



The ITP Support Association

About ITP & The ITP Support Association

REGISTERED CHARITY NO 1064480

ABOUT ITP

What does ITP stand for?

Immune Thrombocytopenia – an autoimmune disorder (Immune) causing a shortage of platelets (Thrombocytopenia). It was previously known as Idiopathic Thrombocytopenic Purpura (idiopathic means of unknown cause, purpura means bruising). Both names are used interchangeably.

What is ITP?

A disorder in which the body's immune system destroys platelets in the blood. 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 a blood 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 can be a secondary condition to certain other illnesses.

ABOUT THE ITP SUPPORT ASSOCIATION

Who runs the Association?

The Association is run primarily by volunteers from their own homes, with 2 part-time employees assisting the (volunteer) chief executive with office administration.

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 offers patient support, provides numerous publications and a quarterly journal, organises annual patient conventions and occasional seminars for health professionals, and periodically runs surveys of its membership with the aim of educating doctors and drug companies on patient concerns.

How are we funded?

The Association receives no state funding and relies on membership subscriptions, voluntary donations from people with an interest in ITP, fundraising events organised by 'friends' of The ITP Support Association, contributions from The Charity Shop in Gt Yarmouth, Norfolk, and from profits made by sales of logo items. We receive grants from several drug companies (without compromising our impartiality) to assist with costs of our quarterly journal, Patient Conventions, Medical Seminars for Health Professionals, and to employ a part-time assistant administrator.

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?

We do not employ fundraisers but rely on the generosity of 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 was the first dedicated ITP group to be established worldwide. ITP organisations and networking groups have since been formed in the USA, Holland, Germany, Denmark, Finland, Italy, Spain, Sweden, Australia and China.

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Derek Elston FRICS

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Volunteers

Shirley Watson MBE (Chief Executive)

Michael Levy FCA (Treasurer)

Howard Anderson (Website Manager)

Anthony Heard (Communications Administrator)

Derek Elston (Group Liaison Officer)

Rhonda Anderson (Advice & Friend Service)

Dave Farrow (Advice & Friend Service)

Frank Watson (Building and Contents Maintenance)

Paid staff (part-time)

Liz Gooch (Fundraising Co-ordinator)

Natalie Baylis (Office Services)

Medical Advisory Panel

Professor Adrian Newland CBE, MA FRCP FRCPath
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