

The Oklahoma ITP Registry Newsletter

August 2010

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Hello!

We would like to welcome you to our sixth Oklahoma ITP Registry newsletter.

The ITP Registry

The Oklahoma ITP Registry began in November 2001. Since that time we have enrolled 106 people. With your participation we hope to document the clinical course and long-term outcomes of patients with ITP

Who's Who

Just to keep you up to date on staff names, new to our staff are:

Zayd Al-Nouri, MD

Graduate Research Assistant

Zayd finished medical school in 2004 and is currently pursuing a master's degree in public health, majoring in epidemiology. His long term career goals include clinical research and patient care.

Cassie Deford, BA

Clinical Trials Coordinator

Cassie has a bachelor's degree in psychology and is currently pursuing a

master's degree in counseling psychology. She is interested in studying the relationship between hematologic disorders and mental health.

Sabina Gurung, BS

Graduate Research Assistant

Sabina has a bachelor's degree in health information management and is currently working on her master's of public health degree. She can speak six languages and is interested in studying infectious diseases.

Carol Lipps, BS

Graduate Research Assistant

Carol has a bachelor's of science degree from Texas A & M University and is currently pursuing a master's of public health degree in epidemiology. She is interested in studying infectious diseases.

Jessica Reese, MS

Clinical Trials Coordinator

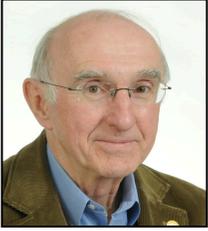
Jessica has a master's of science degree in epidemiology from the University of Oklahoma Health Sciences Center. She is currently working on a project involving fatigue and ITP and will start work on her PhD next year.

Lauren Stewart, BS

Graduate Research Assistant

Lauren has a bachelor's of science in biology from the University of Missouri. She is currently pursuing a master's of public health in epidemiology and is working on a project involving tobacco cessation and lupus.

Dr. George's Perspective



What is the difference between ITP and drug-induced thrombocytopenic purpura (DITP)?

ITP is an autoimmune disease, meaning that patients form antibodies to their own cells. In ITP, patients make antibodies against their own platelets. In adults, ITP typically begins very gradually. Most often people cannot remember how long they have noticed bruising or sometimes excessive bleeding. ITP is also a persistent problem, unless an operation to remove the spleen or treatment with a drug that suppresses the immune system (like rituximab which is also known as rituxan) can suppress the ITP.

Drug allergies occur in many people, and commonly cause itchy skin rashes. These are immune reactions, with antibodies formed against the drug. Certain drugs can cause thrombocytopenia (low platelets) that is like ITP. This happens when the drug attaches to platelets and then the person makes antibodies that react with both the drug and the platelet, and the platelet gets destroyed together with the drug. We call this "drug-induced thrombocytopenia", or DITP.

Different from ITP, DITP typically occurs very suddenly and the platelet count is typically very low, and the patient has lots of petechiae and bruises. When the drug is stopped, the platelet count begins to recover in 1-2 days and is back to normal in a week. We suspect DITP in patients who have episodes of severe "ITP" followed by complete recovery, and then another episode. Quinine is the most common cause of DITP. Sulfa drugs, like bactrim, are another common cause. You can see the drugs that have caused DITP listed on our website, www.ouhsc.edu/platelets.

DITP and Herbal Remedies

Last summer a sophomore pre-medical student from Oklahoma Baptist University worked on a project investigating the

relationship between herbal remedies and thrombocytopenia. Below are the results of his study.

Background: Thrombocytopenia (low platelet count) is a well recognized bad side-effect of many drugs. However, thrombocytopenia has rarely been reported as a bad side-effect of complementary/alternative medicines, herbal remedies, nutritional supplements (vitamins) , foods and beverages, except for reports of thrombocytopenia caused by quinine-containing beverages (i.e. tonic water).

Objectives: To identify all published reports of thrombocytopenia associated with herbal remedies and to assess the strength of evidence supporting their relationship with thrombocytopenia.

Methods/Results: Criteria were defined for article selection and assessment. Each selected article was assessed separately by Dr. George, Dee Terrell, and a pre-medical student to document the presence of the criteria and determine the strength of evidence for a relationship between the reported substance and thrombocytopenia.

