"My ITP has a silver lining!"—you'll love these inspiring stories!

PATIENT GUIDE TO ITP

A low blood platelet disorder

Healthmonitor®
VOL.2, NO.2

PDSA
PLATELET DISORDER SUPPORT ASSOCIATION
for People with ITP

STAY SNIFFLE-FREE THIS WINTER!

BECOME AN ACTIVE PARTNER IN YOUR CARE:

- Ask *these* questions
- Know your treatment options
- Track your platelet counts

"I LOVE MY LIFE!"

Pageant queen Danielle Schmidt conquers the ITP challenge—*beautifully!*

COMPLIMENTS OF YOUR HEALTHCARE PROVIDER

FREE take-home copy

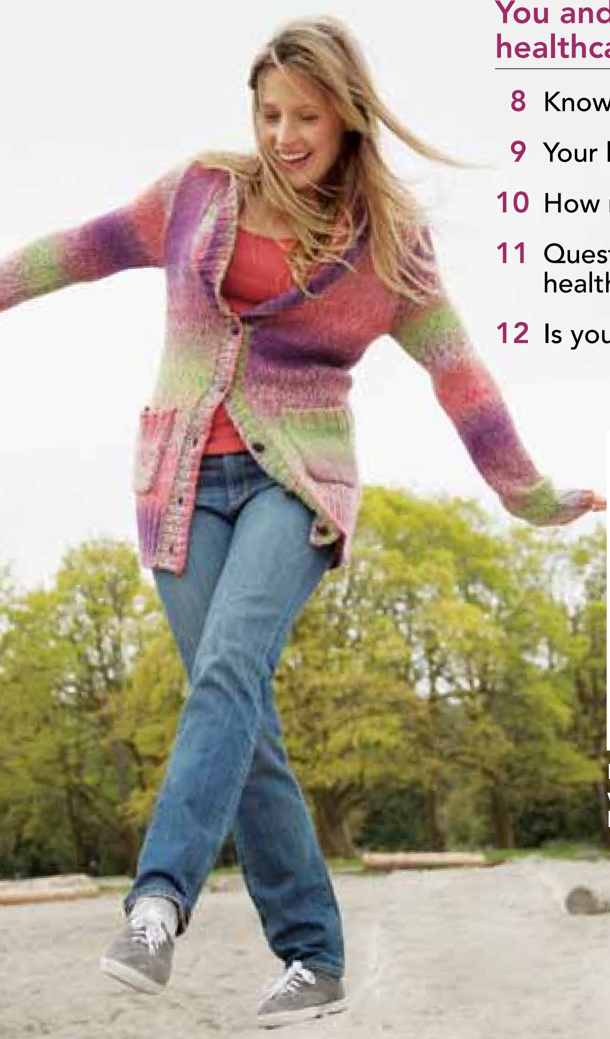
PATIENT GUIDE TO

ITP

A low blood platelet disorder

In the know

You and your healthcare team



Hayley Shimanek, above, won't let ITP keep her from hiking with her family.

Watch Danielle Schmidt's video diary at **Guide2ITP.com** You can also download our platelet tracker app for iPhone and Droid!

Get inspired

Every day with ITP

PDSA
PLATELET DISORDER SUPPORT ASSOCIATION
for People with ITP

Special thanks to the Platelet Disorder Support Association (PDSA) for its medical review of this publication. The PDSA is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research, support and communication. Visit online at *pdsa.org* or call toll-free at **877-528-3538.**

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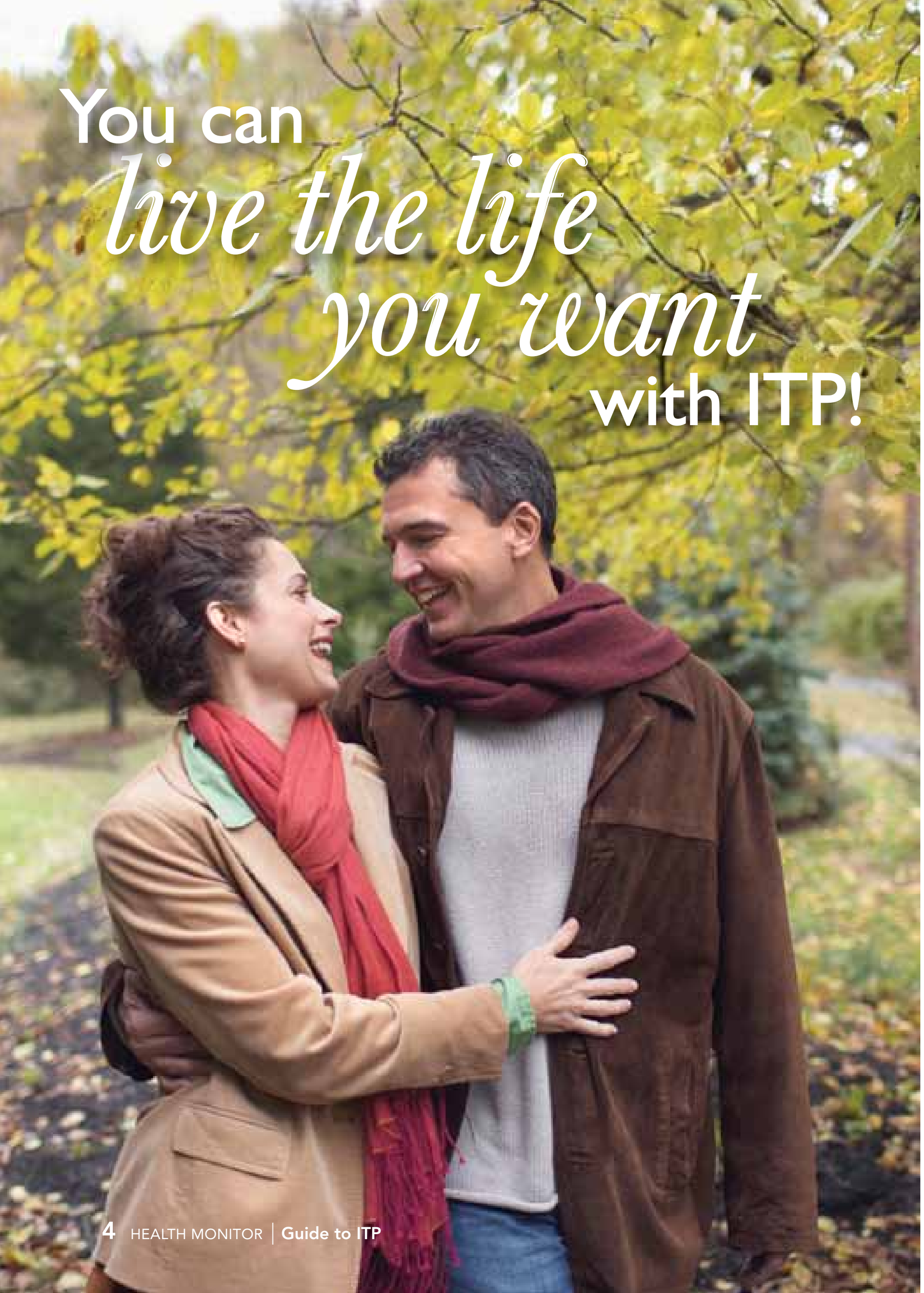
Health Monitor Network is the nation's leading multimedia patient-education company, with publications, websites and mobile apps for ITP patients. For more information: Health Monitor Network, 135 Chestnut Ridge Road, Montvale, NJ 07645; 201-391-1911; healthmonitor.com

