

We hope you found this booklet useful. If you have any questions e-mail us at [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk) and we will do our best to answer them.

The ITP Support Association is always looking for ways to promote ITP awareness and raise funds for ITP research. If you can help us by persuading your school to hold a non-uniform day or by taking part in a fundraising or sponsored event in aid of our charity we would be delighted to hear from you. Anyone who raises money for our cause receives a certificate and if they send a photo it will appear in our quarterly journal *The Platelet*.

#### Acknowledgements.

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# What did you call it?

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## Introduction

This booklet has been written to help answer some of the questions which arise with childhood ITP. It is intended to help you cope with the trauma and fear which accompanies the first few weeks after diagnosis - when you wonder just what lies ahead for you and your child. You probably don't know whether ITP is a serious illness or not, if it is treatable or even life threatening. The questions you may be asking at such a time have been prepared by those who have been through this very experience and know exactly what it is like. We hope it helps you to put ITP into perspective, allowing you to begin to return to a normal life as soon as possible.

Medical science is changing rapidly, so it is important to remember that your child's consultant may have more up to date information about ITP and the techniques of treatment than that available when

this booklet was written. If you are in doubt on any matter, do not be afraid to ask questions as no book or information pack can replace the essential face to face discussions which take place between consultant, parent and patient.



Your child would be advised to carry a personalised ITP Support Association Emergency Card and/or alert jewellery alerting others to the condition. The Association also has free Alert cards should your child have a bleeding or other emergency that requires a trip to A&E. If your child has a splenectomy an asplenic notification card should be carried as well.

## What about holidays?

Before you go:-

- Discuss any vaccinations with your doctor, bearing in mind that they may not be effective within 3 months of steroids or immunoglobulin.
- Order any medication well in advance and make sure that you have enough to last.
- Tell the holiday insurance company in writing about your child's ITP or you may find you are not covered in the event of a claim (they may require a doctor's letter).
- Find out what ITP is called in the country you are going to – in case of emergency. You should be able to obtain this on-line or from the country's embassy.
- Find out where the nearest doctor and hospital casualty departments are situated. Check you have their phone numbers.

The ITP Support Association publishes a Holiday Guide which includes essential information about ITP, flying, and vaccinations, and also has ITP factsheets in various languages with an English translation should you need to explain ITP in a foreign country.

## What research is being carried out into ITP?

Since 2000 The Association has been funding much needed ITP clinical research to increase understanding of all aspects of ITP and why it arises. We also fund the UK childhood and adult registries which are collating data in a long term follow up of ITP patients, and have agreed to fund the Pregnancy in ITP Registry.

We desperately need more funds to support research proposals in the pipeline. There is no state funding for ITP research.

### What about my other children?

Other children in the family may also be affected emotionally. Keep them informed about ITP and make everyone in the family feel equally as important so that jealousy between children does not develop. Siblings need to understand that the child with ITP may have restrictions on some activities so they are not at risk of severe bruising or a fall.

### And what if it goes on?

In this case, you may feel that you're on a roller coaster – going through the ups and downs of your child's symptoms and platelet counts. If your child remains reasonably stable you should be able to carry on a fairly normal life. In any case it is important to 'fold' ITP into your family's life style as much as possible. Of course there will be stressful times, but life will begin to feel more manageable as you learn more about ITP and come to terms with the situation.

### How do I find an ITP specialist?

There will probably be a consultant paediatric haematologist at your nearest Children's or University hospital. The Association website has a map of ITP Clinical Centres in the UK, which are recognised specialist ITP centres. You will need a referral (so the new doctor has access to the full medical notes) which can be made by your consultant or GP. Before you visit your doctor or consultant, write down a brief memo of any questions or problems you wish to discuss as it is easy to forget something important when you are in the consulting room. Don't be intimidated by the medical jargon and if there is something you don't understand ask for a simpler explanation.

### Are there any other precautions?

Do not give your child aspirin or non-steroidal anti-inflammatory drugs like ibuprofen (also sold as Nurofen) or Calprofen, which make platelets work less effectively, but Calpol and paracetamol can be used instead. Remember to tell any doctor prescribing drugs that your child has ITP, as some affect platelet function. (A booklet entitled 'Drugs induced ITP' available from the Support Association has more information about drugs that make platelets less effective.)

### What is ITP?

ITP describes a blood condition where there is a shortage of platelets, caused by a disorder of the immune system. If skin or body tissue is cut or injured, normal blood contains enough platelets to form a plug to stop the bleeding and allow the wound to heal. When ITP is diagnosed, it means that there are not enough platelets to do this job properly and the child can suffer excessive bleeding and bruises.



### So what's the difference between ITP and haemophilia?

In normal blood there are 13 factors which combine to effect the full clotting mechanism after any injury which causes bleeding or bruising. The platelets form a plug as the first part of the process, after which the other 12 factors complete the process and effectively stop the bleeding. A child with ITP is short of platelets, but a person with haemophilia is deficient in one of the other twelve factors. Both are bleeding disorders, but whereas haemophilia is inherited and permanent, ITP can develop at any age and can go into remission.