Twenty-seven articles were identified that reported the occurrence of thrombocytopenia with 25 substances (other than quinine). However only six articles describing five substances (cow's milk, cranberry juice, *Jui* [Chinese herbal tea], *Lupinus termis* bean, and tahini [pulped sesame seeds]) reported clinical data supporting a definite relationship between thrombocytopenia and the substance. Four articles provided probable evidence for four additional substances and five articles provided possible evidence for five additional substances. In the remaining articles the association with thrombocytopenia was unlikely or the articles were excluded from review.

Conclusion: Reports of thrombocytopenia describing definite or probable evidence for an association of complementary/alternative

medicines, herbal remedies, nutritional supplements, foods and beverages are rare. Whether the occurrence of thrombocytopenia with these substances is uncommon or unrecognized is unknown.

For the full results of this study, use the citation below or visit <http://www.ouhsc.edu/platelets>

Royer DJ, George JN, Terrell DR. Thrombocytopenia as an adverse effect of complementary and alternative medicines, herbal remedies, nutritional supplements, foods, and beverages. *Eur J Haematol.* 2010; 84: 421-429.

ITP Fatigue Survey 2009

Last year, surveys that contained questions about fatigue and how it affects patient's lives, were mailed to everyone in the Oklahoma ITP Registry. 69 people completed and returned the survey and the results are below. Thank you to everyone who completed the survey!

Introduction: Idiopathic (also known as immune and autoimmune) thrombocytopenic purpura (ITP) is an autoimmune blood disorder defined by a low platelet count. That means a person with ITP is at an increased risk for bleeding even with minimal trauma if the platelet count is low (such as less than 20,000). Some patients with ITP have symptoms of fatigue (feeling tired and lack of energy) that seem greater than the fatigue that everyone experiences at times. These patients feel that their fatigue is a direct result of their ITP. In order to answer these questions, we asked patients to fill out a survey about their ITP and possible feelings of fatigue.

Methods: Two groups of ITP patients were included in this study. The UK (England) group was the membership of the ITP Support Association and the US group was the Oklahoma ITP Registry. Each patient was mailed a survey that included four parts.

Parts 1 and 2 focused on the patients and their ITP, and included questions about age, gender, time since diagnosis of ITP, platelet

count, medications, and characteristics of ITP. Part 3 was the Fatigue Impact Scale (FIS) with questions about fatigue experienced by patients and how the fatigue functionally limits them in their lives and activities. Part 4 assessed daytime sleepiness with the Epworth Sleepiness Scale (ESS) and assessed dizziness with the Orthostatic Grading Scale (OGS).

Results: For the UK group, 585 (31%) of 1871 surveys were completed and returned. For the US group, 69 (74%) of 93 surveys were completed and returned. Table 1 presents the responses to certain questions about energy levels, fatigue (FIS), daytime sleepiness (ESS) and dizziness (OGS).

Question	Response
<i>Have your energy levels changed since having ITP?</i>	77% (472 patients) reported that their energy levels have changed
<i>Have you noticed any changes in your energy levels when your platelet count is low?</i>	<ul style="list-style-type: none"> • 67% (405 patients) reported having less energy • 32% (192 patients) reported having no change in energy • 1% (5 patients) reported having more energy
<i>Fatigue (FIS)</i>	37% (226 patients) reported having fatigue
<i>Sleepiness (ESS)</i>	35% (216 patients) reported having sleepiness
<i>Dizziness (OGS)</i>	32% (198 patients) reported having dizziness

Most patients reported that their energy levels had changed since having ITP, and most patients reported that they had less energy when their platelet count was low.

Conclusion: The results of this survey documented that fatigue really is a common symptom in patients with ITP and that fatigue occurs when the ITP is active and the platelet count is low. Fatigue is not related to age, gender, or how long you've had ITP. Symptoms of sleepiness and dizziness were closely associated with fatigue, and this may provide a clue for why fatigue could occur and how it could be treated.

Send Your Suggestions

Is there anything you'd like to see in the next newsletter? We'd like to hear from you! Please contact us if you have any suggestions as to what you would like to see in this newsletter in the future either by emailing Dee Terrell at dee-terrell@ouhsc.edu or Jessica Reese at Jessica-Reese@ouhsc.edu or calling at (405) 271-8001 extension 48386.

Resources for ITP Patients

Visit our website, Platelets on the Internet, at <http://www.ouhsc.edu/platelets>.

There is also an informative website from the United Kingdom you can visit at www.itpsupport.org.uk. This site includes a support group with newsletters, publications, and information on ITP. Dr. George contributes "An American Perspective" found on this page, where you can find additional topics about ITP.

www.itpsupport.org.uk/american.htm

Contact Information

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