You can live the life you want with ITP!



Having a blood disease like ITP doesn't have to get in the way of living the life of your dreams. For Haely, a research assistant at University of Oklahoma Medical Center, for example, everything's fallen beautifully into place—she feels healthy, happy and energetic, and she has a clear vision for the future. And believe it or not, she owes it all to the diagnosis of ITP (immune thrombocytopenia) that blindsided her just a few years ago.

At the time, Haely didn't know the first thing about the low platelet disorder. Out of the blue, she developed a stubborn strep throat and eye infection that sidelined her for a month. It was only when she pointed out the unexplained large bruises on her legs to her doctor that the pieces began to come together. Her doctor ordered a blood test, which showed that her platelets, the blood cells that control clotting, were just above 9,000—to put that in perspective, normal levels are anywhere between 150,000 and 400,000.

Suddenly she was reading up on ITP, a condition she had never heard of, and juggling appointments with a hematologist. With his help, she found a regimen that works for her, so these days, she gets her blood checked every three months and visits her hematologist twice a year.

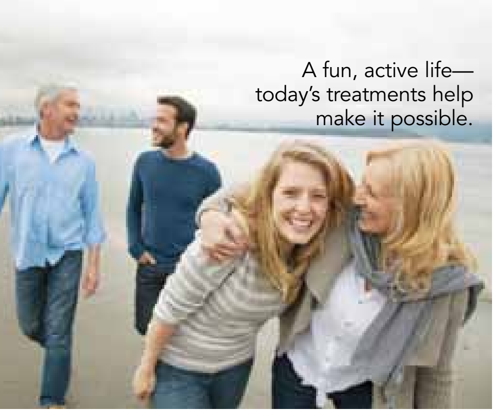
But that's not the only way ITP impacts her: When a little online digging soon after her diagnosis led her to James N. George, MD, a renowned platelet disorder researcher right in Oklahoma City, she set up a meeting with him and has been helping him out in his lab ever since. The one-on-one time she spends with ITP patients just like her has inspired the 24-year-old to pursue a career in medicine.

To those newly diagnosed with the condition, she has these words of encouragement: "ITP *can* be controlled—you just have to experiment with your hematologist to find out what works for *your* ITP."

What is ITP?

ITP is an autoimmune disease in which the body attacks and destroys platelets, cells that play a role in blood clotting. As a result, platelet counts can plummet, putting you at risk for spontaneous bleeding and bruising.

> *"ITP can be controlled. It's a matter of working with your hematologist to find what works for you," says ITP patient Haely.*


A fun, active life—
today's treatments help
make it possible.

What happens in ITP?

Normally, special cells in the bone marrow produce clotting agents called platelets. They circulate in your bloodstream for about 10 days, and are then excreted from the body.

But in a person with ITP, platelets are broken down and flushed from the body more quickly than normal, causing your platelet count to drop to levels as low as 10,000/microliter of blood or under. Many people with ITP have trouble producing enough platelets.

As a result, your blood struggles to form clots, leading to bleeding and bruises. In general, the lower your platelet count, the more symptoms you'll have. You may notice bruises, tiny reddish-purple spots (called petechiae) or larger purplish discolorations (called purpura) on your skin. Nosebleeds, bleeding gums and heavy menstrual bleeding can also be a problem. And the disease can take an emotional toll: When your platelet count fluctuates, you may feel anxious or depressed.

WEB EXTRA! Caroline K. on connecting with others who have ITP at ***Guide2ITP.com/CarolineK***

Who gets ITP?

ITP affects two to three times more women than men, and may strike at any age.

How is ITP diagnosed?

To diagnose ITP, your healthcare provider must rule out other causes of a low platelet count. (Primary ITP is when ITP develops for no known reason. Secondary ITP is associated with other illnesses or infection. It can also occur after transfusion or taking certain medications.) Your doctor will review your medical history, examine you, order blood tests and observe how you respond to treatment.

How long does ITP last?

It depends on the type of ITP you have. Acute ITP usually lasts fewer than 3 months and occurs mainly in children. Persistent ITP lasts between 3 and 12 months. Chronic ITP can last years. Fortunately, treatment can boost your platelet count. But because it can take time to find the best option, partner closely with your healthcare team and be patient. After all, the payoff—peace of mind and a greater sense of well-being—is huge!

Understanding your *platelet count*

When you have ITP, you will become familiar with a blood test called a platelet count, which measures the number of platelets in your blood and their ability to function. What's considered a "safe" platelet count can vary. Ask your doctor about the healthiest count for you.

Your platelet count and what it means

140,000 to 400,000	Normal
100,000-139,000	Fewer than normal, but rarely a risk for bleeding or need for monitoring by your doctor. Not considered low enough to be "ITP."
30,000 to 99,000	Fewer than normal, but rarely a risk for bleeding. May need to be monitored by your doctor but rarely requires chronic treatment.
10,000 to 29,000	You have an increased risk of minor/moderate bleeding and require close monitoring. You will also likely require treatment.
Fewer than 10,000	Your ITP is severe, and you're at high risk for spontaneous bleeding. Treatment and possibly even hospitalization may be necessary.

Know your symptoms

Check any of the items that apply to you and review the answers with your doctor at your next visit.