### What does ITP stand for?

Formerly known as Idiopathic Thrombocytopenic Purpura. (Idiopathic = of unknown cause, purpura = bruising) it is now called Immune Thrombocytopenia meaning a shortage of blood platelets caused by a disorder of the immune system.

### What are the symptoms?

Usually the first signs of ITP are unexpected bruises – which are often pain free. Your child might return home from school with bruises and be unable to explain their cause, or perhaps have frequent nose bleeds and tiny red spots (petechiae) on the skin where capillaries leak minute drops of blood. You might also wonder if your child is being bullied or picking fights with others. Sometimes school teachers or other adults could think that you are mistreating your child. In a caring society these are normal concerns which (although upsetting) should not be taken personally. The more people you inform about ITP, the less likely it will be that someone will make an insensitive remark.

### Why does it happen?

The cause is not yet fully understood. However, it is known that the body's immune system, which protects us from attack by viruses, bacteria and disease, mistakes the platelets in the blood for 'enemies' and destroys them.

### How is it diagnosed?

If ITP is suspected a blood sample will be taken and the platelets counted (electronically). In one cubic millimetre of blood there should be between 150,000 and 400,000 platelets. In the UK this is referred to as a platelet count of 150 to 400. In ITP the red and white cell count is usually normal and only the platelet count is low, as determined by a blood test. The paediatrician may also request a bone marrow test, where a small sample is taken of the liquid part of the pelvic bone. This is done to check that platelets are being made.

### Did my child catch it?

ITP is not contagious. Your child did not catch it from anyone, neither can it be given to others by playing with or being near them. The most probable

### Is it safe for my child's ears to be pierced?

Children with a platelet count of 50 or less would be very unwise to undergo ear piercing, body piercing or tattooing.

### How can I cope with the emotions I'm feeling?

You're very likely to feel a wide range of emotions.

- Fear – because you don't know what lies ahead
- Relief – that it wasn't a more serious illness
- Anger – that it has happened to your child
- Guilt – that you might have caused it in some way
- Helplessness – because you cannot make your child well
- Frustration – platelet counts can rise or fall unpredictably
- Anxiety – because the future is uncertain
- Compassion – for what your child has to suffer

The Association has volunteers who offer a listening ear for you to talk to, (even if you just need reassurance) and share these problems with.

### How will my child react to ITP?

Many children with ITP will experience the same kind of ups and downs that you do. They may be:-

- Scared – of tests, treatment and needles (remember, anaesthetic cream is available to numb the skin before injections or blood tests)
- Guilty – thinking that they may have caused it themselves
- Embarrassed – to be different from other children
- Angry – that nobody can put it right
- Frustrated – about restrictions on activities
- Denial – unable to accept the reality of the illness and the advice of doctors and parents

Discuss these feelings openly with your child and be receptive to any fears or emotions. Let them understand that it is normal for the whole family to experience emotional uncertainty. At appointments with doctors or consultants allow your child to have his or her say, and help your child to understand that they did not 'bring it upon themselves'.

### What should I tell the school?

Take a letter to the head teacher or playgroup leader explaining that your child has ITP. This will account for the fact that your child has multiple bruises, (any professional working with children is trained to look out for bruising as a tell-tale sign of systematic abuse.)

The Support Association publishes a free pamphlet entitled Guidelines for Schools, Playgroups and Clubs. Pass a copy to your child's teacher and the head teacher as well, for it gives general background information about ITP and will help them understand about and cope with the condition.

### Who else should I tell?

You should tell your child's dentist and any club or activity leaders. Also tell anyone who has responsibility for your child at any time, like baby sitters or child minders. If your child needs to see any other medical practitioner bring it to their attention as well.

### What about childhood vaccinations?

If your child has a platelet count of 20 or above, these may be given in the normal way. However, if the count is under 20, it should not be given by an intramuscular injection, but most can be given subcutaneously (under the skin) with pressure applied afterwards.

### How should I stop a nose bleed?

Pinch the sides of the nose just below the bone - above the nostrils. Better still, use a swimming nose clip which gives gentle, even pressure. Sit quietly for five minutes and then remove hand or nose clip. Keep the child still and quiet for a further five minutes. After this, carefully wash the dried blood away in order to help limit the irritation and reduce the temptation for the child to pick the scab. Ice packs on the nose are also useful to stem the blood flow.

### What will happen when my daughter's periods start?

Girls with a platelet count of 20 or below may have prolonged periods with heavier menstrual bleeding. If necessary, this can be controlled with tranexamic acid or a hormonal preparation, such as the contraceptive pill.

reason for the onset of ITP is that it came after a viral infection, like a cold or sore throat, or possibly after certain types of medication, but the majority of cases occur for no apparent reason.

Sometimes a newborn baby may get thrombocytopenia from a mother with ITP if her antibodies cross the placenta but in such cases it rapidly gets better after birth.

