

Survey of Non-Traditional Treatments of ITP

Introduction

From August 2001 through December 2001, we collected 916 responses from our Survey of Non-traditional Treatments of ITP. This survey was created by James Bussel, MD of the Weill Medical Center of Cornell University and the staff of the Platelet Disorder Support Association (PDSA) and placed on the PDSA website to gather replies.

Note: In the survey, the term 'non-traditional' is synonymous with 'complementary.' The survey also collected data on 'traditional' (conventional) therapies for comparison.

(Since these results are from a web-based survey, there is no medical validation of the results. For advice on your unique medical condition, please consult your healthcare provider. No portion of these results may be reproduced without express written consent of PDSA.)

Demographics

- Age at diagnosis
- Gender
- Symptoms
- Platelet counts

Treatments

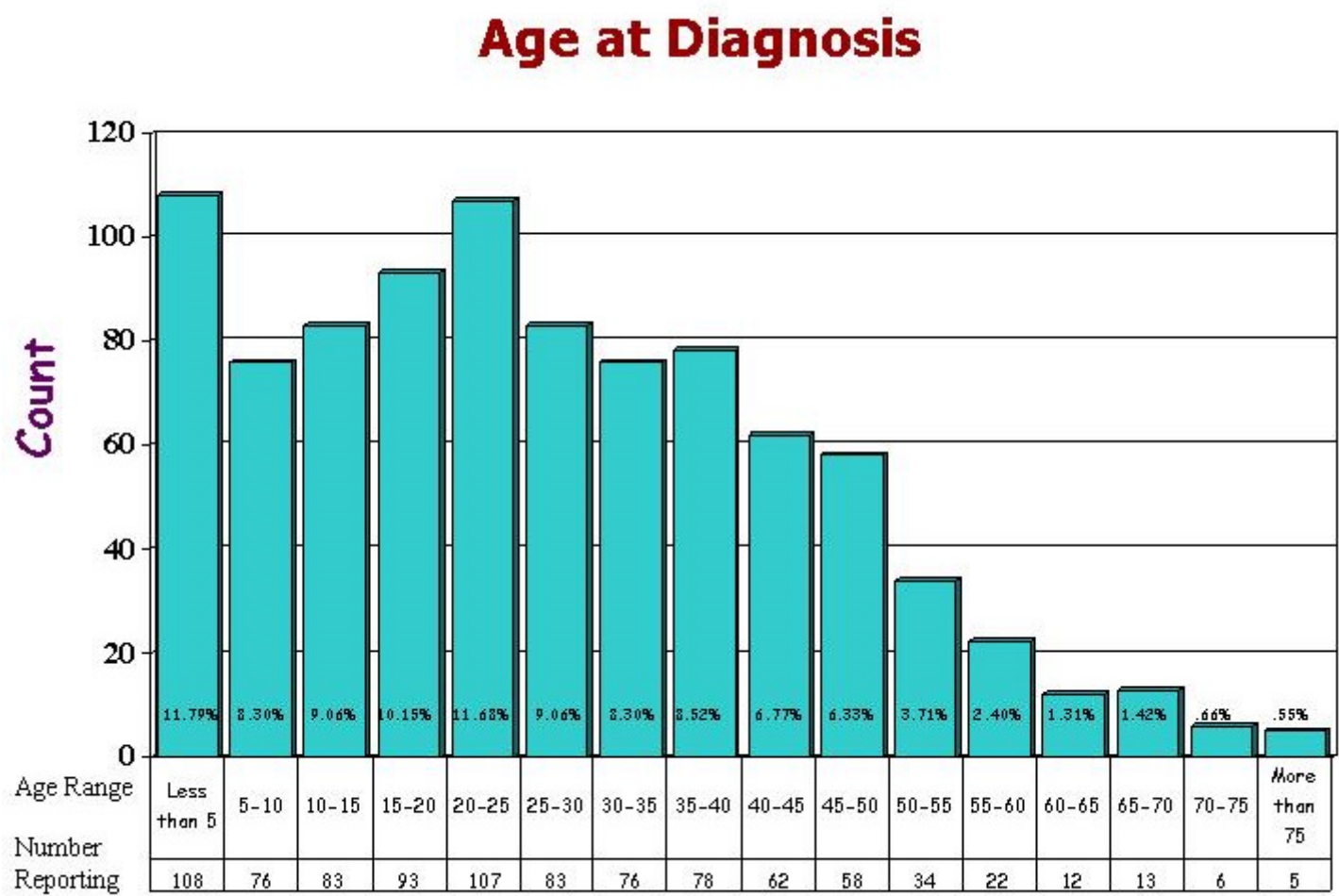
- Explanation of treatment result categories
- Result 1 - WinRho, Imuran, Colchicine, Prednisone
- Result 2 - Cytoxan, Cyclosporin, IVIG, Danazol
- Result 3 - Proscrba, Rituxan, Splenectomy, Vinca Alkaloids
- Result 4 - Acupressure, Acupuncture, Vit C, Vit K
- Result 5 - Moducare, Colostrum, Chlorophyll, Reiki
- Result 6 - Magnets, Healing Touch, Blood Well/Restore Immune, Macrobiotic
- Result 7 - Eat Right, Zone Diet, Atkins Diet, Weight Watchers
- Result 8 - Prayer, Meditation, Visualization, Psychotherapy, Positive Thinking

Treatment Approaches

- Individual treatment philosophy
- Hematologist communication
- Hematologist support

