# When A Child Has ITP

A RESOURCE GUIDE FOR PARENTS







## When A Child Has ITP

A diagnosis of ITP is scary, especially for a child and his or her parent. Days filled with fun and endless activity now include frequent doctor's appointments and needle sticks. The new reality is one focused on preventing worrisome complications caused by this autoimmune blood disorder, including common spontaneous bruising and bleeding and possibly rare life-threatening bleeds. Fortunately, ITP in most children resolves more quickly than ITP in adults, and few children have serious bleeding episodes.

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

ITP is defined by duration of time since diagnosis. There are three phases of ITP:

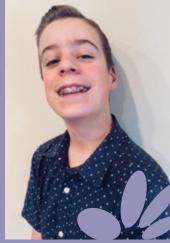
- Newly diagnosed ITP is ITP within the first 3 months from diagnosis.
- Persistent ITP is ITP from 3 to 12 months from diagnosis.
   The majority of children will see their ITP resolve within the newly diagnosed or persistent phases.
- Chronic ITP is ITP lasting for more than 12 months.
   Few children have chronic ITP, but, for those who do, it can be particularly challenging because it is both rare, and not well known, leaving some children and families feeling isolated.

ITP regardless of phase can sometimes be severe or refractory. These are defined as:

- **Severe ITP:** presence of significant bleeding symptoms usually with a very low platelet count (<20-30,000 microlitres of bleed) that requires treatment or more aggressive intervention from prior treatment. Platelet counts can be difficult to increase.
- **Refractory ITP:** does not respond or is resistant to several attempted forms of treatment







#### What is ITP?

Immune thrombocytopenia (*THROM-bo-si-to-PE-ne-ah*), or ITP, is a rare autoimmune hematological condition that can be as challenging to pronounce as it is to live with. ITP is not contagious. 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, leading to easy or excessive bruising and bleeding. Changes in platelet count, bleeding symptoms, and the potential need for ongoing monitoring and medications can lead to a daily roller coaster of emotions and continued medical management.

ITP is a diagnosis of exclusion. There is no accurate, definitive test for ITP. Your doctor may order tests to rule out other causes of low platelets based on your symptoms, family history, physical exam, and other blood counts. Your doctor will look at your blood cells under the microscope and order additional tests as needed. Under certain circumstances, doctors may test for the presence of anti-platelet antibodies, secondary causes of ITP such as other autoimmune disorders (like Lupus), or immune deficiency issues (like Common Immune Variable Deficiency or CVID), and viral exposure (such as Epstein Barr Virus or in some cases HIV), and possibly bone marrow abnormalities. Your doctor might even suggest genetic testing to determine if your child has a hereditary condition causing low platelets, especially if your child's ITP is chronic and/or resistant to initial therapies, if they have never had a normal platelet count, or if there is a family history of low platelet counts.

## Why are platelets important?

Platelets are small, sticky components of the blood formed in the bone marrow (the soft, porous tissue found in bones). Their job is to support the blood vessels and seal small cuts and wounds by forming a blood clot. If the blood doesn't have enough platelets, it is unable to clot as successfully. The result is excessive bruising and risk of bleeding with injury. It is also possible for people with ITP to have spontaneous bleeding, such as bleeding in the mouth (gum bleeding and blood blisters called wet purpura), bleeding from the gastrointestinal system (stomach or intestine), nosebleeds (called epistaxis), and blood in the urine (called hematuria). Females with ITP who have started menstruation (their periods) may have heavier bleeding. Severe, life-threatening bleeding, such as intracranial hemorrhage (bleeding in the brain), is rare, occurring in <1% percent of children with ITP. Severe bleeding is more common in children with other bleeding symptoms (such as wet purpura or significant nosebleeds), so it is important to keep your doctor informed of any new bleeding symptoms.