I've noticed the following marks on my skin:

☐ Pinpoint-sized reddish-purplish spots (called petechiae)
☐ Large bruises (called ecchymosis), especially on my arms and legs, from minor bumps
☐ Bruising or blood-red spots in my mouth
☐ A lump of clotted—or partially clotted—blood under my skin (called a hematoma)

I've also been having these symptoms:

☐ Nosebleeds
☐ Bleeding gums
☐ Blood in my urine or stool
☐ Heavy menstrual bleeding
☐ Prolonged bleeding from cuts
☐ Coughing up blood clots

WEB EXTRA! Concerned about your platelet levels? Download a printable worksheet that lets you plot your blood tests and monitor your treatment at ***Guide2ITP.com/PlateletTracker***

Know your *treatment options*

Scientific advances make it easier to conquer the challenges of having ITP.

Once you've been diagnosed with ITP, your hematologist will take a look at your symptoms. If you're experiencing only mild bruising and petechiae, for example, he may simply observe you for a while. But if your symptoms are more severe, he may recommend treatment right away to raise your platelet counts. To do that, he may prescribe a steroid medication—usually prednisone—to suppress your immune system. He may also recommend a blood product, such as IVIg or anti-D immunoglobulin, which raise platelet levels for a short period.

Report your symptoms! Bruising? Tired a lot? Your doctor needs to know!

If those treatments fail, your doctor may recommend one of the following:

Anti-CD20 monoclonal antibodies. These disable and change specific immune system cells.

Splenectomy. If you have chronic ITP, your hematologist may recommend that you have your spleen removed. Without your spleen, your platelet levels are likely to rise. (Surgery results in higher platelet counts about 66% of the time.) However, splenectomy is a serious procedure and works best in those under 40.

Platelet growth factors. Instead of lowering the number of platelets destroyed, this newer class of medicine actually *boosts* platelet production.

Chemotherapy. While this treatment is best known for treating cancer, its ability to suppress the immune system can also benefit people with ITP.

Ultimately, it may help to remember that every patient is different—how well you respond to treatment depends on factors such as your age, platelet count and bleeding history. And it's common to try various approaches. Work with your hematologist to find the strategy that's best for you.

How a platelet booster can make all the difference

Having low platelets means your blood can't clot effectively, so you're at greater risk for bleeding episodes, bruising and low energy. Treatments that slow platelet destruction are one way to keep your platelets at a healthy level—but they don't work in every person. Fortunately, there's an alternative: a platelet growth factor, or TPO-receptor agonist. (TPO stands for thrombopoietin, a protein that stimulates the bone marrow to produce platelets.) Unlike other ITP treatments, TPO therapy actually boosts production of platelets, and if it works for you, there's another nice benefit—you may be able to take less of your other ITP medications, or quit them altogether!

Your ITP healthcare team

These professionals can help you cope with ITP:

- **Primary care physician:** prescribes medication and can refer you to a specialist.
- **Hematologist:** diagnoses and treats ITP, as well as other blood diseases.
- **Psychologist:** helps you cope with the emotional challenges of living with ITP.
- **Nurse/nurse practitioner (NP)/physician assistant (PA):** works with your doctor to offer routine medical care; serves as your advocate and educator.
- **Infusion nurse**—an RN who administers medications—including those for ITP—through infusions.

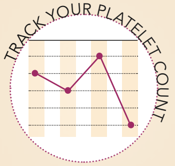
How *medication* can help

	Medication	How it's administered	How it works
FIRST-LINE	Corticosteroid	IV infusion, pill, injection	Raises platelet count by suppressing the immune system.
	Intravenous immunoglobulin-IVIg (a blood product)	IV infusion	Increases platelet count for up to a few weeks.
	Anti-D immunoglobulin (a blood product)	IV infusion	Binds to red blood cells, temporarily boosting platelet count.
SECOND-LINE	Platelet growth factor	Injection, pill	Stimulates bone marrow to produce more platelets.
	Anti-CD20 monoclonal antibody	IV infusion	Disables and changes specific immune system cells, reducing antibody production and boosting the platelet count.
	Immunosuppressant medication	IV infusion, pill, injection	Disables parts of the immune system and raises platelet count.
	Chemotherapy	IV infusion, pill, injection	Slows cell growth and suppresses the immune system.

Questions for your healthcare team

Ask these important questions at your next appointment:

1. What are the results of my blood tests?
2. What's my platelet count?
3. What are my treatment options?
4. What effect will different therapies have on my platelet count?
5. Which treatment do you recommend?
6. When will I know if my treatment is working?
7. How often should I get my platelet count checked?
8. Are there side effects I should tell you or my infusion nurse about immediately?
9. Are there any lifestyle changes I should make?
10. When should I come back for a checkup?



How well is your *treatment* working?

Use this worksheet to track your platelet counts.

Date my treatment began: ______________________

Starting platelet count: ______________________

Date of blood test >>					
100,000+ per microliter of blood					
90,000					
80,000					
70,000					
60,000					
50,000					
40,000					
30,000					
20,000					
10,000					
0					

ITP Help on the Go

Download our **free iPhone or Droid app** to record your info wherever you are. Track your platelet counts, chart your progress, schedule events, share info with your doctor and more.

To download our app and get more useful tools and info **visit Guide2ITP.com.** A sampling of what you'll find:

- **Downloadable platelet tracker**
  A printable worksheet to plot the results of your blood tests and monitor your progress
- **Treatment essentials**
  The info you need about treatment options and strategies to control your ITP
- **Nutrition boosters**
  Delicious recipes and tips to get critical nutrients for strengthening your immune system
- **Active life guide**
  Info to live safely, whether it's managing everyday tasks, enjoying exercise or traveling

Words of wisdom from ITP support groups

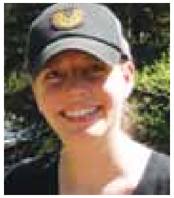
Wouldn't it be great if you could find ways to cope better with having ITP or learn more about your treatment options? Sure, you can get that kind of help from your healthcare team, but don't overlook a special resource—an ITP support group. Group leaders, or facilitators, also have ITP, so you'll get a dose of real-world experience and empathy from members and leaders alike.

"Our group's in Atlanta!"

FACILITATOR
WENDI VAN ELDIK
Living with ITP since 2005

Go to an ITP conference. I've been to three national conferences organized by the PDSA (Platelet Disorder Support Association) and I've learned new things each time. I recommend to anyone with ITP—attend at least one. You meet people like you, and you hear from doctors at the forefront of ITP research. It gives you more hope!