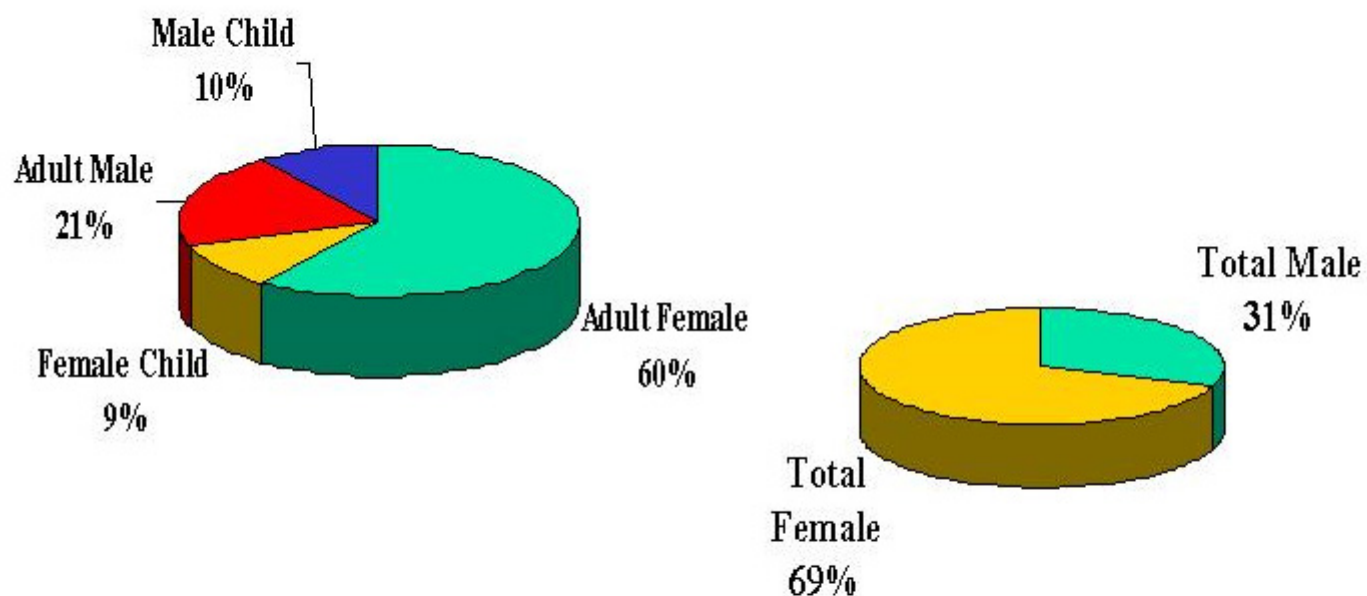
(PDSA and Cornell University are grateful to Albert Fries, John Shin and Liz Strom for their assistance)

Age at Diagnosis



Gender

Demographics - Gender



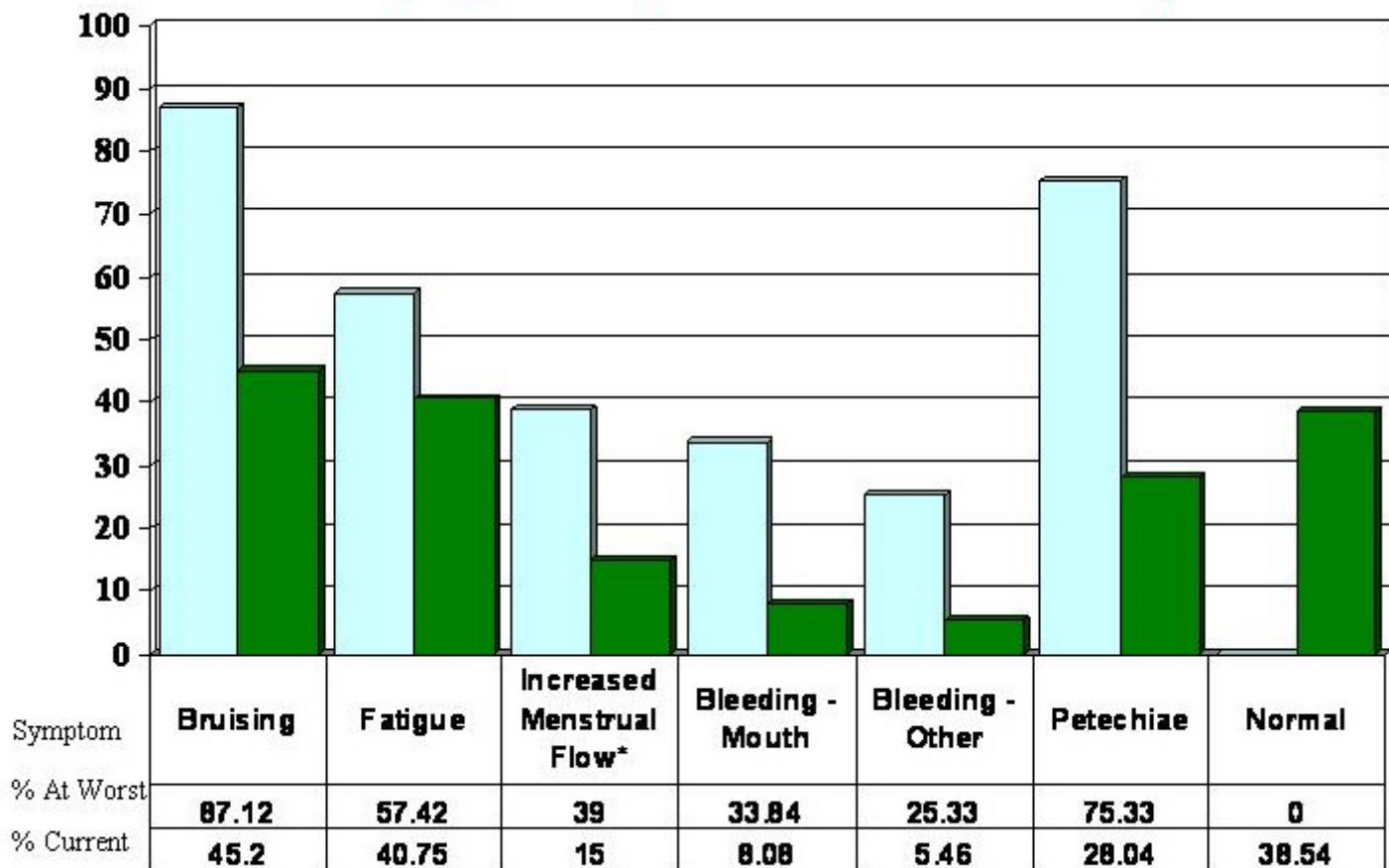
A TOTAL OF 916 RESPONSES

Without Gender Declaration - 5 Adults & 2 Children

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Symptoms

Symptoms (At Worst and Current)