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

Normal platelet counts range from 150,000 to 400,000  $\mu L$ . Individuals with ITP have a platelet count less than 100,000  $\mu L$ . The lower the platelet count, in general, the more bleeding risk increases, although some people may have very low platelet counts (<10,000  $\mu L$ ) without significant symptoms. Determining a safe platelet count depends on a child's symptoms and activities and is an individualized decision to be made in consultation with an experienced treating physician. Many hematologists consider not only the platelet count, but also bleeding symptoms and quality of life when deciding if or when to start treatment. Children who are minimally symptomatic with a low platelet count do not always need treatment, however, if a child is bleeding no matter the platelet count, they need treatment.

### What are the signs, symptoms, and risks associated with ITP?

#### Signs (things you see)

- Petechiae small, reddish-purple spots that look like a rash, but are not raised
- Bruising or purpura dark red or purple bruises (black and blue marks)
   with no known cause
- Blood in urine or stool
- Increased sleepiness, vomiting, significant headaches, seizures can suggest an intracranial hemorrhage
- Any bleeding that may be unusual, heavier, or lasting longer than usual:
  - Heavy menses (period) in women
  - Frequent, heavy, or persistent nosebleeds
  - Bleeding inside the mouth on the cheeks (blood blisters) or from the gums

### Symptoms (things you feel)

- Physical symptoms (such as fatigue)
- Mental health symptoms (such as depression and anxiety)

#### Rare critical bleeding risk

 Any bleed that compromises an organ such as a brain bleed (also called an intracranial hemorrhage)

## Can ITP be life-threatening?

The seriousness of ITP may be related to your child's history of current or past bleeding events. Life-threatening bleeding in ITP is rare, even if your child has bleeding symptoms. Only a small percentage of children with ITP will have severe bleeding however, such an event can be very scary and may need immediate treatment. Overall, the risk for an intracranial hemorrhage (bleeding in the brain) is <1% percent for children with ITP. This risk *may* be higher if your child is already among the small set of individuals who have experienced other serious bleeding episodes, or if your child has had a significant head injury while their platelet count is very low. It is important to talk to your child about feeling safe telling an adult if they hit their head.

#### Do children recover from ITP?

Most (~70%) children with ITP recover spontaneously within the newly diagnosed period (first 3 months). Young children (1-6 years old) are more likely to see their ITP spontaneously resolve (>80% chance for recovery within 12 months), whereas adolescents are more likely to have a more chronic course. Currently, there are no initial therapies that will make children with ITP recover faster, and we cannot predict which children will have a short journey with ITP or a long one. Fortunately, full recovery is often possible even if your child is diagnosed with persistent or chronic ITP.



#### What causes ITP?

The specific cause behind why ITP develops is usually unknown and can differ from child to child. When the cause is unknown, and other possible causes of thrombocytopenia (low platelet count) have been excluded, we call it **Primary ITP**.

In some children, ITP occurs as the result of a trigger or other underlying disease. This is called **Secondary ITP**. Some causes of Secondary ITP\* are:

- An underlying rheumatologic disease such as Lupus
- A viral or bacterial infection
- Medications or immunizations
- Underlying immune deficiency (such as CVID)
- Inflammatory bowel disease (Crohns disease or ulcerative colitis)
- Celiac Disease

\*ITP is considered secondary if the low platelet count is a symptom of a separate underlying health condition such as another autoimmune disorder (like Lupus) or hereditary disorder (such as 'genetic' conditions that predispose to a immune disease).

## How do I know if my child's low platelet count is hereditary?

ITP is not considered an inherited disease, although in some families there is an inherited predisposition to develop thrombocytopenia (low platelet count) due to subtle changes in how the immune system functions. Your child's hematologist can help determine whether your child's low platelet count is due to ITP, or should be evaluated as a hereditary platelet disorder (congenital thrombocytopenia) or familial autoimmune disorder.

Some clues that the low platelet count may NOT be ITP include:

- Unusually large or small platelets
- Resistance to first-line therapy options, such as corticosteroids or IVIG
- Enlarged liver and/or spleen
- Family history of ITP or low platelet counts
- Congenital abnormalities (conditions diagnosed at birth such as heart defects, kidney defects or bone problems)

The hereditary nature of autoimmune disorders is an evolving and expanding area of research, but there are still few definitive answers. It is now possible to undergo genetic testing for many causes of hereditary thrombocytopenia. However, not all causes can be tested at this time. Your clinician can talk to you about accessing appropriate genetic testing or can refer you to a genetic counselor. Several hereditary disorders can mimic ITP in children. Approximately 1 in 7 individuals with ITP are misdiagnosed as having ITP.

