

87. Various Questions

Last Updated: 9/21/2005

Q1: "I developed DVT (deep vein thrombosis) in both legs in 1999 as a result of Factor V Leiden. My hematologist has me on coumadin® therapy and I have had no other DVT. I am 32 years of age. I have had intestinal problems similar to irritable bowel syndrome as a result of coumadin®. I know this because I was off of the coumadin® for 30 days as a result of a false alarm where my doctor and I thought I had another DVT. During this period of Lovenox® therapy my GI problems disappeared. Is there any other anticoagulant on the market that is effective for Factor V? (Plavix)"

A1: First question to be answered: Does this patient really need to be on long-term blood thinners. If yes, then the long-term treatment options are:

1. warfarin (coumadin®),
2. the so-called low molecular weight heparins (Lovenox®, Fragmin®, Innohep®, etc.) as injections underneath the skin,
3. the old-fashioned unfractionated heparin as injections underneath the skin,
4. the newer drug Arixtra® (Fondaparinux) underneath the skin.
5. It may also be worthwhile to consider switching to one of the warfarin-like blood thinners (coumarins) that are widely used in Europe, but not FDA approved in the US, such as (1) Phenprocoumon (= Marcumar®, Marcoumar®, Marcuphen®, Phenpro®, Falithrom®), Acenocoumarol (= Sintrome®, Sintrom®), or Bishydroxycoumarin (= Dicumarol) - also see [Q/A 26](#). Plavix®, Aspirin, and Aggrenox® do not play any significant role in preventing recurrent DVT - they are drugs used to prevent arterial problems (heart attack, stroke). There are several new oral blood thinners in development, but they are, by my estimate, about 2-4 years away from coming onto the market.

Q2: "My granddaughter, Snow, was born with the Protein C Deficiency and has been fighting to stay alive ever since. Her case is so severe she lost her eyesight at 2 days old and portions of her legs were removed to fight the disease. She has been in and out of hospitals and in experimental programs almost every day of her 11years. She gets FFP (fresh frozen plasma) transfusions at every three or four days and now gets severe allergic reactions. There is Protein C that Baxter Pharmaceutical produces and Snow has been waiting for this since the beginning of the year (2005). There is so much more I could write about Snow's health and the pain she goes through every day, but I'm just looking for direction right now. Can you help?"

A2: Baxter does, indeed, produce a protein C concentrate (Ceprotrin®). It is, at this time (9-2005) not FDA approved and is, therefore, not commercially available in the U.S. In Europe the drug was approved and has been available since 2001 - approved by the European FDA-equivalent EMEA (European Medicines Evaluation Agency). Baxter recently finished a protein C concentrate trial and hopes to get FDA approval for the drug and have it available to patients by the end of 2006. At present, it is available on a compassionate use basis: the patient's physician needs to contact Baxter and send (a) a formal request to receive protein C concentrate for compassionate use in a patient, (b) a brief summary of the patient's medical history, (c) an IND (Investigation new drug) application from.

Q3: "Is there any association between Menieres Disease or Vertigo and Factor V Leiden?"

A3: None that is known. Meniere's Disease is due to build up of fluid in the so-called "endolymphatic spaces" of the inner ear. The reason for the excess fluid builds is unclear. Several theories exist to explain how and why this occurs, but all remain unproven. As far as I am aware none of the theories imply a blood clotting problem. A Medline literature search also shows that no study on this topic has been done.