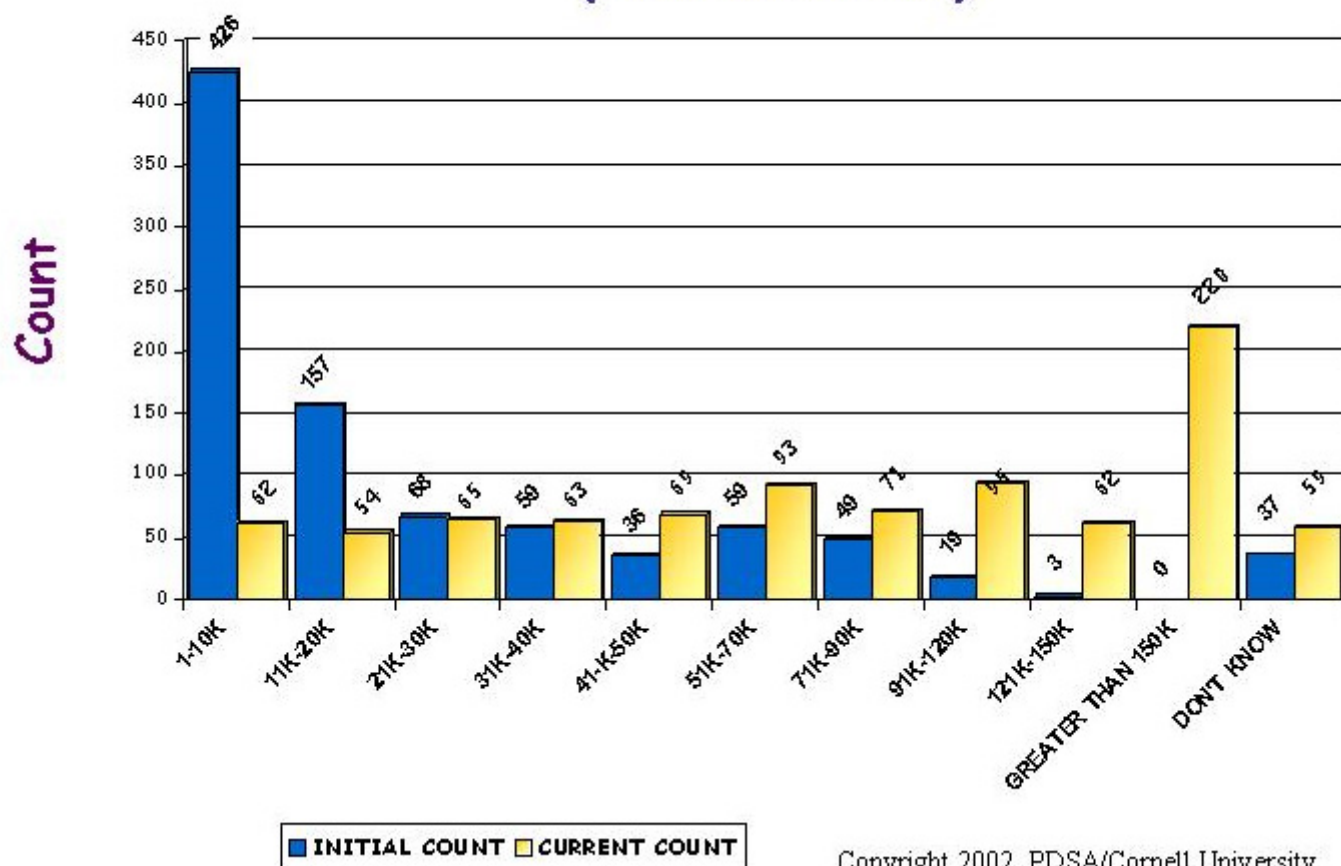


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* Female only

Platelet Counts

Platelet Counts (Initial and Current)



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Explanation of Treatment Result Categories

N - The number of people responding that answered "tried to use" or "currently using" for a particular treatment (Ns)

Platelets: some - The percent of Ns that answered "Moderate effect (had a moderate or short lived positive effect [on counts])" for a particular treatment or "Sustained effect (had a long term positive effect on counts) for a particular treatment

Platelets: sustained - The percent of Ns that answered "Sustained effect (had a long term positive effect on counts) for a particular treatment

Bleeding: some - The percent of Ns that answered "Some - Had some positive effect [on bleeding]" for a particular treatment or "Normal - Bleeding returned to normal" for a particular treatment

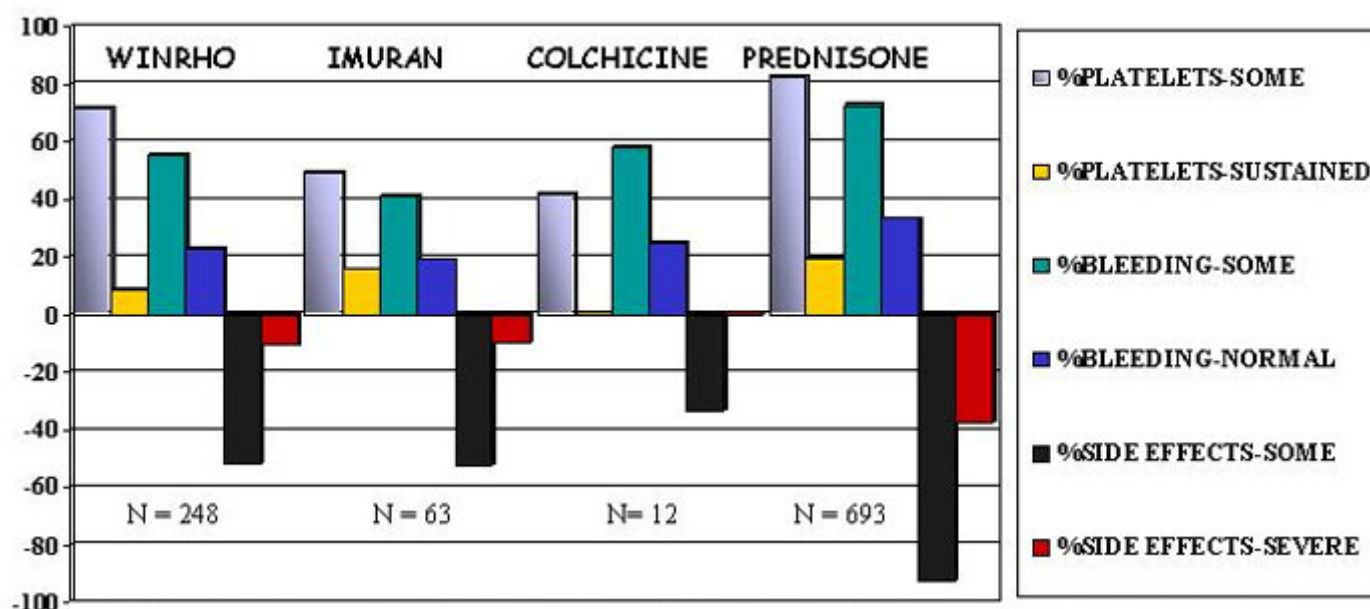
Bleeding: normal - The percent of Ns that answered "Normal - Bleeding returned to normal" for a particular treatment

Side Effects: some - The percent of Ns that answered " Mild - Minor and temporary side effects" or "Moderate - Difficult side effects" for a particular treatment or "Severe - Extreme side effects" for a particular treatment

Side Effects: severe - The percent of Ns that answered "Severe - Extreme side effects" for a particular treatment

