

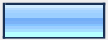
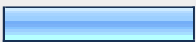
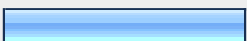
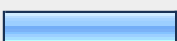

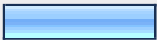
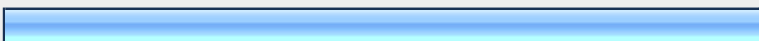





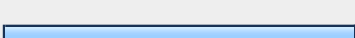



# Gastroparesis Patient Survey




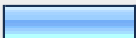
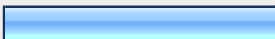
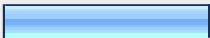
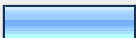


1. Please let us know your age range:			
		Response Percent	Response Count
12 - 18 (parents only answering for child)		7.0%	52
19-25		11.6%	86
26-30		10.8%	80
31-40		20.7%	153
<b>41-50</b>		<b>26.5%</b>	196
51-65		18.8%	139
>66		4.6%	34
		<b>answered question</b>	<b>740</b>
		<b>skipped question</b>	<b>3</b>

2. Your gender:			
		Response Percent	Response Count
Male		16.6%	122
<b>Female</b>		<b>83.4%</b>	614
		<b>answered question</b>	<b>736</b>
		<b>skipped question</b>	<b>7</b>


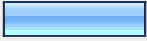
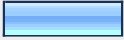

### 3. What is your highest level of education?

		Response Percent	Response Count
Still attending middle school		2.0%	15
Still attending high school		4.6%	34
Still attending College or University		10.0%	73
Did not finish high school		3.4%	25
I am a high school graduate		26.4%	193
<b>I am a College or University graduate</b>		<b>38.7%</b>	283
I have an advanced degree		14.9%	109
		<b>answered question</b>	<b>732</b>
		<b>skipped question</b>	<b>11</b>

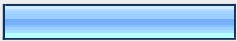
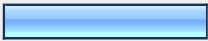


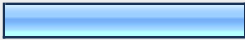
### 4. Please select one. Where do you live?

		Response Percent	Response Count
Eastern Canada		2.0%	15
Western Canada		9.2%	68
Other Canada		1.1%	8
Mid West USA		14.1%	104
<b>Eastern USA</b>		<b>29.8%</b>	220
Southern USA		22.3%	165
Western USA		14.2%	105
Other USA		2.6%	19
Other, international		4.7%	35
		<b>answered question</b>	<b>739</b>
		<b>skipped question</b>	<b>4</b>



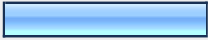


5. How old were you when the doctor diagnosed you with gastroparesis? Please select only one choice.

		Response Percent	Response Count
12 - 18 (parents only answering for child)		9.7%	68
19-25		15.4%	108
26-30		12.8%	90
31-40		21.6%	152
<b>41-50</b>		<b>24.2%</b>	170
51-65		13.1%	92
>66		3.3%	23
		<i>answered question</i>	<b>703</b>
		<i>skipped question</i>	<b>40</b>


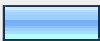
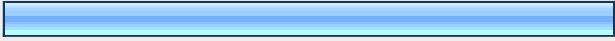




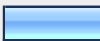
6. How long did it take for you to get diagnosed? In other words, from the start of troubling symptoms which led you to visit doctors, to the point that you finally got an answer as to the cause for your symptoms.

		Response Percent	Response Count
Less than 6 months		25.3%	166
6 months to one year		22.3%	146
1 to 2 years		15.9%	104
2 to 3 years		9.9%	65
<b>more than 3 years</b>		<b>26.6%</b>	174
		<i>answered question</i>	<b>655</b>
		<i>skipped question</i>	<b>88</b>


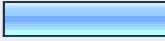
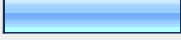







**7. How many different specialists did you ultimately have to visit in order to get diagnosed? (Please just select one answer).**

		Response Percent	Response Count
One		25.2%	163
<b>Two</b>		<b>26.4%</b>	171
Three		22.1%	143
Four		6.6%	43
More than 4		19.8%	128
		<b>answered question</b>	<b>648</b>
		<b>skipped question</b>	<b>95</b>

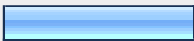



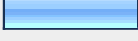
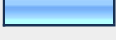




**8. Please tell us what test your doctor used to diagnose your gastroparesis.**

		Response Percent	Response Count
A barium (white chalky liquid) drink		2.0%	13
A scope (endoscopy) to look inside my stomach		10.3%	67
<b>A gastric emptying test (scan) (a test where you eat a "meal" that has a radio-active substance)</b>		<b>67.2%</b>	437
An EGG (electrogastrography)		0.9%	6
Abdominal CAT scan		0.8%	5
Ultra sound of my stomach		1.7%	11
Doctor just told me this is what he thought I had		6.6%	43
Other (please specify)		10.5%	68
		<b>answered question</b>	<b>650</b>
		<b>skipped question</b>	<b>93</b>



