

Our Story

A Life Changing Event

By Ron Johnson, HHT Member and Alumni Board Member

Young's Procedure

The surgical procedure involves closure of the nasal cavity affected with atrophic rhinitis by creating mucocutaneous flaps. These flaps are sutured together in two layers: first the mucosal layer then the skin layer. The nasal cavity is kept closed for a period time ranging from nine months to forever. If, based on an examination, the crusts have disappeared, a revision surgery can be performed and the nasal cavity is reopened. The theory behind Young's Procedure is that the closed nasal cavity has time to heal.

Although HHT can manifest in a variety of ways, 90% of patients experience nosebleeds (epistaxis) that can range from mild to severe. Epistaxis severity determines the appropriate treatment (i.e., ointments, nasal packs, surgery). According to the Utah HHT Center, the Young's Procedure is not indicated for HHT patients with mild to moderate nosebleeds, or even those with severe nosebleeds unless other less invasive treatment options have been tried and have not worked. But given current treatment options for nosebleeds in HHT patients, the Young's Procedure is an option for select HHT patients. Ron Johnson is eager to share his story (written in 2006) with others who are affected by this disorder.

I was a member of the Board of Directors for the HHT Foundation from 1990 to 1997 when I resigned to serve a mission for my church with my sweetheart. I got interested in this Foundation to see if something could be done to help me and my children and my grandchildren who have this disease. My mother lost her life because of this disease and her father lost his life because of it and I am sure others in the ancestry had problems with the disease before that.

I am very pleased with the volunteers of the HHT Foundation Board and the Medical Advisory Board, plus all of the HHT Treatment Centers around the world. What a blessing it is to have all of the research going on in our behalf.

On September 1, 2005, I went in for surgery at the University of Utah Hospital and had a Young's Procedure, closure of the nasal passage, done to stop my constant nosebleeds. It has been over a year now and it literally has changed my life for the better. Just ask my sweetheart, Merna. I am a new man. It is an absolute miracle. I have not had a nosebleed since and my HGB is up to 15.9 and HCT 49.2. It has been a real blessing. You can research this procedure online or ask your ENT at an HHT Center if the procedure is right for you or your family member(s).

I first found out about this procedure by reading in the 2004 spring issue of the HHT Foundation Newsletter, Direct Connection, where it had an overview of methods for the treatment of recurrent nosebleeds in HHT. One of the methods listed was 'Closure of the Nose' (Young's Procedure). I looked into it and found through my ENT,

Dr. Leland Johnson at the University of Utah HHT Center, that a doctor in England, Dr. Valerie Lund, had been very successful with this surgery. I contacted Dr. Lund and had my surgery scheduled in England for Spring 2005. In the meantime, Dr. Johnson had been in touch with her and had, in fact, performed one Young's Procedure in Utah. I was Dr. Johnson's second Young's Procedure patient.

It has been very interesting now that it has been over a year since I had this procedure done. At 71 years of age, I now have the energy to work on projects that I haven't been able to do for several years. Thanks to this procedure and Dr. Johnson, I am doing well and enjoying life with my sweetheart and family and working hard without any loss of blood through nosebleeds. I do not have problems breathing through my mouth only. I cannot smell, which was expected, but I can taste and I am back on schedule to live much longer now than I would have without this special event in my life. I am sure I would not have been around much longer the way I was going down hill prior to the surgery. My Mother died at the age of 71, because of HHT and her Father died at the age of 80 as of a result of HHT.

I would be happy to talk to anyone about my experience. My email address is ronmerna@hotmail.com.

Your Friend,

Ron Johnson

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