Result 1 - WinRho, Imuran, Colchicine, Prednisone

Selected Treatment Results



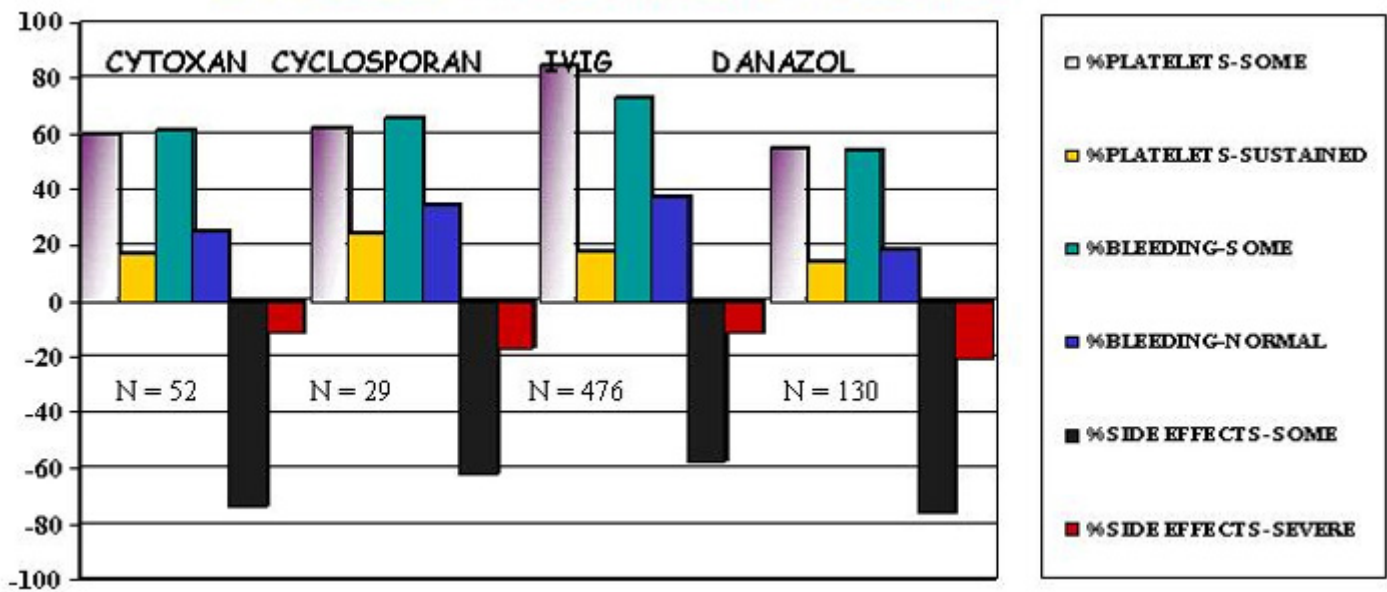
WinRho	27.07%	IMURAN	6.88%	COLCHICINE*	1.31%	PREDNISONE	75.66%
Platelets		Platelets		Platelets		Platelets	
› Some	71.77%	› Some	49.21%	› Some	41.67%	› Some	82.40%
› Sustained	8.47%	› Sustained	15.87%	› Sustained	0.00%	› Sustained	19.34%
Bleeding		Bleeding		Bleeding		Bleeding	
› Some	55.65%	› Some	41.27%	› Some	58.33%	› Some	72.87%
› Normal	22.98%	› Normal	19.05%	› Normal	25.00%	› Normal	33.19%
Side Effects		Side Effects		Side Effects		Side Effects	
› Some	-51.61%	› Some	52.38%	› Some	33.33%	› Some	92.21%
› Severe	-10.89%	› Severe	9.52%	› Severe	0.00%	› Severe	37.66%

* **NOTE:** Colchicine is no longer recommended for the treatment of ITP.

Learn more about Conventional Treatments

Result 2 - Cytoxan, Cyclosporine, IVIG, Danazol

Selected Treatment Results

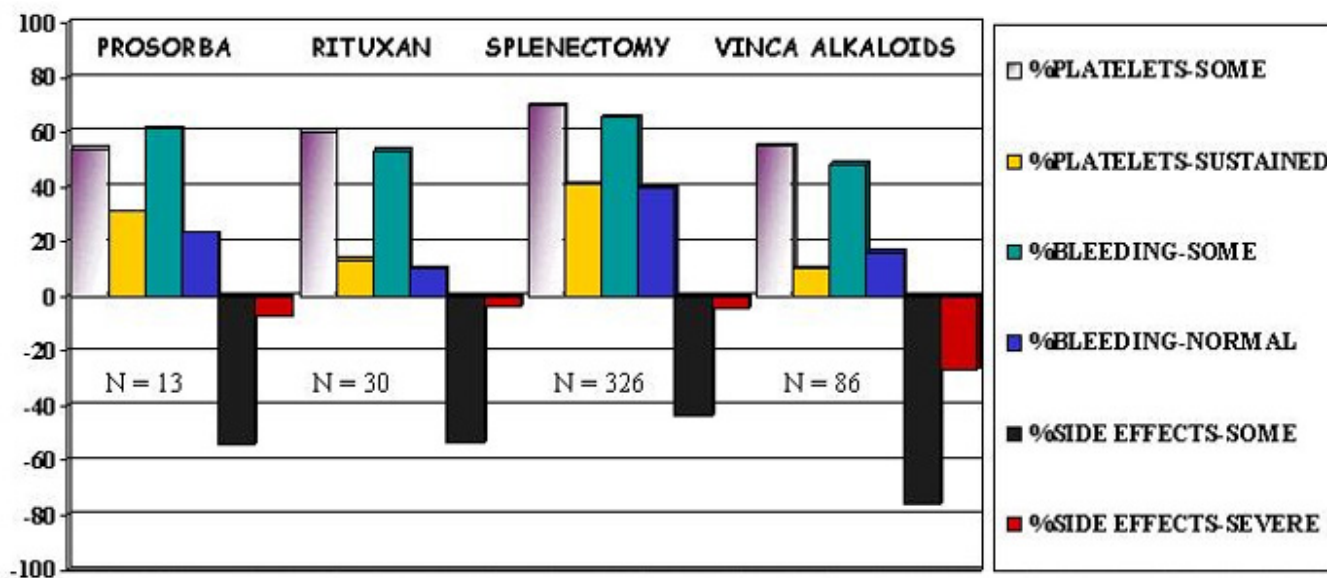


CYTOXAN	5.68%	CYCLOSPORINE	3.17%	IVIG	51.97%	DANAZOL	14.19%
Platelets		Platelets		Platelets		Platelets	
› Some	59.62%	› Some	62.07%	› Some	84.66%	› Some	54.62%
› Sustained	17.31%	› Sustained	24.14%	› Sustained	18.07%	› Sustained	13.85%
Bleeding		Bleeding		Bleeding		Bleeding	
› Some	61.54%	› Some	65.52%	› Some	72.89%	› Some	53.85%
› Normal	25.00%	› Normal	34.48%	› Normal	37.18%	› Normal	18.46%
Side Effects		Side Effects		Side Effects		Side Effects	
› Some	73.08%	› Some	62.07%	› Some	57.35%	› Some	76.15%
› Severe	11.54%	› Severe	17.24%	› Severe	11.55%	› Severe	20.77%

