

ITP in Children

FREQUENTLY ASKED QUESTIONS



Platelet
Disorder
Support
Association

Empowering ITP Patients

ITP in Children



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Q What is ITP?

A ITP stands for immune thrombocytopenia. Primary ITP is an autoimmune disease where the body mounts an immune response towards platelets. As a result, children with ITP have low platelet counts. ITP is defined as an immune disorder characterized by isolated thrombocytopenia with a blood platelet count of less than 100,000 per microliter of blood. ITP affects at least 3,000 children a year under the age of 16 in the USA, most being between the ages of 2-6 years old.

Q Will my child recover?

A Most children with ITP will recover quickly following their diagnosis. It is important to understand that there are three different phases of ITP. The likelihood of recovery depends on what phase your child's ITP falls into. The phases include:

- Newly diagnosed ITP: Within 3 months from diagnosis. Most cases (80-90%) of ITP will resolve during this time whether they receive treatment or not
- Persistent ITP: 3-12 months from diagnosis without remission
- Chronic ITP: lasting more than 12 months from diagnosis

The likelihood of recovery is related to age. Very young children are more likely to see their ITP spontaneously resolve whereas adolescents are more likely to have a chronic course. Recovery is possible even if your child is considered to have chronic ITP.

Q Why are platelets so important?

A Platelets are small, sticky components of the blood formed in the bone marrow (the soft, porous tissue found in the long bones of the body). 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 very low platelet counts to have spontaneous bleeding, such as bleeding or bruising in the mouth, bleeding from the gastrointestinal system (stomach or intestine), nosebleeds (called epistaxis), and blood in the urine (called hematuria). Severe spontaneous bleeding, such as intracranial hemorrhage, is rare occurring in <1% percent of children with ITP.

Q Why doesn't my child have enough platelets?

A In ITP, the immune system can cause your child to not make enough platelets (platelet production problem) and/or it may cause platelets that are made to not last as long (platelet destruction problem). Platelet destruction occurs because the platelets are marked by antibodies as foreign by the immune system and then eliminated in the spleen and, to a lesser extent, the liver. The cells responsible for making platelets in the bone marrow may also be marked as foreign and not be able to make as many new platelets as needed. Many children with ITP have both a platelet production and a platelet destruction problem.

Q What is a normal platelet count?

A Normal platelet counts range from 150,000 to 400,000 per microliter (μL) of blood. Having a platelet count between 100,000 and 150,000 means you have a lower than normal platelet count but it doesn't mean you have ITP unless your count drops below 100,000. People with platelet counts under 10,000 are more prone to bleed although symptoms are quite variable between individuals with ITP and even below this threshold many patients with ITP will not experience any significant bleeding. Determining a safe platelet count depends on a child's current symptoms, previous pattern of bleeding, and activities and is an individualized decision to be made in consultation with an experienced treating physician. Spontaneous bleeding is uncommon in children with ITP with platelet counts less than 30,000.

Q How did my child get ITP?

A The exact cause of ITP is unknown. It often occurs in otherwise healthy children a few days or weeks after a viral or bacterial infection. It's thought this infection causes the immune system to lose the ability to distinguish between the body's own cells and those of invaders. As a result, the immune system breaks down



its own platelets. There is some evidence that certain vaccines and medications may trigger ITP, but this occurs in only a small percentage of cases. Why ITP happens in some children and not others who have had the same infection, virus or vaccine is not known.

Q What are the symptoms of ITP?

A The symptoms of ITP are not the same for every child. Some children do not have any symptoms other than a low platelet count. Others may have mild bleeding such as bruising under the skin and/or small purple/red pinpoint dots on the skin called petechia (pronounced Pe-TEEK-e-eye). A small group of children with ITP will experience more severe bleeding episodes. More serious bleeding risks reported include bleeding from mucosal membranes in the mouth, gastrointestinal tract, urinary tract, nose, and brain. Adolescent females may experience a heavy menstrual flow.

