



# When A Child Has ITP

A RESOURCE GUIDE FOR PARENTS



## What is ITP?

ITP is a non-contagious blood clotting disorder. ITP stands for immune thrombocytopenic purpura. A child with ITP bruises and bleeds easily.

## What causes ITP?

A child with ITP has thrombocytopenia (a low number of platelets), which causes them to more easily bleed and bruise. ITP is not a hereditary disorder. It is a rare disorder, with about 200,000 cases in the U.S. About half of the cases occur in children.

## Why are platelets important?

Platelets are small, sticky particles in the blood that are produced in the bone marrow. Platelets help our blood vessels stay strong and seal off cuts and wounds by forming a blood clot. If a child's platelet count is too low, their blood cannot clot properly when the child is injured, resulting in bleeding and bruising.

## What causes the low platelets of ITP?

The cause of ITP is unknown (called idiopathic). Some cases have occurred after a viral or bacterial infection, a vaccination, exposure to a toxin, or when a child has another illness such as lupus. The child's immune system marks their platelets as "foreign invaders" and the platelets are then destroyed ("eaten" by macrophages) as they pass through the spleen.

## What is a normal platelet count for children?

Normal platelet counts range from 150,000 to 400,000 platelets per microliter of blood. When children have a platelet count less than 10,000 they are at risk for serious bleeding. For many children, a platelet count of 30,000 is enough to prevent any catastrophic bleeding problems.

## What are the symptoms of ITP?

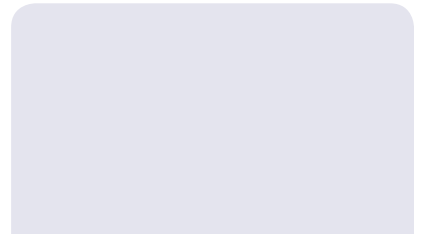
- Easy or excessive bruising
- Petechiae (called “pe-teek-ee-eye”) which are tiny reddish purple dots on the skin caused by bleeding under the surface of the skin, especially on the lower legs
- Cuts or small wounds that take a long time to clot or stop bleeding
- Unexplained bleeding from the nose or mouth
- Blood in urine, stool, or vomit

## Can ITP be life-threatening?

The seriousness of ITP is determined by the symptoms and the platelet count. Children with platelet counts below 50,000 are more likely to bruise or bleed easily. A platelet count of 10,000 or less means a child is at risk for serious bleeding. A rare type of brain bleed called a cerebral hemorrhage occurs in less than 1% of children with ITP. It is life-threatening and needs immediate medical attention.

## Do children recover from ITP?

A majority (about 85%) of cases of childhood ITP are “acute” (short-lived) and the child recovers in less than six months. A small percentage (15%) develops the “chronic” (long-term) form of ITP and will require additional treatment and follow up.



## What are the treatments for ITP?

There are many treatments. All have different risks and benefits. The purpose of treatment is to raise the platelet count to a safe level and reduce bleeding and bruising. Treatments include:

- Corticosteroids (called steroids), such as prednisone;
- Gammaglobulin, such as IVIg and IgG;
- IV anti-D, such as Win-Rho SDF®;
- Rituximab, such as Rituxan®;
- Immunosuppressant chemotherapy drugs, such as vincristine and Cytosan®;
- Mycophenolate mofetil, such as Cellcept®;
- Splenectomy or spleen removal operation (rare for children).



## 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.

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. There can be serious side effects from the rituximab, the vincristine and Cytosan®, and the Cellcept®. 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.

## Can a child with ITP live a normal life?

Children with ITP may attend school and carry on most normal daily activities. However, if their platelet count drops below 20,000 and they experience bruising and bleeding again they may need to limit some activities and sports. If their platelets drop to 10,000 they may need to be hospitalized for treatment.

## 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). It's a good idea to have the child wear a medical alert bracelet or necklace.





## 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.

## Does ITP cause depression and fatigue?

Many people with ITP report being depressed. This might be because the “feel good” neurotransmitter serotonin is carried by the platelets in the blood and delivered to the brain. Anything that interferes with this, such as low platelets, could contribute to depression. It is also 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.

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

Participation depends on the child's platelet count and symptoms. At platelet counts of 30,000 to 50,000 some children may be able to play some non-contact sports (e.g., tennis rather than football or basketball). The child's doctor can determine the types of activities that are safe for the child.

When children participate in sports, they should wear the appropriate safety equipment, such as helmets and knee, wrist, and elbow pads.

## 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)



For more information about ITP, contact the Platelet Disorder Support Association (PDSA) at [www.pdsa.org](http://www.pdsa.org) or call toll free 1-87-PLATELETS (1-877-528-3538).

PDSA is a 501(c) 3 nonprofit organization. All contributions are tax deductible.

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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