Learn more about Conventional Treatments

Result 3 - Prosorba, Rituxan, Splenectomy, Vinca Alkaloids

Selected Treatment Results



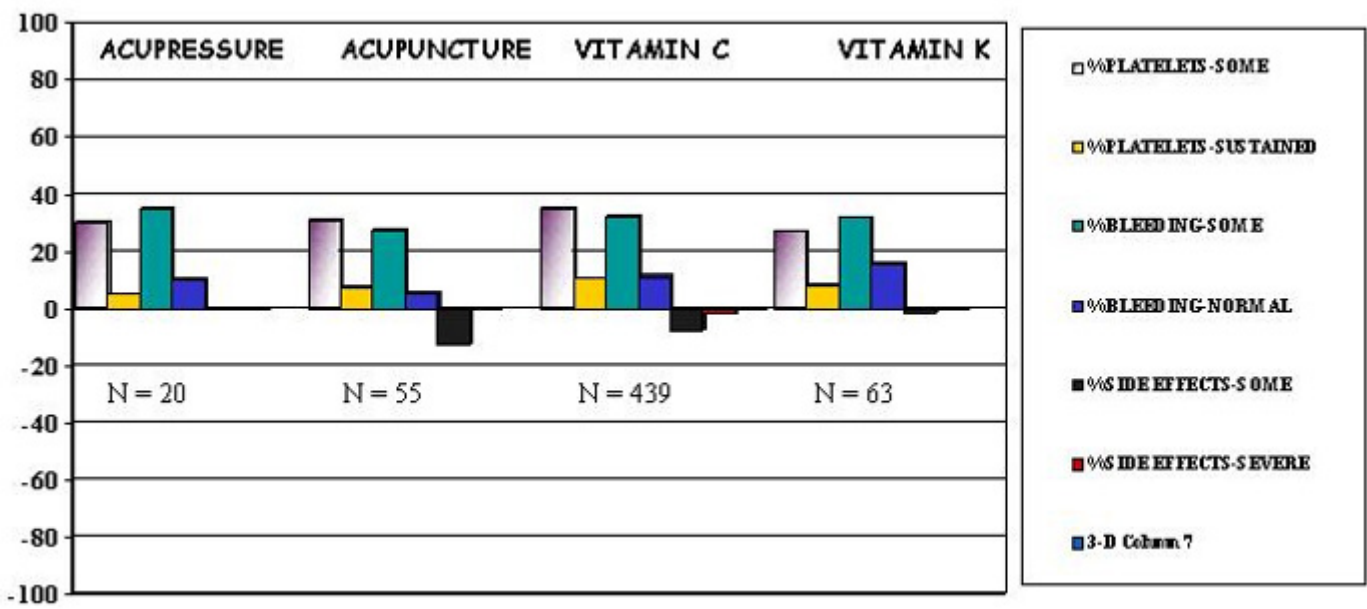
PROSORBA*	1.42%	RITUXAN	3.28%	SPLENECTOMY	35.63%	VINCA ALKALOIDS	9.40%
Platelets		Platelets		Platelets		Platelets	
› Some	53.85%	› Some	60.00%	› Some	69.63%	› Some	54.65%
› Sustained	30.77%	› Sustained	13.33%	› Sustained	40.80%	› Sustained	10.47%
Bleeding		Bleeding		Bleeding		Bleeding	
› Some	61.54%	› Some	53.33%	› Some	65.44%	› Some	48.28%
› Normal	23.08%	› Normal	10.00%	› Normal	39.76%	› Normal	16.09%
Side Effects		Side Effects		Side Effects		Side Effects	
› Some	53.85%	› Some	53.33%	› Some	43.56%	› Some	75.58%
› Severe	7.69%	› Severe	3.33%	› Severe	4.91%	› Severe	26.74%

* **NOTE:** The Prosorba Column is no longer recommended for the treatment of ITP.

[Learn more about Conventional Treatments](#)

