

Survey of Non-traditional Treatments of ITP Preliminary Results

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Last year PDSA in collaboration with Dr. James Bus-
sel of the Weill Medical Center of Cornell University ini-
tiated the Survey of Non-traditional Treatments of ITP.
While non-traditional treatments (those not usually pre-
scribed by hematologists) have been used in treating the
disease, only anecdotal evidence supports this use. Our
survey is the first comprehensive effort to examine and
compare the efficacy of the non-traditional and tradi-
tional treatments for ITP.

The Survey instrument was developed during the
spring and summer of 2001 and published to the PDSA
website in August 2001. The data-gathering phase was
completed at the end of December last year. Because this
was an Internet survey, the responses were not medically
verified and there were no controls. The reported treat-
ment experiences were results that the patients associated
with the treatments. The results experienced may have
been the result of the treatments, other medications being
used concurrently, diet, time, and other unidentified as-
pects of the patient's lives. These results are preliminary
as we continue to examine the data. Some of the prelimi-
nary data was posted to the web site during May 2002.

The survey consisted of 57 multi-part questions. In
addition to gathering personal data (not required) and
data on medical condition, the survey also asked ques-
tions regarding the patient's treatment philosophy. The
survey listed 31 specific treatments and provided 14 op-
portunities for people to write in treatments they had used
or were currently using but which were not listed in the
survey. The survey and preliminary results can be
viewed at <http://www.itppeople.com/surveyres/>.

There were 916 responses for cases of ITP in 546
(60%) female adults, 187 (21%) male adults, 85 (9%)
female children, and 91 (10%) male children (7 did not
indicate gender). Seven hundred thirty five were from
the United States and 150 from 33 foreign countries (31
did not indicate country of origin). Almost 65% of adult
respondents were diagnosed with ITP between the ages of
10 and 40 years of age. Just fewer than 9% were diag-

nosed before the age of 10, 18% between the ages 40 and
55, and about 8% were not diagnosed with the disease
until over the age of 55.

The survey assessed the change in overall medical con-
dition between diagnosis and the time of the survey in
two ways. First, the survey asked patients to report symp-
toms at the worst and currently or at the time of the sur-
vey. Secondly, patients reported platelet count at diagno-
sis and the time of the survey. Respondents reported on
bruising, fatigue, increased menstrual flow, general
bleeding, bleeding in the mouth, and petechiae. In all
categories there was a significant improvement
(reduction) in symptoms from diagnosis to the time of the
survey ranging from a reduction of 30% in reported fa-
tigue to a 78% reduction in reported general bleeding.
Forty percent reported normal bleeding at the time of the
survey.

Reported platelet counts also indicate a much-
improved ITP patient population. Almost 50% of the
patients responding reported a platelet count at diagnosis
of less than 10K. Less than 15% were over 50K and only
2.3% (21 individuals) reported a count over 90K. At the
time of the survey, only 7% reported a platelet count less
than 10K. More than 63% reported counts greater than
50K with 44% reporting greater than 90K and almost
26% reporting greater than 150K. By the two measures
employed in the survey, the ITP patients responding were
significantly improved at the time of the survey.

The survey respondents reported both widespread use
and effectiveness of the non-traditional treatments in both
increasing platelet count and alleviating symptoms.
More than 82% of respondents reported using or having
tried using one or more non-traditional treatments while
94% reported using or having tried using one or more
traditional treatments. There was no significant variation
by age and gender in the percentage of respondents using
both traditional and non-traditional treatments. While a
higher percentage of respondents reported using tradi-
tional treatments, the average number of traditional treat-

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ments currently being used per respondent was 0.56 compared with 1.65 treatments per respondent for non-traditional treatments. In other words, the non-traditional treatments were being currently used at about three times the rate that traditional treatments were being currently used.

The efficacy of the most used treatments both traditional and non-traditional is highlighted in Table 1 below. The four most reported non-traditional treatments, vitamin C, prayer, positive thinking, and meditation, accounted for 48.4 % of the non-traditional treatment experiences reported. The four most reported traditional treatment experiences, excluding splenectomy; prednisone, IVIG, Anti-D, and danazol, accounted for 77 % of the reported traditional treatment experiences.

Table 1 highlights a key finding of the survey. For the four most used treatments in each treatment category, excluding splenectomy, the reported

efficacy of the traditional treatments is greater in restoring normal bleeding and in providing some benefit in raising platelet count. But the reported efficacy of the non-traditional treatments is greater than the traditional treatments in being associated in a higher percentage of treatment experiences with a sustained benefit in platelet count. The greatest difference between the two types of treatments is in reported side effects. Seventy percent of the reported treatment experiences with traditional treatments reported some side effects with over 20% reported to be severe. Only 6% reported any side effects with the non-traditional treatments and just over 1% were reported to be severe.