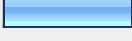

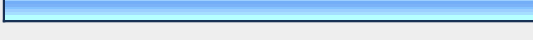
**9. Tell us about your symptoms. Please just select one answer: Please select what you think is your most bothersome symptom:**

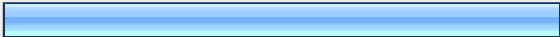
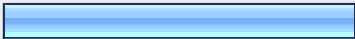
		Response Percent	Response Count
Nausea		33.1%	218
Vomiting		17.6%	116
Abdominal pain		19.4%	128
Heart burn		2.9%	19
Bloating		5.9%	39
Feeling of stomach fullness		7.7%	51
No appetite		2.1%	14
Food coming up into your mouth		3.8%	25
Belching		1.5%	10
Other (please specify)		5.9%	39
		<b>answered question</b>	<b>659</b>
		<b>skipped question</b>	<b>84</b>

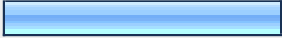










**10. Please tell us what you think is your second most bothersome symptom.**

		Response Percent	Response Count
Nausea		20.7%	135
Vomiting		11.7%	76
Abdominal pain		17.6%	115
Heart burn		5.8%	38
Bloating		14.6%	95
Feeling of stomach fullness		12.0%	78
No appetite		5.5%	36
Food coming up into your mouth		3.5%	23
Belching		2.5%	16
Other (please specify)		6.1%	40
		<b>answered question</b>	<b>652</b>
		<b>skipped question</b>	<b>91</b>




**11. How long have you been suffering with upper digestive symptoms?**

		Response Percent	Response Count
0 to 6 months		6.7%	42
6 to 12 months		9.7%	61
12 month to 24 months		14.0%	88
24 to 36 months		11.0%	69
<b>greater than 36 months</b>		<b>58.5%</b>	<b>367</b>
		<b>answered question</b>	<b>627</b>
		<b>skipped question</b>	<b>116</b>

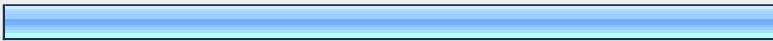
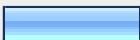
12. Have you been diagnosed with any other, non digestive illness?			
		Response Percent	Response Count
Yes		61.5%	378
No		38.5%	237
		<b>answered question</b>	<b>615</b>
		<b>skipped question</b>	<b>128</b>

13. If you answered yes above, please tell us if you suffer from any of the following illnesses.			
		Response Percent	Response Count
Diabetes		30.4%	124
Fibromyalgia		17.4%	71
Collagen disease (scleroderma, Lupus)		5.1%	21
Endometriosis		14.5%	59
Interstitial Cystitis		3.7%	15
Migraine headaches		28.4%	116
Hypothyroid		16.7%	68
AIDs		0.2%	1
Mitochondrial disease		0.0%	0
Hepatitis C		0.7%	3
Autonomic problem (POTS, dysautonomia)		5.6%	23
<b>Other (please specify)</b>		<b>46.1%</b>	<b>188</b>
		<b>answered question</b>	<b>408</b>
		<b>skipped question</b>	<b>335</b>



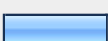
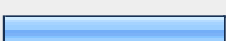
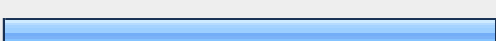

14. If you identified a diagnosed problem listed above, then please tell us: Which symptom groups would you say impair your quality of life more: Your digestive symptoms; or the symptoms which result from your other identified disease?

		Response Percent	Response Count
Digestive symptoms		88.7%	407
The symptoms caused from my other disease		6.8%	31
Other (please specify)		4.6%	21
		<b>answered question</b>	<b>459</b>
		<b>skipped question</b>	<b>284</b>


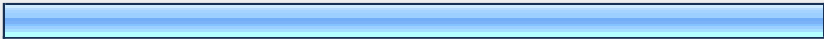
15. At times, do your symptoms prevent you from sleeping through the night?