Result 4 - Acupressure, Acupuncture, Vitamin C, Vitamin K

Selected Treatment Results

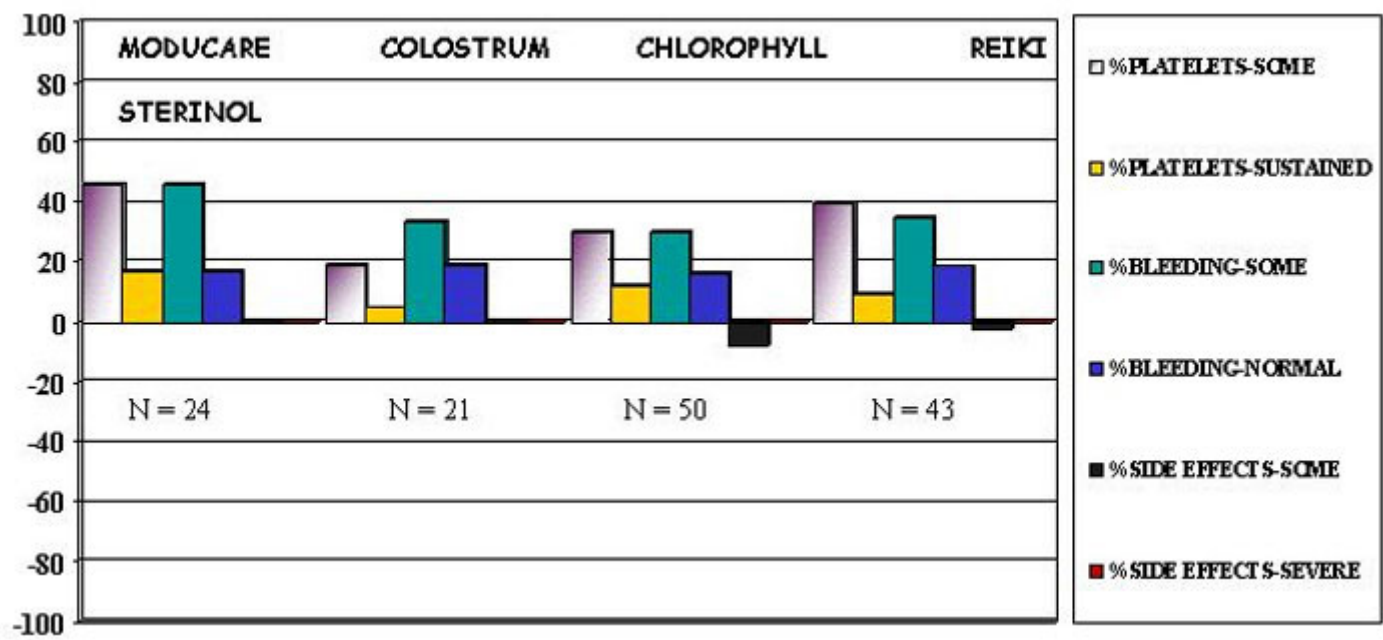


ACUPRESSURE	2.18%	ACUPUNCTURE	6.00%	VITAMIN C	47.93%	VITAMIN K	6.88%
Platelets		Platelets		Platelets		Platelets	
› Some	30.00%	› Some	30.91%	› Some	34.85%	› Some	26.98%
› Sustained	5.00%	› Sustained	7.27%	› Sustained	10.48%	› Sustained	7.94%
Bleeding		Bleeding		Bleeding		Bleeding	
› Some	35.00%	› Some	27.27%	› Some	32.35%	› Some	31.75%
› Normal	10.00%	› Normal	5.45%	› Normal	11.16%	› Normal	15.87%
Side Effects		Side Effects		Side Effects		Side Effects	
› Some	0.00%	› Some	12.73%	› Some	7.52%	› Some	1.59%
› Severe	0.00%	› Severe	0.00%	› Severe	1.82%	› Severe	0.00%

Learn more about Complementary Treatments

Result 5 - Moducare, Colostrum, Chlorophyll, Reiki

Selected Treatment Results

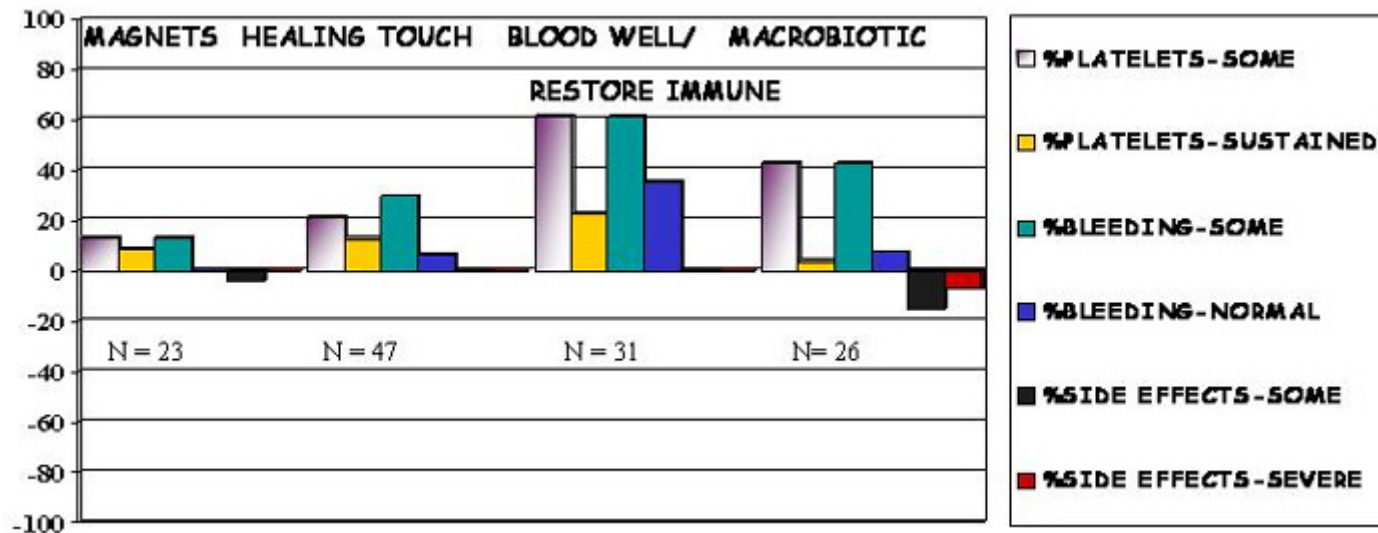


MODUCARE	2.62%	COLOSTRUM	2.29%	CHLOROPHYLL	5.46%	REIKI	4.70%
Platelets		Platelets		Platelets		Platelets	
› Some	45.83%	› Some	19.05%	› Some	30.00%	› Some	39.53%
› Sustained	16.67%	› Sustained	4.76%	› Sustained	12.00%	› Sustained	9.30%
Bleeding		Bleeding		Bleeding		Bleeding	
› Some	45.83%	› Some	33.33%	› Some	30.00%	› Some	34.88%
› Normal	16.67%	› Normal	19.05%	› Normal	16.00%	› Normal	18.60%
Side Effects		Side Effects		Side Effects		Side Effects	
› Some	0.00%	› Some	0.00%	› Some	8.00%	› Some	2.33%
› Severe	0.00%	› Severe	0.00%	› Severe	0.00%	› Severe	0.00%