Stay positive—ITP is a manageable disorder. Finding the right treatment is an ongoing thing. I had a splenectomy in 2006, and so far my platelet levels have been fine. But it's common to try many treatments, and you can get frustrated, angry and emotional if things don't work. That's why it's so important to connect with others in your shoes.



GROUP MEMBER
SARAH WALLACE
Living with ITP since 2009

Find your way at *PDSA.org*. When I was first diagnosed, I went to the Web looking for information. There are so many different treatments—it can be confusing. The PDSA site has everything—all you need to know—in one place. It also has a forum discussion where you can ask others about their experiences. It was the first thing that helped me navigate my way through my diagnosis.

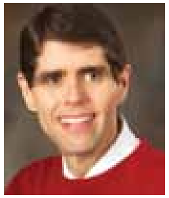
Let your friends and family in on your ITP. When you're first diagnosed, you don't want others to see you differently. But at the same time, you can't hide your ITP—and you shouldn't. The best thing about sharing with my friends and family has been the comforting responses I've gotten.

"Our group's in Milwaukee!"

FACILITATOR
KIM EVERETT
Living with ITP since 1983

Venting gets you through. Being able to talk about your experience in the group is therapeutic, because having ITP can be like walking a tightrope. You can go along with normal platelets and then suddenly you crash. It helps to talk about that, but then it's important to move on and figure out where you go from there and figure out the treatments you can try.

Others' experiences can help me. Since I went into remission in 2008, new drugs have come out. Members are trying them and sharing their experiences at the group meetings. I'm taking notes! You walk away with some valuable information that can help you make your own treatment decisions.



GROUP MEMBER
TOM LANGER
Living with ITP since 2007

Don't let ITP define you. Whatever I face with ITP, it doesn't define me. I don't let it run my life. After all, there are a lot of things I can still do. It's exciting in a way. You start to learn new things.

ITP can be a huge blessing… …if you let it be that. It can give you a sense of depth and clarity you wouldn't otherwise have. It makes it crystal clear what's important. And I've been able to relate to people at a level I never could have before being diagnosed. When I walk out of the meeting, I feel better enabled to deal with ITP.

Want to be a facilitator? Write to *pdsa@pdsa.org*. or call toll-free 877-528-3538.

For adults with chronic ITP if certain other medicines or splenectomy have not worked well

"I Take Possession of the power to help control ITP."

"How? I visit my doctor and learn about ITP and treatment options, like Nplate®."

- Nplate® is a platelet booster—it helps cells in the bone marrow make more platelets to help stay ahead of platelet destruction.
- Nplate® consistently increased and sustained platelet counts in patients studied up to 5 years.

Individual results will vary.

Nplate® (romiplostim) is a man-made protein medicine used to treat low blood platelet counts in adults with chronic immune thrombocytopenia (ITP), when certain other medicines, or surgery to remove your spleen, have not worked well enough.

Nplate® is not for use in people with a precancerous condition called myelodysplastic syndrome (MDS) or low platelet count caused by any condition other than chronic (lasting a long time) immune thrombocytopenia (ITP). Nplate® is only used if your low platelet count and medical condition increase your risk of bleeding. Nplate® is used to try to keep your platelet count about 50,000 per microliter in order to lower the risk for bleeding. Nplate® is not used to make your platelet count normal.

Ask your doctor if Nplate® may be right for you

For more information about Nplate®, visit nplate.com

Important Safety Information

What is the most important information I should know about Nplate® (romiplostim)?

Nplate® can cause serious side effects:

- **Worsening of a precancerous blood condition to a blood cancer (leukemia):** Nplate® is not for use in people with a precancerous condition called myelodysplastic syndromes (MDS) or for any condition other than chronic (lasting a long time) immune thrombocytopenia (ITP). If you have MDS and receive Nplate®, your MDS condition may worsen and become an acute leukemia. If MDS worsens to become acute leukemia you may die sooner from the acute leukemia.
- **Higher risk for blood clots:**
  - —You may have a higher risk of getting a blood clot if your platelet count becomes high during treatment with Nplate®. You may have severe complications or die from some forms of blood clots, such as clots that spread to the lungs or that cause heart attacks or strokes. Your healthcare provider will check your blood platelet counts and change your dose or stop Nplate® if your platelet counts get high.
  - —If you have a chronic liver disease, you may get blood clots in the veins of your liver. This may affect your liver function.
- **Bone marrow changes (increased reticulin and possible bone marrow fibrosis):** Nplate® may cause changes in your bone marrow, but these changes may improve if you stop taking Nplate®. These changes may lead to abnormal blood cells or your body making less blood cells. The mild form of these bone marrow changes is called "increased reticulin." It is not known if this may progress to a more severe form called "fibrosis." The mild form may cause no problems while the severe form may cause life-threatening blood problems. Signs of bone marrow changes may show up as abnormalities in your blood tests. Your healthcare provider will decide if abnormal blood tests mean that you should have bone marrow tests or if you should stop taking Nplate®.
- **Worsening low blood platelet count (thrombocytopenia) and risk of bleeding shortly after stopping Nplate®:** When you stop receiving Nplate®, your low blood platelet count (thrombocytopenia) may become worse than before you started receiving Nplate®. These effects are most likely to happen shortly after stopping Nplate® and may last about 2 weeks. The lower platelet counts during this time period may increase your risk of bleeding, especially if you are taking a blood thinner or other medicine that affects platelets. Your healthcare provider will check your blood platelet counts for at least two weeks after you stop taking Nplate®. Call your healthcare provider right away to report any bruising or bleeding.
- **Lack or loss of response:** If you do not experience results from Nplate®, your body may have created cells that are counteractive to Nplate®. Your healthcare provider will monitor your platelet counts and test your blood regularly to determine if this is an issue.
- **Blood test monitoring:** Your healthcare provider will check your platelet count every week and change your dose of Nplate® as needed. This will continue until your healthcare provider decides that your dose of Nplate® can stay the same. After that, you will need to have blood tests every month. When you stop receiving Nplate®, you will need blood tests for at least 2 weeks to check if your platelet count drops too low.
- **Medication Errors:** Medication errors have been reported in patients receiving Nplate®. Injection of too much Nplate® may cause a dangerous increase in your platelet count and serious side effects. Injection of too little Nplate® may cause a lower than expected platelet count and increase your risk of bleeding.
- **What are the possible side effects of Nplate®?**
  - —Nplate® may cause serious side effects. See "What is the most important information I should know about Nplate®?"
  - —The most common side effects of Nplate® are:
    - Headache
    - Joint pain
    - Dizziness
    - Trouble sleeping
    - Muscle tenderness or weakness
    - Pain in arms and legs
    - Abdominal pain
    - Shoulder pain
    - Indigestion
    - Tingling or numbness in hands and feet
  - —These are not all the possible side effects of Nplate®. Tell your healthcare provider if you have any side effect that bothers you or that does not go away. For more information, ask your healthcare provider or pharmacist.
  - —If you have any questions about this information, be sure to discuss them with your doctor. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Medication Guide for more information about Nplate® on next page.