#### What are the treatments for ITP?

There are many ways to control the symptoms and complications of ITP and many more are being developed. It may take time to find the best approach for you and your child. The key to getting the best results is working closely with your child's doctor to find the plan that works best for you with the least possible side effects. Since ITP in children often resolves on it's own, your clinician may not recommend any medications for your child and instead may recommend close observation with intermittent blood tests to monitor the platelet level. The frequency of monitoring platelet counts is based on your child's bleeding symptoms and where they are in their ITP journey. Newly diagnosed children with ITP are usually seen more frequently for examination, blood work and counseling, and to ensure that the diagnosis is correct. Once the diagnosis of ITP is established, the interval between blood tests may be lengthened but your child will still be monitored until the ITP is resolved. If treatment is recommended to address your child's symptoms (such as bleeding), or increase your child's platelet count, the following medicines may be considered:

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

- Watchful Waiting: More of a strategy than a treatment, 'watchful waiting'
  means choosing not to treat the child's current platelet counts with
  medications while carefully monitoring their symptoms and any changes
  that might require intervention. This requires open communication
  with your child's provider and is an active management approach.
- Corticosteroids (steroids) (prednisone and dexamethasone)
- Intravenous Immunoglobulin (IVIG)
- Anti-Rho(D) (WinRho®)

**Second-Line** (therapies given when first-line doesn't work, doesn't work well, or stops working altogether)

- Thrombopoeitin receptor agonists (Platelet Growth Factors) (romiplostim [Nplate®] and eltrombopag [Promacta®/Revolade®])
- Monoclonal antibodies (B-Cell Depletion Therapy) (anti-CD20, rituximab [Rituxan®])
- Immunosuppressants (non-steroid) (sirolimus [rapamune®], azathioprine [Imuran®], cyclosporine [Sandimmune®] or mycophenolate mofetil [Cellcept®])
- Splenectomy

For additional information on management and available treatments for ITP, including other treatments your doctor may suggest, visit <code>pdsa.org/treating-itp</code>. For guidance on health insurance and assistance programs for ITP patients in the United States, and drug coverage information for those living in Canada, please visit <code>psda.org</code> and the resource section of this booklet.





## Will treatments affect a child's daily life?

Many of the treatments have side effects. A child taking prednisone may become moody or irritable, have stomach upsets, have trouble sleeping, experience increased appetite, gain weight, and/or develop a puffy face. They may also have frequent urination, sugar in their urine, and acne. While taking steroids, children are at increased risk for infection from viruses such as chickenpox, which can be severe. Contact with chickenpox should be avoided. Once the steroid treatment is stopped, the side effects go away. Long-term use of corticosteroids is associated with osteopenia (low bone density), poor growth, and other potential bone and joint problems as well as other complications such as adrenal insufficiency.

Side effects of IVIG and IV anti-D occur at the time of the infusion or treatment, or soon after. These include chills, fever, nausea and vomiting, and anemia (more with anti-D). In rare situations, serious infusion reactions can occur (such as aseptic meningitis).

Headaches are common with IVIG and can occur up to 24-48 hours after the IVIG infusion and may require return visits to the clinic or hospital for evaluation to make sure there is no bleeding in the brain.

Several tips to decrease serious side effects of IVIG infusion (discuss with your child's healthcare team prior to treatment):

- Hydrate well with liquids the day before, of, and after infusion; 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 (Solu-Medrol®)
  - Saline IV
- 3. Decrease the rate of infusion do not exceed 4 cc/kg/hour infusion rate unless directed by your physician.
- 4. Ask for numbing cream (to decrease the discomfort of a poke for the IV).
- 5. Keep a log of infusions, pre-medications, lot numbers and side effects and jot down any questions.

