is what it is called.</p>	<p>Excellent! I look forward to results and hope it helps!</p> <p>(Nicole) Yes, the PATH-HHT Study of pomalidomide is currently recruiting HHT patients at 10+ HHT Centers of Excellence. Learn more at https://curehht.org/wp-content/uploads/2021/05/PATH-HHT-information_website_Revised-05.21.21.pdf</p>
<p>Does the rose geranium oil need to be diluted in a carrier oil before using in the nose?</p>	<p>live answered</p>
<p>Any chance Doxycycline can cause GI bleeding?</p>	<p>live answered</p>
Attendee Comments	
<p>This is more of a statement, I love the Nasal Sclerotherapy that Dr Jay Piccirillo does, it has changed my life. I don't have as many nose bleeds and the recovery time after the procedure is so much shorter than the lasers. All HHT centers need to be doing this for HHT people with nose bleeds.</p>	
<p>My ENT has given be Mupirocin ointment with a Neti Pot to keep my nose moist.</p>	

Questions Asked after the Q&A Period ended

Might Avastin and Tranexamic Acid cause problems to patients with diffuse PAVMS?

When you are saying there is limited evidence for the rose-geranium oil - do you mean evidence above and beyond other lubricants?

Any GI bleeding risk concern in HHT patient getting a routine screening colonoscopy, when patient has no previous GI bleeding signs or symptoms?

Can Avastin cause muscle weakness? I have been taking Avastin for a few years and it has been very helpful with my nosebleeds, however, I have noticed muscle weakness since I started taking it. Is this a side-effect others have experienced and if Avastin is stopped, would the muscle weakness reverse? I also had a reaction to Avastin which presented as a rash and itching on my lower legs and resulted in lymphedema in my lower legs and now take prednisone before each dose of Avastin.

CRISPR / editing genes in the future? this could be an option for us?

What are the benefits of the Avastin Treatment? My son's doctor is suggesting he try this treatment.

Do you recommend liquid tranexamic acid?

Do you think one is at increased risk of a DVT on a long flight if one is on tranexamic acid?