Learn more about Complementary Treatments

Result 6 - Magnets, Healing Touch, Blood Well/Restore Immune, Macrobiotic

Selected Treatment Results

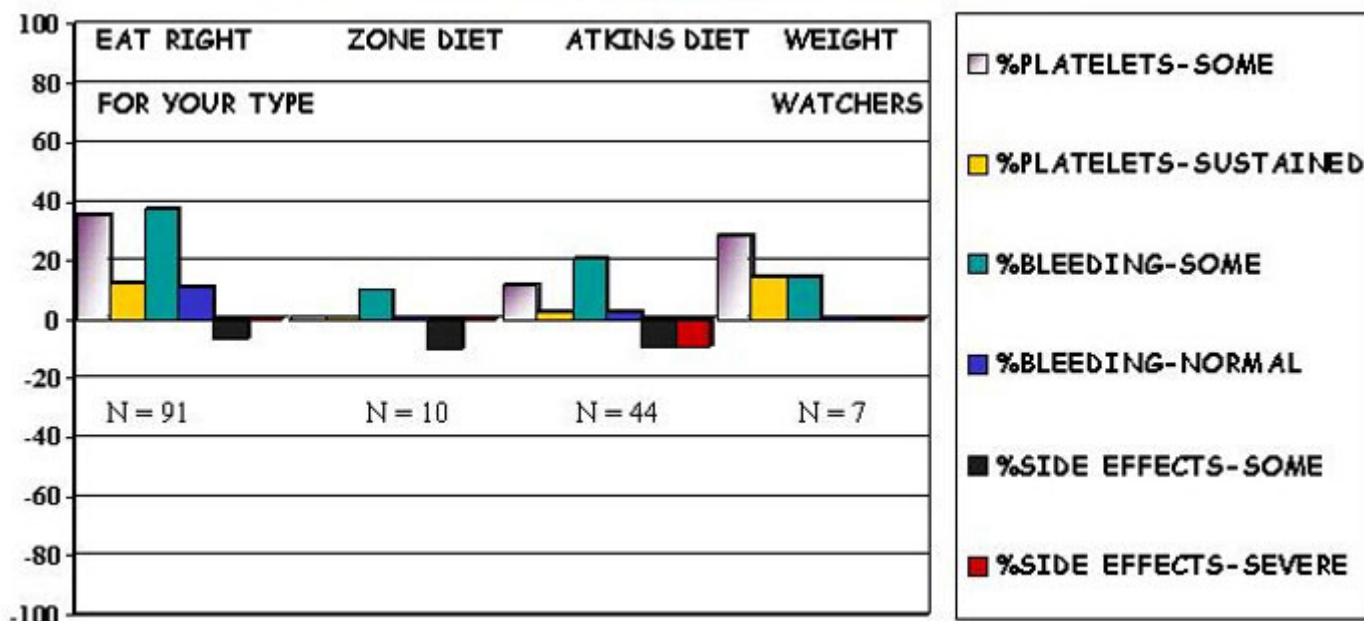


<u>MAGNETS</u>	2.51%		<u>HEALING TOUCH</u>	5.13%		<u>BLOOD WELL/RESTORE IMMUNE</u>	3.38%		<u>MACROBIOTIC</u>	2.84%
Platelets			Platelets			Platelets			Platelets	
› Some	13.04%		› Some	21.28%		› Some	61.29%		› Some	42.31%
› Sustained	8.70%		› Sustained	12.77%		› Sustained	22.58%		› Sustained	3.85%
Bleeding			Bleeding			Bleeding			Bleeding	
› Some	13.04%		› Some	36.17%		› Some	61.29%		› Some	42.31%
› Normal	0.00%		› Normal	6.38%		› Normal	35.48%		› Normal	7.69%
Side Effects			Side Effects			Side Effects			Side Effects	
› Some	4.35%		› Some	0.00%		› Some	0.00%		› Some	15.38%
› Severe	0.00%		› Severe	0.00%		› Severe	0.00%		› Severe	7.69%

Learn more about Complementary Treatments

Result 7 - Eat Right, Zone Diet, Atkins Diet, Weight Watchers

Selected Treatment Results

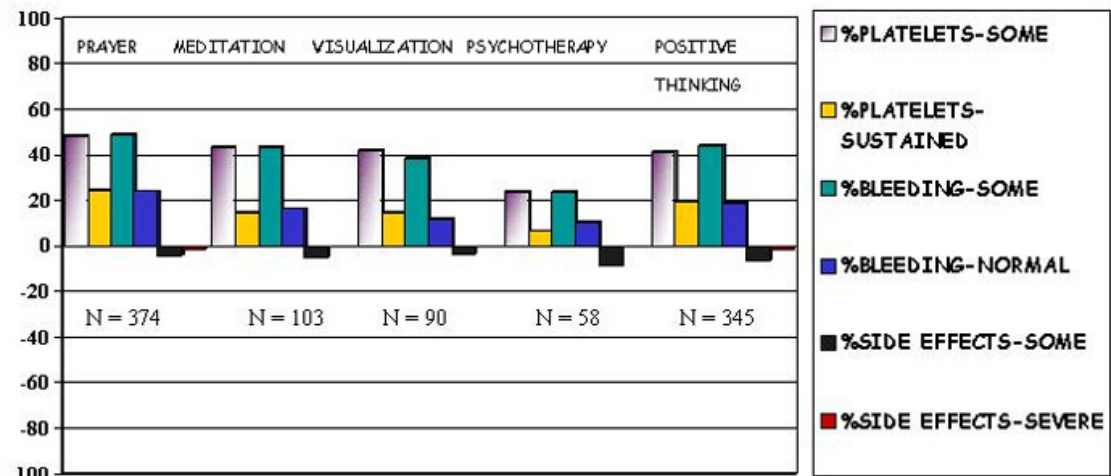


<u>EAT RIGHT FOR YOUR TYPE</u>	9.96%	<u>ZONE DIET</u>	1.09%	<u>ATKINS DIET</u>	4.81%	<u>WEIGHT WATCHERS</u>	0.76%
Platelets		Platelets		Platelets		Platelets	
› Some	35.16%	› Some	0.00%	› Some	11.36%	› Some	28.57%
› Sustained	12.09%	› Sustained	0.00%	› Sustained	2.27%	› Sustained	14.29%
Bleeding		Bleeding		Bleeding		Bleeding	
› Some	37.36%	› Some	10.00%	› Some	20.45%	› Some	14.29%
› Normal	10.99%	› Normal	0.00%	› Normal	2.27%	› Normal	0.00%
Side Effects		Side Effects		Side Effects		Side Effects	
› Some	6.59%	› Some	10.00%	› Some	9.09%	› Some	0.00%
› Severe	0.00%	› Severe	0.00%	› Severe	9.09%	› Severe	0.00%