Q How is ITP diagnosed?

A ITP is a diagnosis of exclusion. Meaning there is no accurate, definitive test for ITP. Your doctor may do tests to rule out other causes of low platelets depending on your symptoms, family history, physical exam, and other blood counts. Sometimes, if all of those other things are normal 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, HIV, hepatitis B, hepatitis C, H.pylori, and possibly bone marrow abnormalities. Your doctor might even suggest genetic testing to determine if you have a hereditary cause for low platelets if your child's ITP is chronic and resistant to initial therapies, especially if there is a family history.

Q I've heard my child may have to have a bone marrow test. What does this entail?

A Bone marrow examinations are not recommended for the majority of ITP patients. In some cases, a pediatric hematologist (blood specialist) will ask to take a sample of bone marrow from the pelvic bone of your child (bone marrow test). This is performed to ensure that the bone marrow is still making platelets and that there is nothing wrong with other blood cells in the marrow. Bone marrow examinations are not used to make a diagnosis of ITP. They might be recommended when children with ITP have atypical and systemic symptoms (bleeding in various tissue types), or when they are suspected by their physician to have bone marrow failure or fail to respond

"16 years ago my daughter was diagnosed with and successfully treated for ITP. Her platelet count has been robust since then, but other autoimmune induced diseases have presented. I am grateful that PDSA was a resource for us all those years ago."



to common ITP therapies. Bone marrow examinations may also be considered before a splenectomy or when other cytopenias are present (low red or white blood cells in addition to low platelets).

Q Is ITP life threatening?

A The potential danger with ITP is primarily related to a risk of bleeding. However, life-threatening bleeding is rare, unless your child has already experienced a previous life threatening bleed. Only a small percentage of children with ITP overall will have severe bleeds. Overall, the risk for an intracranial hemorrhage (bleeding in the brain) is <1% percent for children with ITP. This risk may be elevated if your child is already among the small set of individuals experiencing other serious bleeding episodes or if your child experiences a head injury while their platelet count is low. It is important to discuss with children with ITP that they should feel safe telling an adult when they experience a bump to their head, or receive an accidental bump to their head through active play.

“My son was diagnosed 6 years ago with chronic ITP. I can tell you when his platelets get below 50,000 because he had such severe emotional responses; he had mood swings, he was super tired and he wouldn’t get out of bed.”

Q Are there medications I should avoid giving my child?

A It’s important to note that children with ITP should not be given any medication that contains acetylsalicylic acid (such as aspirin), anti-inflammatory medications containing ibuprofen (such as Advil® and Motrin®) or naproxen (such as Aleve® and Midol®). Children with ITP should also avoid medicines containing glycerol guaiacolate (such as Robitussin® and Mucinex®) since these medicines can prevent the limited number of platelets your child has from working properly. As a precaution, check with your doctor before giving your child any medicine, vitamin, or supplement other than acetaminophen (Tylenol®). Many families wonder about alternative complementary therapies, such as herbs, special diets, supplement, and non-traditional medicine. Please visit the PDSA website pages on “Outside Influences” and Complementary Therapies” using this link: www.pdsa.org/treating-ityp.

Q When is immediate medical attention needed?

A Seek medical attention immediately if you experience any of the following:

- A change in bleeding and/or bruising pattern.
- A nosebleed that cannot be stopped.
- A headache (spontaneous or due to injury) of any degree that is either worsening, persistent, or keeps returning. Especially in the presence of excessive



fatigue, poor/no appetite, vomiting, and fever. These may be the signs of a brain bleed.

- Following a head trauma. Especially if the child is stunned and/or shows signs of unusual behavior.
- Obvious blood in the urine. This is called gross hematuria.
- Dark black stool, bright red blood when going to the bathroom and/or vomit that resembles coffee grounds. Especially if the child's abdomen looks distended (swollen). These are signs of a gastrointestinal bleed.
- An injury that shows signs of significant swelling.

