



ITP Support Association

Confidential Survey 2007 for adults and children with ITP

Please return your completed questionnaire to the address below to receive a **complimentary pack of ten ITP Christmas cards**.
Research is vital if we are to help those with ITP, it will only take a few minutes to fill in. This form is downloadable from the website, www.itpsupport.org.uk

Please return this questionnaire to the address on the last page as soon as possible and not later than 31st October 2007.
 Thank you.

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|--|--|
| <p>If it is your child who has ITP please encourage them to complete the questionnaire on their own. If answering on behalf of a child then please try to answer as they would have done about their ITP.</p> | <p style="text-align: center;">Details of person with ITP:</p> <p>Name _____</p> <p>Date of Birth Day Month Year <input type="text"/> <input type="text"/> <input type="text"/></p> <p>Gender Male Female <input type="text"/> <input type="text"/></p> <p>Duration of ITP <input type="text"/> Years or <input type="text"/> Months</p> <p>Most recent platelet count. <input type="text"/></p> <p>If you are completing this form on behalf of a child please <input type="text"/> state your relationship to the child:</p> |
| <p>Wording</p> <p>Never = none of the time</p> <p>Rarely = almost none of the time</p> <p>Sometimes = once in a while</p> <p>Often = almost all of the time</p> <p>Always = all of the time</p> | |
| <p>All responses to this questionnaire will be treated in the strictest confidence.</p> | |

| Please underline or circle the answers | | | | | |
|---|--------------------------------------|---|-----------|-------|--------|
| 1. Do you tell your friends about your ITP? | Never | Rarely | Sometimes | Often | Always |
| 2. How often do you have bruises? | Never | Rarely | Sometimes | Often | Always |
| 3. How often do you have bleeding? | Never | Rarely | Sometimes | Often | Always |
| 4. What type of bleeding or bruising have you had in the last month? Please score each between 0 (none) to 4 (very bad) <u>or</u> circle yes or no after "I am in remission". | Bruising <input type="text"/> | Blood in urine <input type="text"/> | | | |
| | Nose bleeds <input type="text"/> | Heavy periods <input type="text"/> | | | |
| | Mouth bleeds <input type="text"/> | Other <input type="text"/> <input type="text"/> | | | |
| | Blood in stool <input type="text"/> | I am in remission : yes no | | | |
| 5. Do you try to hide your bruises? | Never | Rarely | Sometimes | Often | Always |
| 6. Does the bruising ever stop you from going out? | Never | Rarely | Sometimes | Often | Always |
| 7. Does your ITP ever stop you going to work or school? | Never | Rarely | Sometimes | Often | Always |
| 8. How many days have you missed in the last six months because of:- | Bleeding <input type="text"/> | Drug side effects <input type="text"/> | | | |
| | Bruising <input type="text"/> | Other <input type="text"/> <input type="text"/> | | | |
| | Hospital visits <input type="text"/> | | | | |

| | | | | | |
|---|-------|--------|-----------|-------|--------|
| 9. Are people ever suspicious that the bruises are a result of physical violence? | Never | Rarely | Sometimes | Often | Always |
|---|-------|--------|-----------|-------|--------|

10. If so, who has been suspicious or commented adversely about your bruises? Please underline or circle the answers.

Stranger Family Friends Teacher Doctor No-one Other

Please provide examples of comments or further details at the end of questionnaire:

| | | | | | |
|--|-------|--------|-----------|-------|--------|
| 11. I get bothered because I can not do the activities I like. | Never | Rarely | Sometimes | Often | Always |
|--|-------|--------|-----------|-------|--------|

12. What activities are you unable to do? Please underline or circle the answers.

Football Rugby Swimming Go out with friends Go on holiday Other

13. If unable to do an activity, why? Please underline or circle the answers.

Low platelet count Too much bruising Fear of bleeding Other

14. Where have you had advice about what activities you can do? Please underline or circle the answers.

Hospital Doctor GP ITP Support Association Internet Other

| | | | | | |
|--|-------|--------|-----------|-------|--------|
| 15. I am concerned that I do not know enough about my ITP. | Never | Rarely | Sometimes | Often | Always |
|--|-------|--------|-----------|-------|--------|

| | | | | | |
|---|-------|--------|-----------|-------|--------|
| 16. I was concerned that my hospital doctor did not know enough about my ITP. | Never | Rarely | Sometimes | Often | Always |
|---|-------|--------|-----------|-------|--------|

