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About ITP & The ITP Support Association

The ITP Support Association
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What does ITP stand for?

Immune Thrombocytopenic Purpura! An autoimmune disorder (Immune) causing a shortage of platelets (Thrombocytopenic) and bruising (Purpura).

What is ITP?

A disorder in which the body's immune system destroys platelets in the blood, but unlike autoimmune diseases such as rheumatoid arthritis and MS it is not progressive but the risk of serious bleeding exists from the day the disease develops. This frightening rare condition can arise in anyone at any age, and there are only three to four thousand people with ITP in the UK. Its symptoms vary from one sufferer to another but include nose bleeds, mouth blisters, heavy periods, large multi colour bruises and, on rare occasions, spontaneous bleeding into major organs. Treatments, which all have their dangers and drawbacks, only temporarily raise the platelet count, but do not cure the disease.

What is the difference between ITP and hæmophilia?

Hæmophilia is inherited and permanent, ITP is not inherited, and can go into remission. Hæmophilia patients are deficient in one of the 12 factors which act together to form the clot. ITP patients are short of platelets which work independently as the initial plug to stop blood leakage, but the rest of the clotting mechanism works normally. Platelet infusions are only used in emergencies as transfused platelets, like the patient's own platelets, are destroyed by their immune system in a matter of hours.

Is ITP contagious?

No it is not caught and can not be passed on. For most people there is no known cause, although for some it follows a simple viral infection such a cold and it has a slightly higher incidence in pregnancy. It can also arise whilst taking some medications or following vaccinations, and is a secondary condition to certain other illnesses.

Why is research into ITP necessary?

We are funding clinical and data research to try to discover the possible causes of ITP, who is at risk of developing it, to predict the course of the disease and its most effective treatments. Our latest project is to fund a much needed Childhood ITP Registry - when a similar scheme was undertaken for childhood leukaemia, the survival rate increased enormously.

What is the Association's mission?

To promote the welfare of ITP patients, fund clinical research and to collaborate with the medical profession in collating and disseminating clinical data. The Association provides patient support, publishes numerous booklets and factsheets on ITP related subjects in addition to its quarterly journal, *The Platelet*, organises annual conventions, and seminars for health professionals.

How are we funded?

The Association is funded entirely by voluntary donations from ITP families, the general public, fundraising events organised by 'friends' of The ITP Support Association and from profits made by sales of Christmas cards and logo items. We receive sponsorship from several drug companies (without compromising our impartiality) to assist with costs of our quarterly journal *The Platelet*, annual Patient Conventions and Medical Seminars for Health Professionals.

What do we spend your donations on?

We welcome donations which are used to fund much needed clinical and data research, on materials and office equipment to print our numerous booklets and factsheets 'in house' and to mail out information packs to sufferers and their families, schools and health professionals.

How much is spent on fundraising?

Nothing, Nor do we employ fundraisers. We are grateful to ITP sufferers, family members and friends of the Association who fundraise on our behalf.

When was our organisation established?

The ITP Support Association, charity registration number is 1064480, was founded in 1995 by the mother of a child with ITP. It is the only UK charity for ITP patients, and we were the first dedicated ITP group to be established worldwide. ITP organisations have since been formed in the US, Holland, Germany, Denmark and Sweden.

Who runs the Association?

The Association has just one part-time assistant administrator but is primarily run by volunteers from their own, or the chief administrator's home where the ITP office is situated. Our honorary president, trustees, volunteers and medical advisors are listed overleaf.