Learn more about Complementary Treatments

Result 8 - Prayer, Meditation, Visualization, Psychotherapy, Positive Thinking

Selected Treatment Results

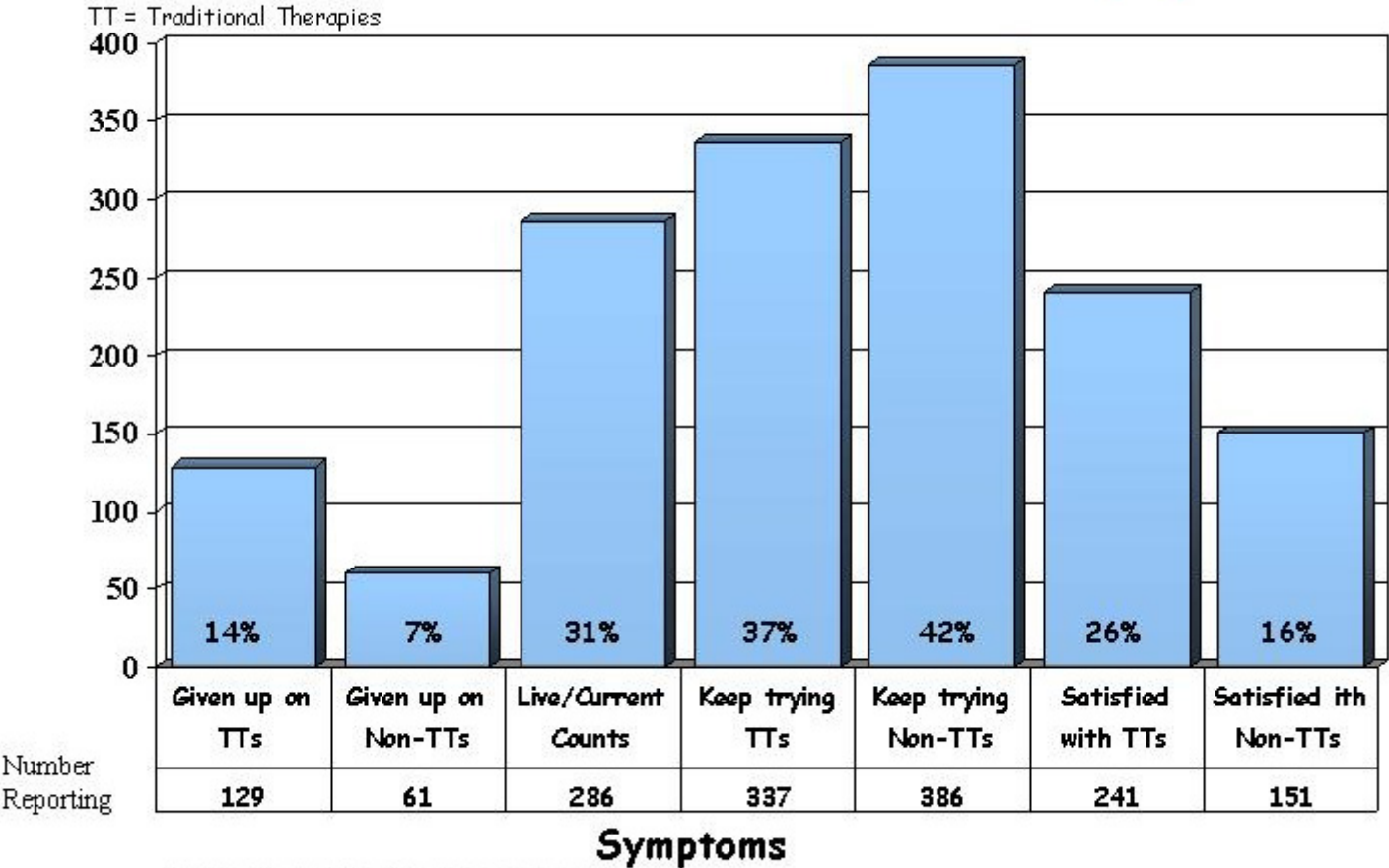


PRAYER	40.92%	MEDITATION	11.27%	VISUALIZATION	9.86%	PSYCHOTHERAPY	6.36%	POSITIVE THINKING	37.91%
Platelets		Platelets		Platelets		Platelets		Platelets	
› Some	48.66%	› Some	43.69%	› Some	42.22%	› Some	24.14%	› Some	41.45%
› Sustained	24.87%	› Sustained	14.56%	› Sustained	14.44%	› Sustained	6.90%	› Sustained	19.42%
Bleeding		Bleeding		Bleeding		Bleeding		Bleeding	
› Some	49.20%	› Some	43.69%	› Some	38.46%	› Some	24.14%	› Some	43.77%
› Normal	24.33%	› Normal	16.50%	› Normal	12.09%	› Normal	10.34%	› Normal	18.84%
Side Effects		Side Effects		Side Effects		Side Effects		Side Effects	
› Some	4.28%	› Some	4.85%	› Some	3.41%	› Some	8.62%	› Some	6.07%
› Severe	1.34%	› Severe	0.00%	› Severe	0.00%	› Severe	0.00%	› Severe	1.73%

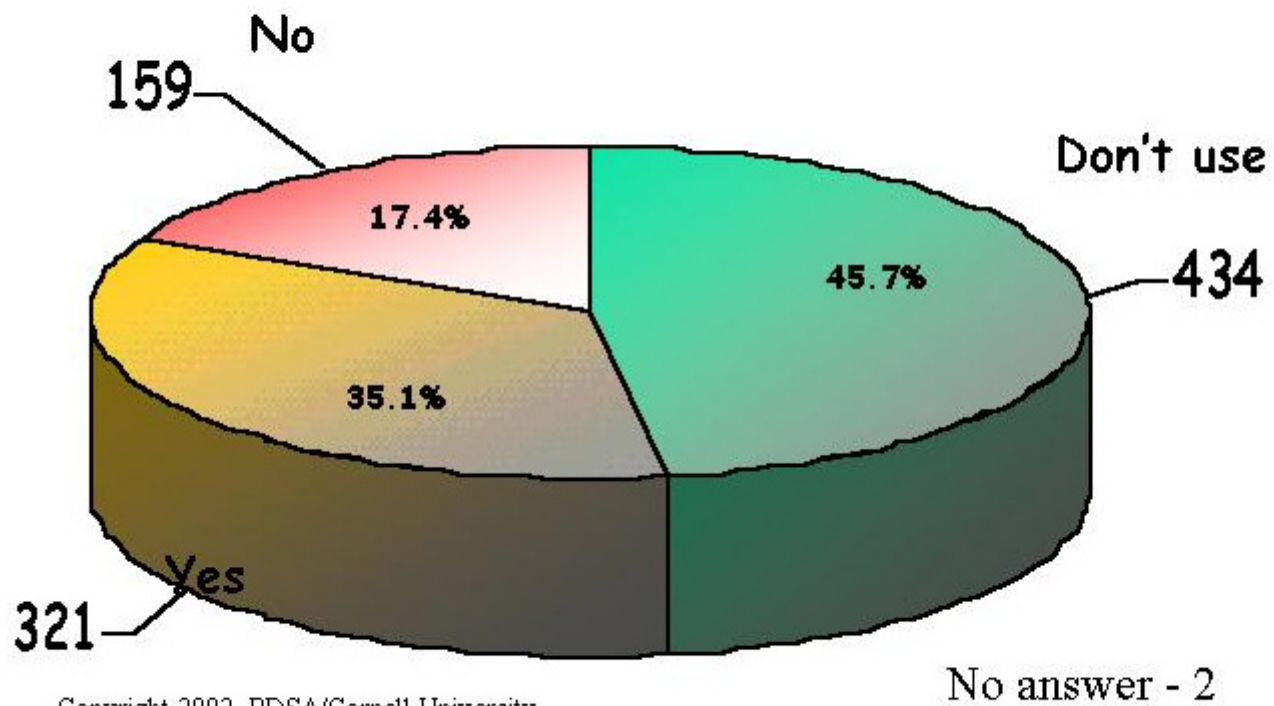
Learn more about Complementary Treatments

Individual Treatment Philosophy

Individual Treatment Philosophy



Told Hematologist about Non-Traditional Therapies Tried



Hematologist Support

Is Hematologist Supportive of Non-Traditional Therapies Tried?

