



No. 44 – When Bad Bleeding

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Title: When Bad Bleeding Happens

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We repeatedly emphasize that fear of bleeding should not cause people with ITP to think of themselves as “patients with ITP” who must greatly limit their activities and change their lives. Even when platelet counts are very low, important bleeding problems are rare. We feel that in people with ITP at all ages, activity restrictions often cause more harm than benefit. Activity limitations, especially for children and teenagers, may create a sense of isolation and withdrawal. Of course good common sense and prudence are always required to avoid unnecessary risks or activities that involve excessive risk for injury, such as motorcycles, boxing, trampoline, competitive football American or British style, etc.

But severe bleeding can occur in people with ITP. When it happens, the platelet count is usually extremely low, such as less than 5,000 per mm³. Also severe bleeding most often occurs in association with trauma. The frequency of severe bleeding, defined as requiring hospitalization and/or blood transfusions, in children at the time of their initial diagnosis has been assessed in 863 children analyzed by the Intercontinental Childhood ITP Study Group (ICIS). Just 25 (3%) of them had severe bleeding, mostly from the nose. A few others had bleeding from the mouth and intestines. The most critical site of bleeding is the brain, often described as “intracranial hemorrhage” and abbreviated as ICH. This most often follows an injury involving the head. In the ICIS study mentioned above, just one child, a 9 year-old girl, had ICH and she recovered. Only 3 of the 838 children who did not have severe bleeding at the time of their diagnosis subsequently developed severe bleeding during the next month, whether they received drug treatment or not.

Another study described 40 children with ICH over a period of 14 years across the US. Half of the events occurred at the time of the initial diagnosis of ITP but about 1/3 occurred in children who had had ITP for more than 6 months. A history of head trauma preceded the brain bleeding in 1/3 of children. Children with ICH often had some other severe bleeding, more than just bruises and petechiae, before the ICH occurred, such as blood blisters in the mouth or bleeding in the urine. Ten children died as a result of ICH.

The lessons from this experience are to be aware that bad bleeding can indeed occasionally happen in patients with ITP. However, we still strongly advocate that children and adults should lead normal lives. The most important advice we can give is to seek medical care immediately if severe bleeding occurs, or is you have symptoms that may be caused by severe bleeding. For example, if your child’s platelet count is very low and she falls off her bicycle onto her head – go straight to the hospital emergency department. If a severe headache occurs in someone with ITP, whether there was a prior head bump or not, that is different from headaches experienced previously - go straight to the hospital emergency department. . If you notice any numbness, tingling, weakness, or paralysis in an arm or leg or if you seem to have difficulty finding words or your words are slurred - go straight to the hospital emergency department. Although we emphasize ICH, bad bleeding from the nose, mouth, rectum, or vagina also requires an emergency department visit. These types of bad bleeding can cause blood loss resulting in severe anemia.

And when you arrive in the emergency department, be certain that the doctors know that you have ITP, that they understand that you may be having severe bleeding, and that bleeding in the brain is possible.

This may all seem obvious, but after someone has had ITP for a long time and has had few problems from it, he or she may feel invincible - like nothing bad can ever happen. And because severe bleeding is so rare most doctors, and even experienced consultant hematologists, may never have seen an ITP patient with bad bleeding.

The conclusion is to lead a normal life but if you have ITP seek emergency help if you think that bad bleeding may be happening.