Q17 to Q22. Which of the following have been helpful in providing information and help about ITP

| | | | | | |
|---|-------|--------|-----------|-------|--------|
| 17. My hospital doctor when the ITP was first diagnosed | Never | Rarely | Sometimes | Often | Always |
|---|-------|--------|-----------|-------|--------|

| | | | | | |
|--------|-------|--------|-----------|-------|--------|
| 18. GP | Never | Rarely | Sometimes | Often | Always |
|--------|-------|--------|-----------|-------|--------|

| | | | | | |
|-----------------------------|-------|--------|-----------|-------|--------|
| 19. ITP Support Association | Never | Rarely | Sometimes | Often | Always |
|-----------------------------|-------|--------|-----------|-------|--------|

| | | | | | |
|--------------|-------|--------|-----------|-------|--------|
| 20. Internet | Never | Rarely | Sometimes | Often | Always |
|--------------|-------|--------|-----------|-------|--------|

| | | | | | |
|--------------------|-------|--------|-----------|-------|--------|
| 21. ITP Specialist | Never | Rarely | Sometimes | Often | Always |
|--------------------|-------|--------|-----------|-------|--------|

| | | | | | |
|--------------------------------|-------|--------|-----------|-------|--------|
| 22. Other <input type="text"/> | Never | Rarely | Sometimes | Often | Always |
|--------------------------------|-------|--------|-----------|-------|--------|

| | | |
|--|--------------------------|----------------------------|
| 23. Referring only to Q17, my hospital doctor was an:- | Adult Haematologist | A&E doctor |
| | Paediatric Haematologist | Adult non-haematologist |
| | Paediatrician | Other <input type="text"/> |

| | | |
|------------------------------------|--------------------------|--------------------------------|
| 24. My current ITP specialist is:- | Adult Haematologist | I have never seen a specialist |
| | Paediatric Haematologist | Other <input type="text"/> |
| | Paediatrician | Don't know |

| | | | | |
|--|-------|-------------------|---------------------|--------------|
| 25. How often would you like to see an ITP specialist? | Never | At diagnosis only | After 6 months only | All the time |
|--|-------|-------------------|---------------------|--------------|

26. How far would you be prepared to travel to see a specialist? miles or hours

| | | | | | |
|---|-------|--------|-----------|-------|--------|
| 27. Have you ever been refused a referral to an ITP specialist or hospital of your choice? | Yes | No | | | |
| 28. Do you have difficulty getting dental work done because of ITP? | Never | Rarely | Sometimes | Often | Always |
| 29. Have you had surgery (other than splenectomy for ITP) postponed or delayed because of a low platelet count? | Yes | No | | | |
| 30. Have you had difficulty obtaining or been refused insurance? Please underline or circle | | | | | |
| Travel insurance Life insurance Other <input type="text"/> | | | | | |
| 31. Have you been unable to have a tattoo or body piercing because of ITP? | Yes | No | | | |
| 32. Are you currently receiving medication from your doctor for ITP | Yes | No | | | |
| 33. Is your doctor giving you treatment because : | | | | | |
| Your symptoms are troublesome, Your platelet count is low, Don't know | | | | | |
| 34. Have you ever taken prescribed drugs for your ITP. | Yes | No | | | |
| 35. If yes, were you concerned about possible side effects of drug treatment? | Yes | No | | | |
| 36. Have you ever tried alternative therapies or vitamin & mineral supplements for your ITP? | Yes | No | | | |
| 37. If yes were you concerned about possible side effects of alternative therapies or supplements? | Yes | No | | | |
| 38. Did the onset of your ITP appear to follow a viral infection (i.e. within 14 days)? | Yes | No | | | |
| 39. If yes, which virus did you have? <input type="text"/> | | | | | |
| 40. Does your ITP have an impact on other members of your family? | Never | Rarely | Sometimes | Often | Always |
| 41. Have you been bothered by tiredness or fatigue that you attribute to your ITP? | Never | Rarely | Sometimes | Often | Always |
| 42. Have you ever been unable to go to work or school because of tiredness and fatigue? | Never | Rarely | Sometimes | Often | Always |
| 43. Do you live in:- England, Scotland, Wales, Northern Ireland, Other <input type="text"/> | | | | | |

Signature _____ Date _____

Please return this questionnaire as soon as possible and not later than 31st October 2007 to the address on the next page. Thank you.

PTO

Please provide any supplementary information or comments here or on additional pieces of paper.

Include anything you consider would be of help in the understanding of ITP and its effect on you, including side effects of treatment or any aspect not covered above.

Privacy notice.

All names or other forms of personal identification will be permanently removed before the overall results of this survey are published in the Platelet and on the website. Survey results **only** will be passed to clinicians and drug companies. No identifiable personal details will be available anywhere outside of the ITP Support Association. We comply with all the requirements of the Data Protection Acts.

The cost of sending ITP Christmas cards to those who respond has been kindly sponsored by Jays Refractory Specialists Ltd.

To receive your complimentary pack of assorted ITP Christmas cards please add your name and address at the right.
(Your cards will be mailed out in early Nov.)

We can offer 3 packs of 3 blank cards to people for whom Christmas cards are not acceptable on religious grounds. (Sorry, we can only make these available to those with religious objections because of limited stock). Please tick here if you wish to receive blank greetings cards.

Please return this questionnaire as soon as possible and by 31st October 2007. Thank you.

Send to:-
The ITP Support Association
"Synehurste"
Kimbolton Road
Bolnhurst
Bedfordshire
MK44 2EW
United Kingdom

Your details:-

Name _____

Address _____

Postcode _____ Country _____