When A Child Has ITP

A RESOURCE GUIDE FOR PARENTS

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Platelet Disorder Support Association

Empowering ITP Patients

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A diagnosis of ITP is scary for anyone, but especially for a kid and his or her parent. Days filled with fun and endless activity now have to include doctor’s appointments and needle sticks. The new reality is one focused on preventing worrisome complications caused by this autoimmune disease, including common spontaneous bruising and bleeding from the mouth and nose, and rare, but possibly life-threatening bleeds. Fortunately, most kids with ITP usually recover more quickly than adults with ITP.

At PDSA, we know that strong social and emotional support is a powerful tool for those living with ITP. We’re dedicated to providing resources to educate and empower you, ease your anxiety, boost your overall health and take control of ITP.
The Phases of ITP

Newly diagnosed ITP: within 3 months from diagnosis
Persistent ITP: 3 to 12 months from diagnosis. During this phase, patients have not reached spontaneous remission or maintained a complete response off therapy
Chronic ITP: lasting for more than 12 months
Severe ITP: presence of bleeding symptoms that need treatment or need an increase from prior treatment
Refractory ITP: does not respond or is resistant to attempted forms of treatment

What is ITP?

Immune thrombocytopenia (THROM-bo-si-to-PE-ne-ah) or ITP is a rare autoimmune condition that can be as challenging to pronounce as it is to live with. Characterized by low blood platelet counts, you may hear ITP called by its original name of idiopathic thrombocytopenic purpura. Historically, “idiopathic” was used because the cause of the condition was unknown. Today we know ITP is caused by the body’s immune system destroying healthy platelets that leads to easy or excessive bruising and bleeding, in addition to sometimes initiating a daily roller coaster of emotions and ongoing medical management. ITP is not contagious.

What causes ITP?

The specific cause behind why ITP develops is usually unknown and can differ from child to child. ITP has been shown to develop:

- After a viral or bacterial infection
- After certain immunizations
- After exposure to a toxin
- In association with another illness, such as lupus or HIV (human immunodeficiency virus)

Currently, ITP is not usually considered an inherited disease. If multiple family members have been diagnosed with ITP, the hematologist should verify that the cause of low platelets is truly autoimmune and is not due to an inherited disorder that affects platelet production. The hereditary nature of autoimmune disorders is an evolving and exciting area of research, but there are still few definitive answers.

The most important factor in advancing research regarding the link between genetics and ITP is you. Your family health history is an important component of a primary care visit to help tell the story of many common, chronic conditions as well as rare genetic disorders.
To help determine the possibility of inherited thrombocytopenia, your doctor may consider:

- Have the platelets always been low?
- Do they look different?
- Is there a history of low platelets or treatment for ITP in the family?
- Does the person have other congenital abnormalities?

**Why are platelets important?**

Platelets are relatively small, disc-shaped cells circulating within the blood that bind together when recognizing damaged blood vessels. For example, when a child gets a cut, platelets bind to the site to cause a blood clot — and stop the bleeding. A normal platelet count is between 150,000 and 400,000 per microliter of blood. If a child has a platelet count lower than 100,000 per microliter of blood with no other reason for low platelets, they are considered to have ITP. And, because they have fewer platelets, children with ITP are more prone to prolonged bleeding.

**What is a normal platelet count for children?**

Normal platelet counts range from 150,000 to 400,000 platelets per microliter of blood. While it is true that in general a platelet count of <10,000 is associated with a greater risk of bleeding, it is difficult to correlate platelet count with bleeding. Many hematologists not only use the platelet count but also bleeding symptoms when deciding about therapy in ITP. Children who are minimally symptomatic with a low platelet count don’t always need treatment, however, if a child is bleeding no matter the platelet count, they need treatment.
What are the symptoms of ITP?

The symptoms of ITP can vary greatly from person to person, and some with ITP may show no signs of having the condition. In general, the lower your platelet count, the more symptoms you may have including:

- Easy or excessive bruising (purpura)
- Petechiae (pe-TEEK-ee-ay), tiny red dots on the skin caused by broken blood vessels or leaks in a capillary wall
- Bleeding from the gums or nose
- Blood in urine or stools
- Unusually heavy menstrual flow
- Feeling tired or fatigued

Can ITP be life-threatening?

The seriousness of ITP is primarily related to your child’s degree of bleeding. Platelet counts below 50,000 may increase a child’s likelihood of bruising or bleeding and in children known to experience excessive bleeding, platelet counts of 10,000 or less may increase the child’s risk of serious complications.