It is very important that in an emergency medical staff are quickly made aware that your child has ITP. Schools should have an emergency protocol, and children should consider wearing a medical alert bracelet. PDSA has a variety of medical awareness jewelry available for purchase through the Platelet Store pdsa.org/products-a-publications/the-platelet-store.

Q Is ITP contagious?

A No. ITP is not contagious.

Q What treatments are available?

A Because ITP in children generally resolves on its own, your clinician may not recommend any medicines for your child and instead, may recommend close observation with frequent clinical visits and blood tests to monitor the platelet level as well as education about how to monitor for bleeding. 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 platelet counts and observation. As soon as the platelet count increases, the interval between blood tests may be lengthened; but your child will still be monitored until the platelet level returns to normal and is stable. If treatment is recommended to increase your child's platelet count and reduce or stop bleeding, the following medicines may be used:

Corticosteroids (Prednisone or prednisolone) These are synthetic medicines (i.e. steroid) similar to cortisone, a natural substance produced in the body's adrenal glands. They are used in the treatment of ITP because they have been shown to increase the platelet count and decrease bleeding symptoms while it is being taken. Response to steroids is temporary. These medicines are given for a short duration (usually 4-7 days) because they lead to serious side effects with long-term use.

When the medicine is stopped, these side effects will begin to disappear.

Intravenous gamma globulin (IVIG). IVIG is a liquid concentrate of antibodies purified from the plasma (the liquid portion of the blood that doesn't contain red blood cells) of healthy blood donors. IVIG is believed to work by overwhelming the spleen with antibody so that it cannot recognize the antibody-coated platelets. IVIG treatment will usually result in a rapid (24 to 48 hours) increase in your child's platelet count, but improvement is generally short-lived.

If IVIG is the recommended treatment for your child, it will be given directly into a vein in the arm (intravenous infusion) for several hours a day over a period of 1 or 2 days and may be done inpatient or outpatient depending on your child's symptoms and the treating center. The IVIG experience can be improved if the treatment is given more slowly, at room temperature, and the child receives pretreatment with diphenhydramine (Benadryl®) and acetaminophen (Tylenol®) and hydrates well with liquids.

Anti-Rho (D) immune globulin (WinRho®). WinRho® is also a liquid concentrate of antibodies derived from healthy human plasma. However, this medicine is targeted against the Rh factor* on red blood cells. It is thought that WinRho® binds to red blood cells to such an extent that the spleen is fully occupied eliminating red blood cells and does not have much opportunity to remove the antibody-coated platelets. Like IVIG, the response is usually rapid but temporary.

If a doctor recommends treating your child with WinRho®, it will be given by intravenous infusion. The procedure takes less than a half hour and can be done during an outpatient visit; however, because of the risk of side effects, children must be monitored in the clinic for a period of time after receiving WinRho®. WinRho® will generally not work in children who are Rh-negative or who have had a splenectomy (removal of the spleen).

Monoclonal antibodies — Rituximab (Rituxan®) is a monoclonal antibody approved by the FDA in November 1997 for treatment of lymphoma, a type of cancer. Because of how it works it has also been used for decades to also treat ITP. It reduces the number of B cells, a type of white blood cell, in your body as well as changing the character of T-cells (another type of white blood cell)

“Our son is actually on the very lowest dose of Nplate® that we can give him, so we’re starting to have the discussion about what happens if we take him off. And I’m very nervous about it because we’ve had so many experiences with so many different treatments where he’s crashed and then it didn’t work the next time.”