Table 2 shows the reported results for the four most effective treatments in each treatment category. The traditional treatments are reported more effective in controlling bleeding symptoms than the non-traditional treatments. Also in raising platelet counts, the traditional treatments were re-

ported to provide some effect in a higher percentage of reported cases than the non-traditional. However, in sustained effect in raising platelet count, the non-traditional were reported effective in a higher percentage of cases than the traditional treatments.

The survey included a series of questions addressing patient philosophy regarding approach to treatment, relationship with the hematologist, and future treatment choices, i.e., to treat or not treat, to use traditional or not, to use non-traditional or not. Interesting was the finding that only 67% of the patients who used non-traditional therapies told their hematologist and of those 58% reported that their hematologist was supportive. Fourteen percent reported giving up on traditional therapies working and 7% on non-traditional ones. Just under one-third were living with their current count and 37% were going to keep trying traditional treatments while 42% indicated that they would continue trying

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TABLE 1
Four Most Used Treatments in Each Category

Treatment	Number Used or Tried	Platelets		Bleeding		Side Effects	
		% Some Benefit	% Sustained Benefit	%Some Benefit	%Normal Bleeding	Some Percent	Severe
Traditional							
Splenectomy	326	69.63	40.80	65.44	39.76	43.56	4.91
Prednisone	693	82.40	19.34	72.87	33.19	92.21	37.66
Ivig	476	84.66	18.07	72.69	37.18	57.35	11.55
Anti-D	248	71.77	8.47	55.65	22.98	51.61	10.89
Danazol	130	54.62	13.85	53.85	18.46	76.15	20.77
Total		293.45	51.26	255.06	111.81	277.32	80.87
Average		73.36	12.82	63.77	27.95	69.33	20.22
Non-Traditional							
Vitamin c	439	34.85	10.48	32.35	11.16	7.52	1.82
Prayer	374	48.66	24.87	49.20	24.33	4.28	1.34
Positive thinking	345	41.45	19.42	43.77	18.84	6.07	1.73
Meditation	103	43.69	14.56	43.69	16.50	4.85	0.00
Total		168.65	69.33	169.01	70.83	22.72	4.89
Average		42.16	17.33	42.25	17.71	5.68	1.22

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non-traditional therapies. Satisfaction with traditional treatments was 26% and with non-traditional it was 17%.

This study raises more questions than it can answer. Prospective, monitored, controlled trials are required to demonstrate the efficacy of the non-traditional treatments and to develop effective treatment strategies. The non-traditional treatments could work in conjunction with the traditional treatments to maintain safe platelet counts. This might allow for fewer splenectomies as well as fewer side effects and lower costs associated with treatment. The non-traditional treatments alone or in conjunction with traditional treatments may serve to “buy time” for the chronic ITP patient to permit the slow healing that appears to occur in many ITP patients. The study also demonstrates the need for the development of traditional treatments with curative effects and fewer side effects, especially fewer severe side effects.

Send questions or feedback to bfries@pdsa.org.

The *Platelet News* is published quarterly by the

Platelet Disorder Support Association

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TABLE 2
Four Most Effective Treatments in Each Category
Ranked on Percent of Some Benefit Increasing Platelets

Treatment	Number Used or Tried Using	Platelets		Bleeding		Side Effects	
		% Some Benefit	% Sustained Benefit	%Some Benefit	%Normal Bleeding	Percent Some	Severe
Traditional							
Splenectomy	326	69.63	40.80	65.44	39.76	43.56	4.91
Ivig	476	84.66	18.07	72.69	37.18	57.35	11.55
Prednisone	693	82.40	19.34	72.87	33.19	92.21	37.66
Anti-D	248	71.77	8.47	55.65	22.98	51.61	10.89
Cyclosporine	29	62.07	24.14	65.52	34.48	62.07	17.24
Total		300.90	61.55	266.73	127.83	263.24	77.34
Average		75.23	15.39	66.68	31.96	65.81	19.34
Non-Traditional							
Noni juice	26	61.54	23.08	53.85	19.23	0.00	0.00
Blood Well	31	61.29	22.58	61.29	35.48	0.00	0.00
Prayer	374	48.66	24.87	49.20	24.33	4.28	1.34
Moducare Sterinol	24	45.83	16.67	45.83	16.67	0.00	0.00
Total		217.32	87.20	210.17	95.71	4.28	1.34
Average		54.33	21.80	52.54	23.93	1.07	0.34