Commercially insured patients can reduce out-of-pocket prescription costs for Nplate® to as low as $25

The Nplate FIRST STEP™ program can help eligible commercially insured patients with their Nplate® prescription deductible, co-insurance, or co-payment requirements.

For each prescription, patient is responsible for the first $25, then the Nplate FIRST STEP™ card will pay up to $5,000 each 6-month period to cover out-of-pocket costs for Nplate®. The program is not open to uninsured patients or patients receiving prescription reimbursement under any government-funded insurance programs (for example, Medicare or Medicaid) or where prohibited by law. Visit nplate.com/FS or call 1-855-MYCENTER for a complete list of eligibility requirements and restrictions.

Nplate®
romiplostim injection
Count me in

MEDICATION GUIDE
Nplate® (N-plāt) (romiplostim)

Read this Medication Guide before you start Nplate and before each Nplate injection. There may be new information. This Medication Guide does not take the place of talking to your healthcare provider about your medical condition or your treatment.

What is the most important information I should know about Nplate?

Nplate can cause serious side effects:

- **Worsening of a precancerous blood condition to a blood cancer (leukemia).** Nplate is not for use in people with a precancerous condition called myelodysplastic syndromes (MDS) or for any condition other than chronic (lasting a long time) immune thrombocytopenia (ITP). If you have MDS and receive Nplate, your MDS condition may worsen and become an acute leukemia. If MDS worsens to become acute leukemia you may die sooner from the acute leukemia.
- **Higher risk for blood clots.**
    - You may have a higher risk of getting a blood clot if your platelet count becomes high during treatment with Nplate. You may have severe complications or die from some forms of blood clots, such as clots that spread to the lungs or that cause heart attacks or strokes. Your healthcare provider will check your blood platelet counts and change your dose or stop Nplate if your platelet counts get high.
    - If you have a chronic liver disease, you may get blood clots in the veins of your liver. This may affect your liver function.
- **Bone marrow changes (increased reticulin and possible bone marrow fibrosis).** Nplate may cause changes in your bone marrow, but these changes may improve if you stop taking Nplate. These changes may lead to abnormal blood cells or your body making less blood cells. The mild form of these bone marrow changes is called "increased reticulin." It is not known if this may progress to a more severe form called "fibrosis." The mild form may cause no problems while the severe form may cause life-threatening blood problems. Signs of bone marrow changes may show up as abnormalities in your blood tests. Your healthcare provider will decide if abnormal blood tests mean that you should have bone marrow tests or if you should stop taking Nplate.
- **Worsening low blood platelet count (thrombocytopenia) and risk of bleeding shortly after stopping Nplate.** When you stop receiving Nplate, your low blood platelet count (thrombocytopenia) may become worse than before you started receiving Nplate. These effects are most likely to happen shortly after stopping Nplate and may last about 2 weeks. The lower platelet counts during this time period may increase your risk of bleeding, especially if you are taking a blood thinner or other medicine that affects platelets. Your healthcare provider will check your blood platelet counts for at least two weeks after you stop taking Nplate. Call your healthcare provider right away to report any bruising or bleeding.

When you are being treated with Nplate, your healthcare provider will closely monitor your Nplate dose and blood tests, including platelet counts.

- Injection of too much Nplate may cause a dangerous increase in your blood platelet count and serious side effects.
- During Nplate therapy, your healthcare provider may change your Nplate dose, depending upon the change in your blood platelet count. You must have blood platelet counts done before you start Nplate, during Nplate therapy, and after Nplate therapy is stopped.

See "What are the possible side effects of Nplate?" for other side effects of Nplate.

What is Nplate?

Nplate is a man-made protein medicine used to treat low blood platelet counts in adults with chronic immune thrombocytopenia (ITP), when certain other medicines, or surgery to remove your spleen, have not worked well enough.

Nplate is not for use in people with a precancerous condition called myelodysplastic syndrome (MDS) or low platelet count caused by any condition other than chronic (lasting a long time) immune thrombocytopenia (ITP).

Nplate is only used if your low platelet count and medical condition increase your risk of bleeding.

Nplate is used to try to keep your platelet count about 50,000 per microliter in order to lower the risk for bleeding. Nplate is not used to make your platelet count normal.

It is not known if Nplate works or if it is safe in people under the age of 18.

What should I tell my healthcare provider before taking Nplate?

Tell your healthcare provider about all your medical conditions, including if you:

- Have had surgery to remove your spleen (splenectomy).
- Have a bone marrow problem, including a blood cancer or MDS.
- Have or had a blood clot.
- Have chronic liver disease.
- Have bleeding problems.
- Have any other medical condition.
- Are pregnant, or plan to become pregnant. It is not known if Nplate will harm your unborn baby. ***Pregnancy Registry:*** There is a registry for women who become pregnant during treatment with Nplate. If you become pregnant, consider this registry. The purpose of the registry is to collect safety information about the health of you and your baby. Contact the registry as soon as you become aware of the pregnancy, or ask your healthcare provider to contact the registry for you. You or your healthcare provider can get information and enroll in the registry by calling 1-800-77-AMGEN (1-800-772-6436).
- Are breast-feeding or plan to breast-feed. It is not known if Nplate passes into your breast milk. You and your healthcare provider should decide whether you will take Nplate or breast-feed. You should not do both.

Tell your healthcare provider about all the medicines you take, including prescription and nonprescription medicines, vitamins, and herbal products. Know the medicines you take. Keep a list of them and show it to your healthcare provider and pharmacist when you get a new medicine.

How should I take Nplate?

Before you receive Nplate you should first talk with your healthcare provider and understand the benefits and risks of Nplate.

- Nplate is given as a subcutaneous (SC) injection under the skin one time each week. You may not give Nplate injections to yourself.