The most frightening complication of ITP is a rare type of brain bleed called a cerebral hemorrhage that occurs in less than 1% of children with ITP. Such life-threatening bleeding is very rare, most often occurs in children with ITP within the first 12 months following diagnosis and can be treated if caught early. Alerting your child’s doctor to any changes in his/her condition is of utmost importance.
Do children recover from ITP?

Most kids (between 80 to 90 percent) with newly diagnosed ITP suddenly develop bleeding signs and symptoms that fortunately disappear within a few weeks or several months. Recovery from ITP may occur within a few months, and is not dependent on whether or not they initially require treatment. Currently, there are no therapies that will make children with ITP recover faster.

ITP in adolescents is often similar to ITP in adults in that the bleeding is often more persistent (lasting over three months), or even chronic (lasting more than a year) and may require drug treatment to control its symptoms. Fortunately, full recovery is often possible even if your child is diagnosed with persistent or chronic ITP.

What are the treatments for ITP?

There are many treatment options to control the symptoms and complications of ITP — and many more are being developed. The key to getting the best results is working closely with your child’s doctor to find the treatment that works best for you with the least possible side effects.

First-Line (first therapies given to treat a disease)

- Corticosteroids (steroids) – (prednisone and dexamethasone)
- Intravenous Immunoglobulin (IVIG)
- Watchful Waiting: More of a strategy than a treatment, ‘Watchful Waiting’ means choosing to live with your child’s current platelet counts while carefully monitoring the disease and treatment options.
- Anti-Rho(D) – (WinRho®)

Second-Line (therapies given when first-line doesn’t work, or stops working)

- B-Cell Depletion Therapy – (anti-CD20, rituximab [Rituxan®])
- Immunosuppressants – (azathioprine [Imuran®], cyclosporine [Sandimmune®] and mycophenolate mofetil [Cellcept®])
- Platelet Growth Factors – (romiplostim [Nplate®] and eltrombopag [Promacta®/Revolade®])
- Splenectomy
Will treatments affect the child’s daily life?

Many of the treatments have side effects. A child taking prednisone for a few weeks may become moody or irritable, have stomach upsets, have trouble sleeping, experience increased appetite, gain weight, and develop a puffy face. They may also have frequent urination, sugar in their urine, and acne. While taking steroids children are at increased risk from Chicken Pox, which can be severe. Contact with Chicken Pox should be avoided. Once the steroid treatment is stopped, the side effects go away. Longer term use of corticosteroids is associated with osteopenia.

Side effects of IVIG and IV anti-D occur at the time of the infusion or treatment. These include chills, fever, nausea and vomiting, and anemia. Immunosuppressants increase risk of infections. After a spleen is removed, a child will need to be watched for signs of infection and fever, which can be more serious once their spleen is removed.
Several tips to decrease serious side effects of IVIG infusion (discuss with your child’s healthcare team prior to treatment):

1. Hydrate well with liquids the day before, of and after infusion day — avoid caffeine.

2. Pre-medicate a half an hour to an hour prior to infusion. Possible pre-meds to discuss with your child’s healthcare team include:
   - Diphenhydramine (Benedryl)
   - Acetaminophen (Tylenol)
   - Prednisone
   - Hydrocortisone
   - Methylprednisolone (Solumedrol)
   - Saline IV

3. Decreasing the rate of infusion — do not exceed 4 cc/kg/hour infusion rate unless directed by physician.

4. Ask for numbing cream.

5. Keep a log of infusions, pre-medications, lot numbers and side effects and jot down any questions.

What should be done when a child has a nosebleed?

To stop a child’s nosebleed, pinch (using the thumb and forefinger) firmly just below the bone, above the nostrils while keeping the child sitting still. After about 10 minutes, remove the fingers from the child’s nose. Keep the child quiet and still for another 5 minutes. Carefully wash off dried blood around the nose to remove irritation and avoid the temptation for the child to pick at the new clot (scab). Ice packs are also useful to stem the blood flow. The child should not engage in any rough activities for the next couple of hours.

When to seek medical help for the child with ITP:

- Easy or excessive bruising
- If bleeding cannot be stopped, following a nosebleed, lost tooth, or any other injury such as a cut or scrape
- If the child complains of a headache
- Following any head injury, especially if the child is stunned
- If a child vomits blood, or has blood in their urine or stool
- When an injury shows signs of swelling, such as a sprain or strain
What if an accident requires emergency treatment?

It is very important that medical staff are quickly informed that the child has ITP (and whether the child has their spleen or not). A child’s school should have instructions as to what to do in case of an accident or bleeding event. It’s a good idea to have the child wear a medical alert bracelet or necklace. PDSA has a variety of medical alert jewelry available in the Platelet Store: https://bit.ly/2LEnGK1

When to contact parents:

Parents should be contacted in any of the above situations that require medical help, in addition to any previous parental arrangement. Contact the parents if there is any sign of infection or fever, especially in children without their spleen.