* Most people have Rh-positive blood. This means they produce the Rh factor, an inherited protein found on the surface of red blood cells. A small percentage of people lack the Rh factor. They are considered Rh-negative.

to those that are more likely to recognize the platelets as normal. Rituximab reduces the general population of all B cells with a specific receptor called CD20. These are the B cells that are responsible for making antibodies. Before administration of Rituxan, it is important to evaluate for any chronic infections (ex, hepatitis, HIV) and evaluate the immune system (T/B cell [white blood cell] flow cytometry and immunoglobulins). After Rituxan® treatment, the body can take up to a year to replace the eliminated B cells and have the immune system and antibody production back in full working order. Rituximab is given by intravenous (IV) administration for 4 weekly doses. Hypersensitivity reactions do occur in some patients. The manufacturer recommends premedication with acetaminophen (Tylenol®) and diphenhydramine (Benadryl®) before each infusion and prednisone is also helpful.

Thrombopoietin Receptor Agonists: platelet growth factors or thrombopoietin (TPO) receptor agonists stimulate the bone marrow to produce more platelets. TPO, a protein made in the liver, naturally stimulates platelet production in the bone marrow. TPO receptor agonists bind to the same receptor as the TPO produced in the body, which prompts the megakaryocytes in the bone marrow to produce more platelets. Many people with ITP have low platelet production in addition to increased platelet destruction. The additional bone marrow stimulation prompted by the TPO receptor agonists creates a sufficient number of platelets to overcome the platelet destruction or platelet production problems in most people who receive the treatments. A few different platelet growth factors have received FDA approval for treatment in children. These include, romiplostim (Nplate®) and eltrombopag (Promacta®).

Romiplostim (Nplate®) is a manufactured peptibody (part peptide and part antibody) liquid that is given by subcutaneous injection (under the skin) once a week.

Eltrombopag (Promacta®) is a small molecule (pill or liquid) taken once daily. Eltrombopag must be taken on an empty stomach as food, especially calcium-containing food (e.g., milk, yogurt, seeds, beans, oily fish) affects its absorption.

Oral immunosuppressants: Several oral medications which suppress the immune system can also be used in the treatment of ITP. These include mycophenolate, 6-mercaptopurine/azathioprine, and sirolimus. These are taken one or two times daily and monitored in different ways.

For additional information on management and available treatments for ITP, including other treatments your doctor may suggest, guidance on health insurance and assistance programs for ITP patients in the United States, and drug

"My daughter, Sara, now 21, seems to be doing well since she's been on Promacta after leaving Texas Children's Hospital. Her dosage is 25 mg every other day and her last count was 160 (she's been over 100 for 3 months)... She still tires easily but she lives a fairly normal life."



"I've been doing the Watchful Waiting approach with my daughter now for 2 years and I have to say although her platelet count was 2, 3, 4, 5 – pretty low – she's had days or weeks with no symptoms and sometimes minimal symptoms. But recently, she had strep and although the strep is clear her body has been haywire, to the point where she got huge blood blisters in her mouth, the size of a half inch, quarter inch deep, really ugly stuff – that's when I have no choice and I have to give her the IVIG."

Q What are the side effects of these treatments?

A Side effects vary per person. For information on reported side effects specific to each treatment option, please visit the "Conventional Treatments" link at www.pdsa.org/treating-itp.

Q What about alternative/complementary treatments?

A Although few scientific studies have been conducted to assess how effective alternative and complementary therapies are in the treatment of ITP, some patients report success with herbal therapies, vitamin C, antioxidants and mind/body interventions. Be sure to let your child's doctor know if you are considering (or taking) alternative and complementary treatments. For additional information, please visit the link to "diet and lifestyle" and "complementary therapies" which can be found in the resource section in this booklet.

Q Can my child's ITP return?

A Less than 5% of children with ITP who appear to have recovered will later have a recurrence of ITP. A recurrence of ITP may indicate chronic ITP or secondary ITP (such as systemic autoimmunity or specific immune disorders) and should be carefully monitored. Consult your doctor for more information.

Q When should my child be treated?