Immunosuppressants can increase the risk for infections, particularly when used in combination with each other or with corticosteroids. Generally, the doses used for ITP when used as a single therapy are very well tolerated, but care must be taken especially when used in combinations. If a child's spleen has been removed, they will need to be watched for signs of infection and fever, which can be more serious without a spleen. Most children will be started on antibiotic prophylaxis (daily antibiotics) for at least a period of time.

Side effects vary per person. For information on reported side effects specific to each treatment option, please visit *pdsa.org/treating-itp*.

#### What should be done when a child has a nosebleed?

To stop a child's nosebleed, pinch (using the thumb and forefinger) the nostrils while keeping the child sitting still. Have the child lean forward and breath through the mouth while you pinch the nostrils closed. After about 2 minutes, remove your fingers from the child's nose (use a timer to help you and the child keep track of the time and to help the child keep calm). If the nose is still bleeding after 2 minutes, topical neo-synephrine (Afrin) can be sprayed up the opposite nostril to try to stop the bleeding by helping to clamp down the blood vessels in the nose. Resume pinching the nose for 5 additional minutes. If still bleeding after that point, you can apply topical clotting powders like NasalCease or NosebleedQR. If the nose is still bleeding after another 5 minutes, contact your physician or hematologist for further guidance. If the nose has stopped bleeding, keep the child quiet and still for another 5 minutes (you don't need to pinch the nostrils any more). 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). The child should not engage in any rough activities for the next couple of hours.

If your child has nasal allergy symptoms, it is important to keep these under good control to help prevent nosebleeds. Other things that can help minimize the risks of nosebleeds, which can be very frightening, include:

- Turning the heat down at night
- Using a cool mist humidifier
- Keeping the fingernails trimmed short (and keeping the fingers out
  of the nose); if your child has a tendency to get nighttime nosebleeds,
  have them wear gloves to bed to decrease nosepicking in their sleep
- Use petroleum jelly at the entrance to the nares to help increase the amount of moisture that is being breathed into the nose

# What should be done when a child has an injury, especially to the head?

It is very important children know to tell their parents and teachers when they hurt themselves playing, especially when they hit their head. Even if they feel it was not a significant head injury. Open communication with your child's clinical providers is integral so they can provide advice on whether or not you need to bring your child in for an assessment should they hit their head accidentally.

## Seek medical advice for the child with ITP under the following situations:

- Easy or excessive bruising
- A change in bleeding and/or bruising symptoms
- Bleeding that cannot be stopped, following a nosebleed, lost tooth, or any other injury such as a cut or scrape
- Headache (even if the headache goes away and returns and especially if the headache is persistent)
- Following any head injury, especially if the child is stunned
- Blood in urine or stool or vomit
- Vomiting, with or without fever, especially with headache or after a head injury
- If your child has had a splenectomy and has a fever >101 degrees F
- 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 is 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 at *pdsa.org/shop*.

## 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. If your child's quality of life is suffering, it is important you speak to their clinician about this. You could also look into psychological services such as cognitive behavior therapy to help your child better adjust to living with a rare disease. Needing emotional support is not a sign of weakness, and it is important to address all of the medical needs, including the mental and emotional well-being of you and your child during this difficult ITP journey.

## 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

## How can I help my child with ITP?

Every child is different and has their own unique needs. Some children find it helpful to connect with other children who are going through the same age, so they don't feel 'different.' You can join a family support group in your area, or through PDSA.

It may also be helpful to learn as much about ITP as possible and listen when your child is not feeling well.

Keep your child active. Encourage your child to engage in activities that you and your child's doctor decide are safe. Exercise is an important part of physical and mental well-being and it is critically important to identify and encourage safe participation in as much physical activity as possible to reduce fatigue and impact on overall quality of life. In addition, children should not be prevented from participating in most school activities or field trips (although modifications may need to be made to keep them safe depending on their particular clinical situation).