Your healthcare provider will check your platelet count every week and change your dose of Nplate as needed. This will continue until your healthcare provider decides that your dose of Nplate can stay the same. After that, you will need to have blood tests every month. When you stop receiving Nplate, you will need blood tests for at least 2 weeks to check if your platelet count drops too low.

Tell your healthcare provider about any bruising or bleeding that occurs while you are receiving Nplate.

If you miss a scheduled dose of Nplate, call your healthcare provider to arrange for your next dose as soon as possible.

What should I avoid while receiving Nplate?

Avoid situations that may increase your risk of bleeding, such as missing a scheduled dose of Nplate. You should arrange for your next dose as soon as possible and call your healthcare provider.

What are the possible side effects of Nplate?

Nplate may cause serious side effects. See **"What is the most important information I should know about Nplate?"**

The most common side effects of Nplate are:

- Headache
- Joint pain
- Dizziness
- Trouble sleeping
- Muscle tenderness or weakness
- Pain in arms and legs
- Abdominal pain
- Shoulder pain
- Indigestion
- Tingling or numbness in hands and feet

These are not all the possible side effects of Nplate. Tell your healthcare provider if you have any side effect that bothers you or that does not go away. For more information, ask your healthcare provider or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

You may also report side effects to Amgen at 1-800-77-AMGEN (1-800-772-6436).

General information about the safe and effective use of Nplate.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. This Medication Guide summarizes the most important information about Nplate. If you would like more information, talk with your healthcare provider. You can ask your healthcare provider or pharmacist for information about Nplate that is written for health professionals.

What are the ingredients in Nplate?

Active ingredient: romiplostim
Inactive ingredients: L-histidine, sucrose, mannitol, polysorbate 20, and hydrochloric acid

This Medication Guide has been approved by the U.S. Food and Drug Administration.

Nplate® (romiplostim)

Manufactured by:
Amgen Inc.
One Amgen Center Drive
Thousand Oaks, California 91320-1799

Revised: 12/2011

This product, its production, and/or its use may be covered by one or more U.S. Patents, including U.S. Patent Nos. 6,835,809, 7,189,827, 7,994,117 and 8,044,174, as well as other patents or patents pending.

www.nplate.com

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Loving life each and every day!

"With ITP, life can be a roller coaster," avows Danielle Schmidt, who was diagnosed with the platelet disorder in 2007. "But life is beautiful—I am grateful for my blessings." And to "give back," the bright-eyed former beauty pageant queen from Roswell, GA, does what she most enjoys—volunteering! Within the past few weeks, that's meant a walk to benefit breast cancer research, a weekend spent helping out at an ITP camp for kids and a shift preparing meals at a Ronald McDonald house.

But is all that busyness tiring? "Others have a lot worse to deal with in their lives," says Danielle, who also works for Home Depot on its Home Decorators Collection. "I feel blessed to be able to help where I can."

ITP was my platform! Back in 2009, when Danielle was representing the state of Georgia at the Miss International Pageant and glowing in her sparkly white gown, you'd never guess she wasn't in peak form. Truth is, a little makeup deftly applied hid the bruises on her arms that sometimes appear when her platelet counts dip. She got through the event "on adrenaline," she says, but made sure to baby herself with early bedtimes during pageant week in Chicago.

It was Danielle's idea to compete in the contest as a way of raising awareness about her disorder. Diagnosed only two years earlier, she had endured the baffling round of symptoms familiar to many women with ITP—the fatigue, bruises and rashes, along with nosebleeds and heavy menstrual cycles that can accompany low platelet levels. There were tests to rule out lupus and leukemia. And then there were the treatments, including a three-day hospitalization and two platelet transfusions when her levels dipped to 10,000. It was an ordeal from which Danielle was bound and determined to draw something positive.

When a friend suggested the Miss International contest, with its focus on community service, Danielle knew she'd found her opportunity. She aimed to spread the word about this disorder she never knew existed until her mom, a nurse, noted her low platelet levels after a routine checkup and blood test in 2005.

Naturally, winning "Miss Georgia International" and placing in the top 10 in the Miss International contest itself was amazing. But even better? "Getting onstage and being able to share with the audience about ITP—that was an important moment," she says.

Danielle at the Miss Georgia pageant

At this point, Danielle considers herself ITP-savvy. She created a folder to hold all the information about ITP that she could find. And she's diligent about her "stay healthy" strategies:

› ***She has her platelet count monitored regularly.*** "My platelet counts fluctuate between 40,000 and 50,000. If they go below 30 [thousand], I start treatment."

› ***She fends off stress.*** "I take a yoga class two or three times a week. Not only does it help with my muscle and joint aches, it also brings my stress levels down, which helps keep my ITP at bay."

› ***She takes gentle care of herself.*** "I do get run-down," she admits. "You sometimes don't realize how exhausted you are. I make sure to drink a lot of fluids and turn in early when I can."

› ***She looks for spiritual comfort.*** "I read scripture and daily devotionals," Danielle says. "It definitely helps to take your mind someplace peaceful."

WEB EXTRA! Watch Danielle talk about her life with ITP on her video diary at ***Guide2ITP.com/Danielle***

’tis the season to be *healthy* …yes, with ITP!

It’s here again—that time of year when cold, flu, sniffles and sore throats can really cramp your style. When you have ITP, that can be a problem, since some medications to ease your symptoms can be off-limits. (See Guide2ITP.com/DrugSafety for a list of remedies you should avoid.) While you can’t do anything about the folks coughing into your airspace at the supermarket, you can boost your immune system so you’re better able to withstand such assaults. Here are six handy tips that can make this winter more fun than you’ve had in a long time!

1 **Exercise (outdoors!) to stay strong.** No need to write off exercise just because you have ITP—or because it’s winter. A 2011 study in the journal *Environmental Science & Technology* found that people who exercise outdoors feel more energized and experience less stress and depression than indoor exercisers. They also enjoy their exercise more! So bundle up and take that walk, build a snowman or throw snowballs with the kids. Naturally, if your platelet counts are low, you have petechiae or purpura, or you’re currently having bleeding episodes, check with your hematologist before venturing outdoors to find out what type of physical activity is safe. But don’t automatically deprive yourself of the mood and immunity boost from moving your body!