### Will it be treated?

In most cases, childhood ITP simply goes away because the body cures itself. Therefore a child with few symptoms may be given no treatment at all. Statistically, 85-90% of children with ITP will return to a normal platelet count (150-400) within a year of developing it. For some children, however, it may not go away of its own accord and a parent and consultant will need to decide on the best possible course of action. A chronic sufferer is defined as one who has had the disorder for a year or more.

### What is the treatment?

The first option is usually 'watch and wait' unless symptoms are very severe. If drugs are prescribed, the two most frequently used are:-

**Steroids:** Prednisolone or some related drug can be given by mouth for a short period (2 to 3 weeks) and this can slow down the destruction of the platelets. Steroids may also stabilise the blood vessels, reducing the risk of bleeding.

**Intravenous immunoglobulin:** This is drip fed directly into the vein during a stay in hospital lasting up to 5 days. Immunoglobulin blocks the destruction of the platelets by the immune system.

### Does treatment work?

There is no treatment yet which actually cures ITP. Your doctor or consultants main concern at this stage will be to try to raise the platelet count to an acceptable level, keeping your child out of danger from excessive bleeding.

### What should I do if it doesn't work?

Drugs which work well for one child may not work as well for another. It may take a while, therefore, for the best course of treatment or its dosage level to

be determined. During this time try not to become impatient if your child does not recover quickly, for providing you ensure that your child is safeguarded from contact sports or falls which cause excessive bleeding, the child should be able to follow their normal life as much as possible.

### Are there any risks from treatment?

Most drugs cause side effects to a lesser or greater degree. Side effects should be noted and if they become serious inform your child's consultant. Steroids can cause mood changes ranging from euphoria to irritability; they can cause weight gain, roundness in the face and neck and irritation of the stomach. There is also an increased risk of infection, colds and flu, etc. Long term use of steroids should be avoided as there are more serious side effects, including stunting of growth. The dosage given by the doctor or consultant will therefore be carefully determined to try to avoid such problems. Children who receive immunoglobulin may experience temporary headaches, nausea, light headedness, shakes and shivers or a slight fever. If symptoms are severe anti-histamine and cortisone can be given prior to the next treatment. Very rarely, a child can be allergic to immunoglobulin and treatment will have to be discontinued.

### What is a splenectomy?

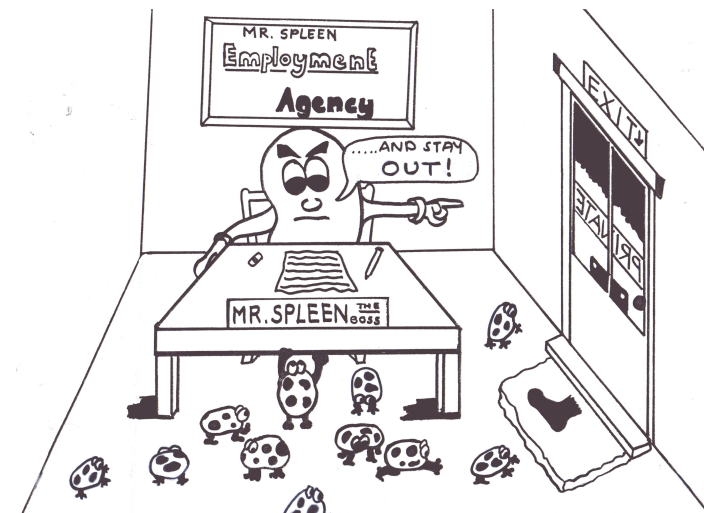
A splenectomy is the surgical removal of the spleen. It is rarely undertaken in children as having no spleen gives a lifelong risk of overwhelming infection. Splenectomy is only ever performed in chronic cases where a child has severe symptoms and refractory to other treatment. It is effective in about 60-70% of cases. Remember that many children get better within a year, so removing the spleen is only done when everything else has been tried.

### Why remove the spleen?

The spleen is an organ which filters out 'foreign' or waste materials from the blood. Healthy platelets normally pass through the spleen unmolested, but with ITP patients the platelets become coated with 'antibodies'. These fool the spleen into believing that they are foreign to the body and need to be removed. It is also thought that the spleen might be partially responsible for coating the platelets with antibodies in the first place.

### What are the risks of a splenectomy?

Splenectomy is rarely performed in children as it increases the risk of certain types of infection. A child without a spleen will then need to take long term antibiotics by mouth and be vaccinated against pneumococcus and haemophilus influenzae.



### Should I restrict my child's life style?

Try to let your child live as normal a life as possible, but remember that activities which involve energetic body contact, aggressive sports, or a fall from any height should be avoided. Sports protective clothing, such as knee pads, should be worn where appropriate, and if your child rides a bicycle, it is essential that a crash helmet is worn.

### Will ITP affect my child's life span?

It is extremely unusual for a child to suffer a life-threatening bleed in ITP. The vast majority of children and adults with ITP lead a normal if partially restricted life.