Use "maybe" instead of "no" if you feel an activity or outing is uncertain. Always defer to your child's doctor to decide on what activities are considered safe for your child when you are uncertain. Purchase a medical alert bracelet for the child to wear. Maintain academic expectations (if your child is of school age) and continue household responsibilities because that is life, too. Concentrate on what they *can* do, not what they cannot.

For younger kids, you can provide soft surfaces for them to play on and choose exciting activities that don't involve rough and tumble. For older kids, encourage them to be involved when visiting the doctor and discussing treatment options.

Discovering your child has ITP can be a frightening experience for any family. But remember, most children get better and serious consequences are rare. As your child gets older and approaches adulthood, it is important to start preparing them to take a more active role in their own care. Involve them in making, recording and attending new appointments and follow-ups. Teach them the importance of tracking and preparing a list of updates regarding their ITP symptoms and any questions they may have prior to their health care visit. Actively involve older children in the process of taking any required medication(s) without reminders, and letting you know when their medication is running low. By taking a less active role yourself and guiding your child while they are still living at home, you are preparing them to become their own best advocate when they are no longer under your daily supervision and guidance. While this may seem overwhelming initially for your older child, continue to encourage them, because this approach usually leads to feelings of empowerment and a sense of control over their ITP.





### How can I help my older child cope with ITP?

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.

Having ITP shouldn't stop your child from having fun. Physical activity is important and should be encouraged daily at every platelet count. However, if the platelet count is low, certain activities may need to be restricted in order to lower the risk of bleeding. As long as your child's platelet count is over 75,000  $\mu L$ , it is usually safe to play most sports; just be sure they protect themselves as any athlete would. There are some sports that are considered dangerous for anyone even without a bleeding disorder. Deciding on what sports your child can participate in will depend on the degree of risk associated with it. It may also depend on your child. For instance, swimming is generally considered to be a safe sport, unless your child participates in jumping off the side from a high distance into the water or diving, then the risk increases. Your child's doctor will help you assess which sports and activities are safe for your child. Remember to make sure your child wears the recommended safety equipment such as helmets, kneepads, elbow pads and wrist pads appropriate to the sport or activity.





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.

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 have modeled these suggestions on those used by the National Hemophilia Foundation for other types of bleeding disorders, which may not be directly applicable. These activities are classified as low, medium, vs high risk but should be modified based on your child's bleeding symptoms. These recommendations should be discussed with your provider before you allow your child to participate to help you determine which activities are safest for your child given their personal experience with ITP to date.

	Low Risk	Medium Risk	High Risk
Basketball		/	
Bike riding (wearing a helmet, of course)	1		
Boxing			<b>/</b>
Diving as a sport or within a pool (Depending on level)		1	<b>√</b>
Fishing	1		
Football (American)			<b>/</b>
Frisbee	1		
Golf	1		
Gymnastics	1		
Hang-gliding			<b>√</b>
Hiking	1		
Hockey – ice, field, or street hockey			<b>√</b>
Horseback riding		/	
Ice skating (wear a helmet)		/	
Jogging	1		
Karate, Kung Fu or Tae Kwon Do (no kicks to the head!)		<b>/</b>	
Lacrosse (Depending on level of competition)	1	1	<b>/</b>
Motorcycle riding			<b>√</b>
River rafting		1	
Roller blading / skating (with protective equipment)		1	
Roller coaster riding			<b>√</b>

	Low Risk	Medium Risk	High Risk
Rowing	1		
Rugby			<b>/</b>
Running	/		
Skateboarding (with protective equipment)		/	
Skiing or snowboarding (be sure to wear a helmet)		<b>/</b>	
Skydiving			1
Soccer (avoid heading the ball – not because the ball is problem but hitting another head as you try to go for the ball together is the risk)	1		
Swimming	1		
Tai Chi	1		
Tennis	1		
Track and field events	1		
Volleyball	1		
Walking	1		
Water skiing	1		
Weight lifting	1	1	
Wrestling		1	

## Can a child with ITP be encouraged to do fun things?

Yes. The focus should be what your child can do safely. Lots of activities can be modified to accommodate children with ITP. Children with ITP should not let 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. In addition, they should be encouraged to be active, which might mean trying a new sport with a lower risk level, but this can certainly be approached as a new adventure and an opportunity for the family to try something new.