A If your child is newly diagnosed, and/or has never had a serious bleeding event, regardless of their platelet count they will likely be followed using the 'Watchful Waiting' management approach. Within this approach, children are followed closely through observation and frequent check-ins in place of treating with drugs. This approach is an active approach that ensures that children will not be over treated with drugs that have significant side effects when the majority of children can expect their ITP to resolve within a few months, with minimal bleeding risk. This management strategy is not appropriate for children who present with bleeding symptoms or develop bleeding symptoms, especially if they are higher risk bleeds. The decision to treat or not to treat is one made by the family along with a hematologist. Many factors go into making the observation decision including the platelet count, bleeding symptoms, quality-of-life for the family and the child, and the child's activity level. In all

cases, it is important for the family to be able to recognize and have a plan for a bleeding emergency. According to [The American Society of Hematology ITP Guidelines \(updated 2019\)](#), “Children with no bleeding or mild bleeding (defined as skin manifestations only, such as bruising and petechiae) should be managed with observation alone regardless of platelet count”. During each visit however, you should discuss with your doctor if there are reasons you or the doctor are not comfortable with this so the treatment approach can be individualized to your child. It is also important to disclose any new bleeding symptoms your child develops with their health care provider, ideally their hematologist. When new bleeding symptoms appear, a change in management may be appropriate.

Q What if my child doesn't get better?

A If your child's ITP persists beyond 12 months from the time of diagnosis, your child will be classified as having chronic ITP. The management will focus on optimizing your child's everyday while reducing the risk of bleeding. Treatment may be required to stop a bleeding episode or to raise the platelet count to a safer level. There is no established 'safe' platelet level since it's different with every child based on their activity levels, previous history of bleeding, and other symptoms. There are many different types of medical treatments. A very small percentage of children with chronic ITP, who are older than 5 years, and who suffer from persistent symptoms and do not improve with medical treatments, may be assessed for the risks/benefits of a splenectomy.

Q Will my child get other illnesses because of ITP?

A If your child is otherwise healthy, he/she should be no more susceptible to contracting illnesses or viruses than children who do not have ITP. However, if your child is being treated with steroids (prednisone) or a drug that suppresses the immune system, or has had a splenectomy, your child's ability to fight infections will be lowered.

Q If I have more children, will they get ITP?

A ITP is not hereditary so it is unlikely that you will have additional children with this condition. In one study, approximately 1 in 7 individuals with ITP were misdiagnosed. If your child's low platelet count is due to an underlying hereditary thrombocytopenia but is diagnosed with ITP then the recurrence risk to have another child with thrombocytopenia could be as high as 50%. If there is a family history of low platelets it is important that you share this with your doctor. Inherited causes of low platelets are not common.



Q How will my other children feel?

A Other family members, including children, may feel confused, guilty, scared, angry and jealous.

Confused — because they don't understand what's going on.

Guilt — because they think something they did may have caused their brother or sister to get ITP.

Scared — because they are worried about their brother or sister with ITP and wondering if they will get sick too.

Angry and jealous — because everyone's attention is focused on the sibling with ITP, and normal family life has been disrupted.

ITP affects the entire family and, as such, your other children and family members should be kept as informed as possible about what's going on — although this can be difficult for young children who may find it hard to understand why the family routine has suddenly changed. Many parents of children with ITP find that encouraging children to express their emotions and setting aside some time alone with each of them at least once a week can help.

Q What should I tell people?

A What you tell people 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. Below is a guide that will help you tell other people about ITP.

For acquaintances you may want to say...

"ITP is a blood clotting disorder. She/he bruises and bleeds very easily. But it's not contagious."

For teachers, scout leaders, day-care staff, and coaches you may want to say...

"ITP puts him/her at risk of injury. If she/he bleeds, this is how to stop it, and this is how to reach me. If trauma occurs that causes loss of consciousness, call 911 immediately, then contact me."

If your child is on medication, you may want to add...

"The medicine makes him/her feel hungry/tired/irritable, but the disorder itself doesn't make him/her feel bad."

Please feel free to distribute this booklet among caregivers, friends and family members. The information it contains will not only increase their understanding of ITP but minimize their fear and anxiety.