It is also important for children with ITP injured through risks they have been asked not to take to share the injury with an adult immediately. Open conversations and understanding are key in keeping a child with low platelet counts safe.

Does ITP cause depression and fatigue?

Many people with ITP report feeling depressed and anxious. It is difficult to deal with a serious, possibly chronic illness like ITP. Fatigue is also a common experience reported with ITP. It may be caused by the ITP itself or as a side effect of the treatments.

How does having ITP make a child feel?

- Scared of tests, treatments, IV needles; scared of possibly dying, or of “catching” some other illness.
- Guilty, thinking he/she somehow caused the ITP to happen.
- Embarrassed to be seen as “different” from the other kids and embarrassed by the bruises, petechiae, and bleeding.
- Angry at ITP, their own body, their parents, and medical staff for the difficulty of the treatments and side effects.
- Frustrated by restrictions on their physical activities, changes to their normal routine, or over their lack of “control” over ITP.
- In denial of the reality of having a serious illness and its impact on their life, tempted to ignore advice of parents and medical care givers.
What are ways to help an adolescent deal with having a chronic illness like ITP?

Here are some guidelines offered by Robert H. Phillips, Ph.D., Founder & Director, Center for Coping, Long Island, NY:

It is difficult enough for anyone to live with chronic illness; but the adolescent with a chronic illness has added, age-related problems. Increased awareness of the potential impact of chronic illness can pave the way to a better understanding of the unique needs of adolescents, and it can lead to methods for better alleviating the problems that may occur.

• Be sensitive to the adolescent’s unique needs. Chronic illness can be difficult to live with, especially for an adolescent who has less “life experience” and consequential coping strategies in place. Don’t assume that the young person has the emotional strength or the social support network to handle chronic illness-related problems successfully.
• Communicate appropriately. Try to view any chronic illness-related issues through the eyes of the adolescent. See what the young person sees. Feel what he/she feels. Issuing commands or using anger and aggressiveness in forcing issues is rarely productive. Calm, constructive discussion is a much more positive way to address chronic illness-related issues.

• Try to treat the adolescent as an adult. Plan together the appropriate ways to treat, and live with, chronic illness. The more you treat the adolescent like an adult, the more likely it is that this will generate adult-like behavior in return.

• Educate significant others. Any individuals who are not familiar with living with medical problems, including family members, friends, and teachers, can be obstacles to successful living with chronic illness. This is especially important in school since the adolescent is going to spend a good number of hours there each day. Provide pamphlets and other information to teachers, guidance counselors, and even classmates, so that school can truly be a “home away from home.”

Can a child with ITP live a normal life?

Children with ITP may attend school and carry on most normal daily activities. While each child is different, children at increased risk of bleeding should limit some activities and sports. Talk to your doctor about recommendations for your child.

Can a child with ITP participate in sports and other activities?

Here are some guidelines from “ITP Kid’s” created by Dana-Farber/Boston Children’s Cancer and Blood Disorders Center. Playing sports is an important part of having fun and living your life. Having ITP should interfere as little as possible. Just keep in mind smart play such as wearing helmets, elbow pads, wrist guards and knee pads or any other protective equipment that is recommended for the sports you wish to play and try to avoid injury.

What sports can I play with ITP?

The following is a list of sports you can play or should avoid based on your platelet count. Just remember to have fun and be safe.

DISCLAIMER: There are no formal national guidelines for sports and activities with ITP. We’ve modeled these suggestions on those used by the National Hemophilia Foundation for other types of bleeding disorders.
Sports and outdoor activities can be pretty easily divided into three groups.

1. Sports that are safe for anyone, even with a bleeding disease. Walking, swimming, tennis are examples.

2. Everything else: basketball, soccer, baseball are examples.

3. Sports that are potentially dangerous for anyone, even without a bleeding disease. Hang gliding, tackle football, ski racing, wrestling are examples. For many patients, an important choice is whether it would be better to avoid some riskier contact sports, or to be treated to raise the platelet count in order to play. This question doesn’t have a single best answer. It is important to consider this choice with your child’s hematologist. The answer for one child may be quite different from the next. Always check with your child’s hematologist if your child’s platelet count is on the low end of any of these parameters for any serious sports playing. Normal platelet counts are >150,000/mm3. As long as your child's platelet count is over 75,000, it is usually safe to play most sports, just be sure to protect yourself as any athlete would.
High Risk
- play ice hockey with checking, field hockey (because of the sticks), or street hockey
- box
- dive competitively
- hang-glide
- play tackle football
- play rugby
- play lacrosse
- ride a motorcycle
- play racquetball (because of potential eye injury from racquets in close quarters)
- rock climb
- wrestle