#### Who needs to know about a child's ITP?

Who you tell about your child's ITP will primarily depend on their role in your child's life, and how much your family wants other people to know. Generally, it is helpful to inform the following people (who may interact with your child with ITP) about the disorder and what signs to watch for:

- Family members
- The child's regular pediatrician and dentist
- The school nurse (if present)
- The child's school teacher(s), principle, and some 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)

## Where can I go to connect with other families dealing with ITP?

The Platelet Disorder Support Association (PDSA) offers several ways for parents to meet other families of children with ITP. These include a discussion group, a name exchange program, an annual conference with a kid's camp and teen session, and regional meetings during the year. PDSA offers the ITP Parents Teleconference Support Group every 2 to 3 months. For additional details, see the resource section of this booklet.

#### Resources:

You can find more information within the following helpful resources for children and families managing ITP on our webpage, including:



#### ITP POKE-R CLUB<sup>SM</sup> Empowering Kids with ITP www.pdsa.org/poke-r-club

#### **Parents Teleconference Group**

Kids join in the first 30 minutes to talk with each other about life with ITP pdsa.org/join-the-community/local-groups/item/1667-itp-parents-teleconference

#### ITP Helpline

(440) 746-9003 or PDSA@PDSA.org

#### **Discussion Forums**

pdsa.org/discussion-group

Medical Emergency Cards and Medical Alert Jewelry for Patients with ITP pdsa.org/shop

## Depending on your circumstance, one of our other booklets may also be helpful and can be found at pdsa.org/booklets.

These booklets are available in multiple languages at pdsa.org/translated-publications.

#### ITP Student Factsheet

ITP Pamphlet (perfect for sharing with families)

**Resource Guide for Parents** 

When a Child has ITP

ITP in Children — Frequently Asked Questions

ITP in Teens — Frequently Asked Questions

Understanding ITP: A Story for Kids about Immune Thrombocytopenia

ITP and the Female Lifecycle: Bleeding Issues in the Stages of a Woman's Life

Coping with ITP — Frequently Asked Questions

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?

For more information about ITP, and other available resources, additional copies of this booklet, or to become a member of PDSA, please contact us:



8751 Brecksville Road, Suite 150 Cleveland, OH 44141 (440) 746-9003 pdsa@pdsa.org • www.pdsa.org

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. Membership benefits include a quarterly newsletter, discounts to the annual ITP Conference, optional participation in the ITP POKE-R CLUB and Name Exchange Program, and the good feeling of helping others.

This patient information guide is supported by an educational donation provided by Novartis. The information in this guide is for educational purposes only. For your unique medical condition, please consult a physician.

Thank you to PDSA medical advisors, Michele Lambert, MD MSTR, and James B. Bussel, MD, for their valuable assistance and contribution of information for this free educational booklet.

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#### Use this form to:

- MAKE A DONATION TO PDSA
- JOIN PDSA
- REQUEST FUNDRAISING INFORMATION

Please check the appropriate box(es). All donations to PDSA are gratefully received and will be acknowledged. (Please make checks payable to: PDSA) (Do not send cash) I would like to join the Platelet Disorder Support Association (PDSA) to receive an information packet and The Platelet News quarterly newsletter for one year, and enclose \$25 for membership. I enclose a donation to PDSA of: \$ I would like to raise funds for the PDSA. Please send me fundraising information. I would like to receive an *ITP Emergency ID* card (1st one is free) Please complete: Name: \_\_\_\_\_ City: State/Province: Country: \_\_\_\_\_ Zip code: \_\_\_\_\_ 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 friend/other health professional industry professional For additional information about ITP and PDSA visit our Web site: www.pdsa.org or send email to pdsa@pdsa.org SEND THIS FORM TO: Platelet Disorder Support Association 8751 Brecksville Road, Suite 150 Cleveland, OH 44141

Call the PDSA office at (440) 746-9003 if you need assistance or to use a credit card.

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

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