2 **Vary your veggies!** Winter vegetables such as broccoli and cauliflower, Brussels sprouts and acorn squash are brimming with health-boosting plant chemicals—exactly what you need if you want an immune system capable of fighting microbes that can make you sick, according to Joel Fuhrman, MD, author of *Super Immunity*. But variety is key, since a combination of plant compounds is more effective at bolstering immunity than any one compound, writes Dr. Fuhrman. So purée some squash, make some cabbage soup, and roast onions and carrots with broccoli.

3 **Wash your hands.** ITP or no, one of the easiest things anyone can do to stay healthy is to keep your hands clean. Just wet your hands with clean, running water and lather up with soap. Rub your hands together for at least 20 seconds, then rinse and dry thoroughly. Wash hands before preparing and eating food, before and after caring for someone sick, and after using the bathroom, handling garbage and tidying up after your pet.

Tip: Carry hand sanitizer with you for those times you can’t wash!

4 **Get more ZZZs.** It’s no news that ITP can leech your energy. Getting enough sleep consistently can help with that. But if insomnia is interfering with a good stretch of quality sleep—7 to 9 hours for adults, according to the National Sleep Foundation—you

might want to try this: For 10 minutes before bedtime, focus your mind on a serene and inviting place—like a beach or a quiet lake—and breathe slowly and deeply. The technique, developed at the Walter Reed National Military Hospital in Bethesda, MD, as part of a cardiac risk reduction program, should help soothe away your stress so you can fall asleep more easily, enjoy a better quality sleep and ease your fatigue. What's more, regular sound sleep can help you avoid getting run-down and becoming a target for every disease going around!

5 **Get a flu shot.** Most doctors recommend it. Yet it's sometimes a matter of debate among people with ITP: Should you get a flu shot? "Yes, absolutely," answers James N. George, MD, professor of medicine at the University of Oklahoma Health Sciences Center and top platelet disorder researcher. According to the CDC, the viruses in the flu shot are killed, so you cannot get the flu from a flu shot. While vaccines, like any medicines, can cause allergic reactions, most people who get the shot develop no serious problems. "There are no contraindications for getting the flu vaccine if you have ITP," says Dr. George. But check with your doctor if you've had major surgery recently (including a splenectomy) or are severely immune-compromised, he adds.

6 **Manage your stress.** Ask Danielle Schmidt what triggers her platelet crashes (see Danielle's story on page 20), and she'll say stress! If it's the same for you, try mindfulness meditation—which focuses the mind on the present. Researchers from UCLA and Carnegie Mellon University in Pittsburgh found that older adults who took part in an eight-week program using the technique experienced less loneliness and less inflammation, a significant cause of disease.

WEB EXTRA! Looking for even more stress-busting tips? Visit *Guide2ITP.com/StressReduction*

Conquering the *other* effects of ITP

When you have ITP, worry about bleeding, bumps and bruises comes with the territory. But you may be unprepared for a few less obvious issues. Here, the challenges you may face and how to overcome them.

Brain fog Feeling scattered, forgetful and a little, well, off your game? If you're taking corticosteroids such as prednisone to help increase your platelet count, brain fog can be a side effect. Plus, ITP itself can make you feel fatigued, says Amy Geddis, MD, a San Diego physician who specializes in the genetics of platelet disorders, and tiredness can contribute to cloudy thinking.

WHAT YOU CAN DO: Assume you will forget—everything from deadlines to lunch dates—and write it all down. You can use a smart phone, sticky notes or an old-fashioned pad; whatever works for you will do. *Also:* Reserve jobs that require more focus and energy for times of day when you are feeling your best. Eliminate distractions so you can stay on task—turn off the TV and set your phone to silent. You may also find that establishing simple routines helps you get through the day with less stress and more productivity. Ask your doctor about medication changes that can help lift the confusion without compromising your ITP treatment.

TIP!
It's wise to wear medical-alert jewelry so others know about your ITP—visit *medicalalert.com* for options. And get a free medical card from *pdsa.org.*

Obsessing about your platelet count

Elated when your platelet count is high? Depressed when it drops? Thinking about your counts most of the day and constantly checking your skin for red spots?

WHAT YOU CAN DO: It may not be realistic for you to cast aside all thoughts of ITP, but you *can* take some control over them. "Have scheduled times to check for bruising and allow yourself to check only at those prescribed times," suggests psychotherapist Tina Tessina, PhD, author of *It Ends With You: Grow Up and Out of Dysfunction*. ***Also:*** Notice when ITP worries come over you and catch yourself in the act. Say aloud: "I'm obsessing, and it's not time for me to worry." Then bring your attention to the here and now: Tune into your breath. Name four or five colors surrounding you. Touch a nearby surface and note how it feels. Making a habit of interrupting obsessive thoughts can bring them to a halt.

Needlephobia

You feel dizzy and breathless. Your heart is pumping wildly and your palms are clammy. And it's all because you're about to have blood drawn or receive an injection. While needlephobia is nothing to be ashamed of—in fact, about one in 10 people have it—it's important to address it, as it may interfere with your ITP treatment.

WHAT YOU CAN DO: "Have heat applied to the area," says Kelly Mercer, RN, BSS, an infusion nurse at the Johns Hopkins Kimmel Cancer Center. "It's soothing and it also helps bring up the veins, which can mean a faster and more comfortable 'stick.' Or get a prescription for a cream you can apply an hour before in order to numb the area. Look away before the injection—we don't want you to pull away while we're making the stick." Mercer also advises telling the staff that needles make you anxious; a more experienced nurse can be drafted, so you're less likely to need multiple sticks.

Heavy cycles

Heavy and/or lengthy menstrual cycles are a common symptom of ITP. In fact, heavy menstrual periods are often the first sign a woman has that something is wrong. For Rosie, her periods were so bad, it "was difficult to leave the house for a couple of days."

WHAT YOU CAN DO: First off, know what's "normal" for you. "Menstrual bleeding should not last more than five to seven days, and you should experience no more than two or three heavy days," says Terry Gernsheimer, MD, medical director of the Platelet Antibody Lab at the Puget Sound Blood Center. If you're not sure what a heavy period means for you, Dr. Gernsheimer recommends talking to your physician about how many pads and/or tampons you should be using to avoid bleeding through. And discuss options to lighten your period, such as iron supplements, aminocaproic or tranexamic acid, oral contraceptives and progesterone.

“My ITP has *a silver lining!”*

For the 200,000 Americans living with ITP, it’s a story of perseverance. Yet it often comes with an unexpected benefit, a silver lining that makes life (yes, even with ITP) more worthwhile. The proof? These uplifting anecdotes shared by everyday folks living with ITP.