Moderate Risk
- play baseball (just not catcher; wear a helmet on the bases)
- play basketball
- bowl
- dive in the pool (just no high dives or competitions)
- practice gymnastics
- horseback ride
- ice skate (wear a helmet if you’re unsteady!)
- practice karate, Kung Fu or Tae Kwon Do (no kicks to the head!)
- mountain bike (wearing a helmet of course)
- go river rafting
- roller blade or roller skate (with protective equipment)
- run
- row
- skateboard (with protective equipment)
- cross country or downhill ski or snowboard (be sure to wear a helmet). Ski racing demands a higher platelet count.
- play soccer
Moderate Risk (continued)
• play tennis
• compete in track and field events
• play volleyball
• practice weight lifting

Low Risk
• water ski
• lift weights
• ride a bike (with a helmet of course)
• go fishing
• play frisbee
• play golf
• go for a hike
• practice Tai Chi or Karate
• go for a walk
• swim
• jog
... anytime!

Can a child with ITP be encouraged to do fun things?
Children with ITP should not let having the disorder control their lives. They can go hiking, spend time with friends, learn new things, play board games, read a book, see a movie, play video games, and participate in games that do not involve bodily contact or being hit.

Who needs to know about a child’s ITP?
The following people who interact with a child with ITP should be informed about the disorder and what signs to watch for:
• The child’s regular pediatrician and dentist
• The school nurse
• The child’s school teacher(s) and classmates
• Coaches and P.E. instructors
• Caregivers, such as nannies and babysitters
• Daily bus driver, if the child rides each day
• Scout Troop or other group leaders
• Emergency medical staff (at the ER or in an ambulance)

Thank you to PDSA medical advisors, Amy Geddis, MD and Michele Lambert, MD for their valuable assistance and contribution of information for this free educational booklet.
Other helpful resources for children and families managing ITP:


Parents Teleconference Group: kids join in the first 30 minutes to talk with each other about life with ITP — visit: https://bit.ly/2NxvHTn

ITP Student Factsheet

Resource Guide for Parents

Medical Emergency Card for Patients with ITP

PDSA Online Discussion Group

ITP Helpline – 877-528-3538 or PDSA@PDSA.org

Twenty Steps to Better Health

ITP Diet Suggestions

ITP Diet & Lifestyle Resource List

Depending on your circumstances, one of our other booklets may also be helpful:

*ITP in Children — Frequently Asked Questions* (also available in Chinese, French, Finnish & Spanish)

*ITP in Teens — Frequently Asked Questions* (also available in Spanish)

*Understanding ITP: A Story for Kids about Immune Thrombocytopenia* (English) (also available in Chinese, Dutch & Finnish)

*ITP and the Female Lifecycle: Bleeding Issues in the Stages of a Woman’s Life* (also available in Spanish)

*ITP in Adults — Frequently Asked Questions* (also available in Finnish, French & Spanish)

*Coping with ITP — Frequently Asked Questions* (also available in French & Spanish)

*Living with ITP: Answers to Common Questions*

*The Role and Function of Platelets in ITP*

*Health Insurance and Assistance Programs for ITP Patients*

*Who Pays for Drugs in Canada?* (also available in French)

The Platelet Disorder Support Association is dedicated to enhancing the lives of people with ITP and other platelet disorders through education, advocacy, research and support.

PDSA Members are an engaged, active community of patients, caregivers, family members, friends, and clinicians passionate about raising public awareness, and advancing research and better outcomes for people living with ITP. They are vital partners in driving our mission and in sustaining life-altering resources for patients and caregivers as they navigate the ITP journey — wherever they are in their diagnosis. Benefits include PDSA’s exclusive quarterly news publication, discounts to the annual ITP Conference, and optional participation in the Name Exchange Program.

PDSA would like to thank Novartis for their assistance in printing this guidebook.

The information in this guide is for educational purposes only. For your child’s unique medical condition, please consult a doctor.

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☐ I enclose a donation to PDSA of: $ ______________.

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☐ I would like to receive an **ITP Emergency ID** card (1st one is free)

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Please help us update our records by completing this section of the form:
I am: ☐ an ITP patient ☐ parent of an ITP child ☐ family member
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For additional information about ITP and PDSA visit our Web site:
[www.pdsa.org](http://www.pdsa.org) or send email to pdsa@pdsa.org

SEND THIS FORM TO: Platelet Disorder Support Association
8751 Brecksville Road, Suite 150
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Call the PDSA office if you need assistance or to use a credit card:
877-528-3538 (toll-free) or (440) 746-9003

PDSA is a 501(3)c non-profit organization. All contributions are tax deductible.
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