"My son has a mood disorder separate from his ITP and I've noticed that when his platelets are low his mood is dramatically worse. It's a big problem managing the two things right now."



Q Are there special problems for adolescent children who are coping with ITP?

A Adolescents may experience many of the same problems living with chronic illness that adults do (physical symptoms, or medication side effects), but certain problems are more exclusive for adolescents.

Denial — Adolescents, more than other age groups, have a common, non-verbalized (sometimes loudly verbalized) belief about their medical status: “I’m fine!” They don’t want to feel sick; they don’t want to be sick; and they don’t want to be different. This can be frustrating for other family members, who are trying to be protective and helpful, and for healthcare professionals who have more difficulty treating a young person if the answers to questions about symptoms are evasive or denying.

School — The adolescent’s primary “job” is to go to school. For adolescents with chronic illness, the attitude about school varies with some who are upset and frustrated if their illness interferes with consistent school attendance and schoolwork performance. Others see school as less important and may have few or no qualms about missing excessive time in school. We encourage families, doctors, and teacher to understand how ITP has affected them at school and make sure that assistance is in place to help them continue to attend school.

Peer Pressure — Adolescents with chronic illness may have a more difficult time in school if they have to deal with hostility or criticism from classmates or friends (“Why can’t you go out with us tonight?”) or the ignorance of teachers (“You’ve missed too much school work; either get with the program or you’re going to fail.”). Because of chronic illness, adolescents may feel ostracized and even excluded from activities that were once within their physical capabilities. ITP can often be thought of as an ‘invisible’ condition because it is not always obvious to others the struggles people with ITP frequently experience, such as fatigue.

Peer pressure may affect young people with chronic illness. The need to fit in is strongest during adolescence which can be devastating and embarrassing when dealing with noticeable physical effects (e.g. bruising, petechia, bloating, bleeding, visible blood blisters, etc.) and behavioral effects (slower, tired, etc.). It is heartwarming to hear stories of young people with chronic illness whose friendships continue despite their illness. Yet it is sad to hear of stories in which the adolescent with chronic illness is ridiculed and even abandoned by former friends.

“When our son Cayden was diagnosed with ITP at age 6, my husband and I went straight into panic mode. We didn’t sleep for days. We searched and searched for the answers. There wasn’t any. It wasn’t until I found PDSA that we knew that Cayden was going to be ok.”



Parents — Adolescents with chronic illness may have parents who are overprotective (“Avoid all physical activity and stay home.”), not protective enough (“You want to play ice hockey? Do whatever you want.”), or insensitive to their needs (“Stop complaining about your fatigue already. Get up and finish your schoolwork.”). Any of these parental reactions may be difficult for adolescents to understand.

Parents may be concerned about the effects their child’s chronic illness will have on the family, such as financial issues, problems with or neglect of other children, or even feeling as though their independence is being inhibited. These concerns can likewise affect the young person with chronic illness.

Guilt — Already unhappy because of having chronic illness, but feeling responsible for problems within the family, an adolescent may feel guilty to the extent that it interferes with physical — and emotional — health. For example, the young person may not tell parents about a serious physical symptom, knowing that it might mean another trip to the doctor or even the possibility of hospitalization.

Siblings — Brothers and sisters of an adolescent with chronic illness may be very resentful. Being less able to understand the physical impact of the disease, they may dislike the added “attention” being directed at their sick sibling. They also may not like getting less attention and may act out in an attempt to regain their “share” of parental interactions. Resentment toward their sibling with ITP may be manifested in hurtful ways, such as anger, ignoring instructions, spiteful behavior, or concealing important information from their parents. For some helpful suggestions on how to help adolescents with ITP please visit the link for “When a Child has ITP” which can be found in the resource section of this booklet.

“Lily is almost 3 years old. She doesn’t understand ITP and the effects it may have for her future. She loves wearing her helmet but doesn’t know why it is an integral part of her daily wardrobe.”