“I’m a comfortable public speaker now.”

“I used to be very nervous speaking in front of people,” says Dale Paynter of Cambridge, Ontario, Canada. “Now, as a spokesperson for ITP, I am learning to ‘go with the audience.’ It has always been very important for me to do things for others, and now I can do that for people who want me to speak on their behalf. I never felt that way before!”

“I count every day as a blessing!”

“I now take time to stop and smell the roses,” says Sharon Putnam, who was diagnosed in 1995. “I appreciate every minute of every day, and I count each day a blessing.” What’s more, says Sharon, who volunteers at ITP conferences, “raising ITP awareness has become a ministry for me. I can listen and talk to others with the disorder. And I can relate to anyone who is on prednisone!”

ITP forged a friendship between Kristin, left, and Melissa.

“I found a friend for life—and my purpose in life!”

“I can’t forget all the amazing people I have met because of having ITP,” says Kristin Hunt, of Saint-Hubert, Quebec, Canada. “While attending the PDSA conferences, I have made friendships that I know will last for a lifetime. The day I met Melissa, it felt like we had known each other our entire lives. It makes dealing with ITP so much easier when you have people you can talk to who have gone through the same thing as you.” Another silver lining since her 2004 diagnosis? “ITP is what led me to want to pursue a medical profession,” says Kristin, a student at McGill University. “I want to dedicate my life to helping other people like myself.”

“I’ve discovered I’m a great role model!”

For Melissa Hilsabeck, a junior studying civil engineering at California Polytechnic State University, Pomona, being diagnosed with ITP two years ago has revealed a new side of her. “I have come to realize that I have the personality to raise awareness about ITP. I am young, vibrant and full of energy. At school, I hold four officer positions for three different campus clubs. I am also involved with PDSA, raising awareness for ITP. I don’t let ITP dictate my life!”

“Now I go for that extra hug!”

“There are many things I’ve felt unable to do since my diagnosis in December 2011—mostly because I never know if my platelets are high enough for me to avoid injury,” says Hayley Shimanek of Ames, IA. “However, I’ve learned to slow down. I try to say yes more than no to my kids and go back for that extra hug when they are stalling at bedtime.” ⓗ

Eat for energy!

Take a few fresh, wholesome ingredients and whip them up
into this fatigue-fighting dish the whole family will love

Striped bass with sun-dried tomato and Kalamata paste

- Heat grill to medium-low.
- In a food processor or blender, combine the tomatoes, olives, oil, basil and pepper. Process until the mixture forms a thick paste. Stir in the capers and set aside.
- Rinse the bass and pat dry. Paint the underside lightly with olive oil and place it oiled-side down on grill or a pan over medium-low heat. After about 7 minutes, flip the bass and coat the cooked side to taste with the paste.
- Close the grill or cover the pan and continue to cook for 5 to 10 minutes, or until the bass is cooked through.
- Serve immediately.

Makes 4 servings

1/8 cup sun-dried tomatoes, soaked in hot water for 15 minutes, drained,
¼ cup pitted Kalamata olives
2 Tbsp extra-virgin olive oil
¼ cup fresh basil, rinsed and dried, optional
¼ tsp fresh ground black pepper
2 tsp capers
1½ lb skinless striped bass fillet

NUTRITION FACTS (per serving)
Calories 250, fat 13 g (saturated fat 2 g), cholesterol 140 mg, protein 31 g, carbohydrates 2 g, fiber 0 g, sodium 280 mg, sugars 1 g

WEB EXTRA! More delicious energy-boosting meals at ***Guide2ITP.com/Recipes***

Easy Vegan. Ryland Peters & Small, $19.95; rylandpeters.com
Photo credit: Copyright Ryland Peters & Small, 2010

"PDSA is an amazing organization that supports people and their families with platelet disorders.
My daughter is 14 and has had ITP for over 7 years now. It's been an awful roller coaster. When her platelet counts are low she can't do the things she loves to do like ride a bike or play volleyball. The PDSA has been a wonderful resource to help with information to pass along to our family and her schools. They have wonderful support groups and even an annual conference where my daughter has been finally able to meet other teens just like her." – *Susan F.*

Visit PDSA.org:
Communicate with 2,300+ others through PDSA's online discussion groups

Meet someone in your area: Join one of PDSA's 36 regional ITP groups to talk face-to-face to other people like you.

Teleconference:
You can gain a fresh perspective via bimonthly calls with other parents of children who have ITP.

SAVE THE DATE !
National
ITP Conference
2012,
JULY 19-21,
Washington, D.C.

"Having ITP can be very isolating because you rarely come across people who know how you feel emotionally and physically," says Caroline Kruse, executive director of the Platelet Disorder Support Association (PDSA). Joining an ITP online community or support group is a great way to find others who understand.

PDSA.ORG
Where you'll find a wealth of information waiting including...

- BOOKLETS
- PUBLICATIONS
- PATIENT SUPPORT & REFERRAL SERVICE
- SOCIAL MEDIA
  Join the conversation on **Facebook https://www.facebook.com/plateletdisorder** and follow us on **Twitter https://twitter.comPDSA_ITP**
- NATIONAL WALK/RUN
- NATIONAL ITP AWARENESS MONTH

15 Years PDSA Platelet Disorder Support Association

Resources you need

Are you looking for more information on ITP and other blood disorders? Hoping to connect with others who understand you? Get the answers you want and the support you need by checking out these organizations. **Log on to *Guide2ITP.com/Resources* to visit them all with a click!**

PDSA

The Platelet Disorder Support Association is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research, support and communication. Our organization is devoted to offering the most timely, accurate and comprehensive information for medical professionals and patients with ITP and other platelet disorders.

Infusion Nurses Society

The Infusion Nurses Society (INS) is committed to bringing innovative new resources and opportunities to a wide range of healthcare professionals who are involved with the specialty practice of infusion therapy.

The DAISY Foundation

DAISY is an acronym for Diseases Attacking the Immune System. We say thank you to the nursing profession in three ways:

- Honoring the super-human work nurses do in direct care of patients and families every day: The DAISY Award
- Funding nursing research: The J. Patrick Barnes Grants for Nursing Research and Evidence-Based Practice Projects
- Honoring nursing faculty: The DAISY Faculty Award

Ig-NS

Ig-NS is committed to developing and sustaining the advancement of knowledge, education and practice of nursing in the field of Ig therapy.