Q In which sports and activities can my child participate?

A 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, it is usually safe to play most sports, just be sure to protect yourself 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. For more information, please check out the resource section at the end of this booklet, and click on the link "When a Child Has ITP".

Q What will happen when my daughter starts menstruating?

A Girls with ITP may experience heavy bleeding (menorrhagia) and prolonged menstruation with their first or all of their periods. If this becomes a problem, hormonal therapy such as oral contraceptives can be used to decrease the severity of menstruation. In cases where oral contraceptives fail to control bleeding, Depo-Provera (a form of progesterone that inhibits ovulation) can be given by injection over time to completely stop menstruation until the ITP has resolved or is better controlled. In some adolescents, an intrauterine device is effective in decreasing menstrual bleeding. While some girls and families do not like the idea of being on a "birth control" medication, it is helpful to understand that in the case of ITP these are considered "bleeding control" medications. In some cases, tranexamic acid, a non-steroidal medication (such as Lysteda®) can be given. It helps prevent clots from breaking down. Your child's ITP doctor may refer you to an adolescent physician or a gynecologist to assist with the different options. For more information, please check out the resource section at the end of this booklet, and click on the link "ITP and the Female Lifecycle".

"My 6-year-old son has chronic ITP, and I'm a very scared mother. I ask myself why. Please help me to understand this."

Q Where can I meet other parents of children with ITP?

A 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 Local Support Group every 2 to 3 months. For additional details see the resource section of this booklet.

Q What else can I do to help my child?

A Try to find other children with ITP or join a family support group in your area. Learn as much about ITP as possible and be there to listen when your child is not feeling well. Keep your child active. Encourage your child



in engage in activities that you and your child's doctor decide are safe.

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 can't.

For younger kids, 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 within six months or less and serious consequences are not common.

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 home, you are preparing (s)he to become her/his own best advocate when (s)he is 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.

Thank you to Cindy Neunert, MD, Jennifer Rothman, MD, and Rachael Grace, MD, members of the Pediatric ITP Consortium of North American (ICON), for their valuable assistance and contribution of information for this free educational booklet.

"My granddaughter was diagnosed with ITP when she was less than a year old. It lasted several months, and her count decreased at one point to 5,000. She has been fine ever since. She is now over 4."

Resources

Helpful resources for children and families managing ITP:



ITP POKE-R CLUBSM: 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 – www.pdsa.org/join-the-community/local-groups/item/1667-itp-parents-teleconference

ITP Helpline – (440) 746-9003 or PDSA@PDSA.org
www.pdsa.org/discussion-group

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

Depending on your circumstance, one of our other booklets may also be helpful, and they can be found by visiting our webpage at www.pdsa.org/booklets

ITP Student Factsheet

ITP Pamphlet (perfect for sharing with families) (also available in Spanish)

Resource Guide for Parents

When a Child has ITP (also available in Spanish, Arabic & Finnish)

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

(also available in Chinese, Spanish, Dutch & Finnish)

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

(also available in Spanish)

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

Living with ITP: Answers to Common Questions (also available in French)

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)

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

Platelet Disorder Support Association

8751 Brecksville Road, Suite 150, Cleveland, OH 44141

telephone: (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 ITP Annual Conference, and optional participation in the ITP Poke-R-Club and Name Exchange Program, and the good feeling of helping others.

PDSA is a 501(c)3 organization. All contributions are tax deductible. This patient information guide is supported by an educational donation provided by Amgen.

The information in this guide is for educational purposes only. For your child's unique medical condition, please consult a doctor. The names of actual companies and products mentioned herein may be the trademarks of their respective owners.

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: _____

Address: _____

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 website:
www.pdsa.org or send email to pdsa@pdsa.org

SEND THIS FORM TO: Platelet Disorder Support Association
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Call the PDSA office if you need assistance or to use a credit card:
(440) 746-9003

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Empowering ITP Patients

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