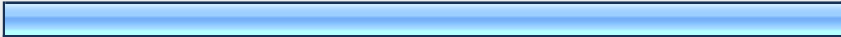

		Response Percent	Response Count
yes		85.2%	552
no		14.8%	96
		<b>answered question</b>	<b>648</b>
		<b>skipped question</b>	<b>95</b>




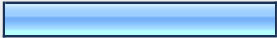

16. Do your symptoms prevent you from eating foods which you enjoy?

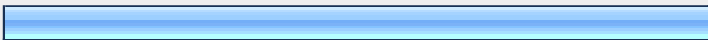

		Response Percent	Response Count
Never		0.3%	2
Seldom		2.0%	13
Sometimes		11.1%	72
Often		24.0%	156
<b>Frequently</b>		<b>54.4%</b>	<b>353</b>
All the time, I am on a feeding tube		8.2%	53
		<b>answered question</b>	<b>649</b>
		<b>skipped question</b>	<b>94</b>

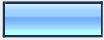



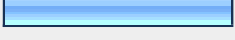
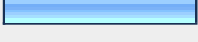


17. Are you dependent upon some sort of feeding tube in order to remain nourished?			
		Response Percent	Response Count
Yes		9.3%	60
No		90.7%	583
<b>answered question</b>			<b>643</b>
<b>skipped question</b>			<b>100</b>

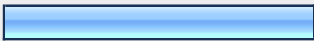
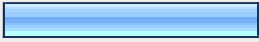

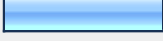

18. At different times, do your symptoms interfere with your ability to do things like house work, shopping, attending social functions?			
		Response Percent	Response Count
yes		92.7%	598
no		7.3%	47
<b>answered question</b>			<b>645</b>
<b>skipped question</b>			<b>98</b>

19. Over the last 3 months, how often do your symptoms interfere with activities?			
		Response Percent	Response Count
Once a month or less		7.9%	51
About 2 times a month		9.2%	59
3 times in a month		7.9%	51
weekly		30.0%	193
Daily		45.0%	290
<b>answered question</b>			<b>644</b>
<b>skipped question</b>			<b>99</b>

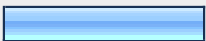
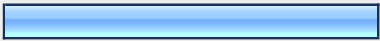
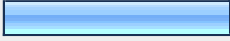


20. Have your symptoms interfered with your ability to work or attend school?			Response Percent	Response Count
Yes			77.8%	495
no			22.2%	141
			<b>answered question</b>	<b>636</b>
			<b>skipped question</b>	<b>107</b>

21. If you answered yes to the above question, please tell us how often your symptoms interfered with your work or school activities.			Response Percent	Response Count
Once a month or less			10.6%	54
About 2 times a month			8.8%	45
3 times in a month			12.0%	61
weekly			22.6%	115
<b>Daily</b>			<b>25.0%</b>	127
I am disabled and house bound			21.0%	107
			<b>answered question</b>	<b>509</b>
			<b>skipped question</b>	<b>234</b>

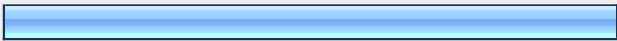
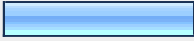



**22. Please try to estimate how much time is used up in physician appointments, travel to and from appointments, time spent on the phone dealing with billing and insurance issues, or time needed to prepare infusions of feeding formulas / medications, and other time needed to manage your medial care related to gastroparesis**

		Response Percent	Response Count
0 to 5 hours in a month		34.0%	214
6 to 12 hours in a month		27.8%	175
13 to 20 hours in a month		16.8%	106
more than 21 hours in a month		17.5%	110
Other (please specify)		4.0%	25
		<b>answered question</b>	<b>630</b>
		<b>skipped question</b>	<b>113</b>

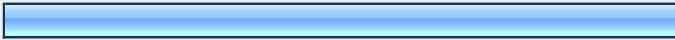
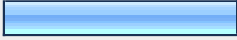
**23. Please give a rough estimate as to the direct costs you have to pay out of pocket for medial co-payment, special formulas, and prescription medications. Please note that Canadian and US dollar amounts will be treated as equivalent in order to simplify this process.**

		Response Percent	Response Count
0 to \$50 each month		21.9%	136
\$51 to \$200 each month		41.3%	256
\$201 to \$500 each month		24.8%	154
\$501 to \$1,000 each month		6.9%	43
over \$1,000 each month		5.0%	31
		<b>answered question</b>	<b>620</b>
		<b>skipped question</b>	<b>123</b>

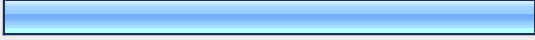
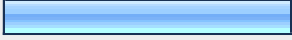


24. Please provide an estimate of out of pocket expenses for alternative medical care. Some examples: chiropractors, acupuncturists, homeopaths etc.

		Response Percent	Response Count
0 to \$50 each month		67.7%	404
\$51 to \$200 each month		20.6%	123
\$201 to \$500 each month		8.2%	49
\$501 to \$1,000 each month		1.7%	10
over \$1,000 each month		1.8%	11
		<b>answered question</b>	<b>597</b>
		<b>skipped question</b>	<b>146</b>

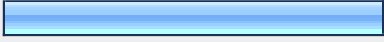
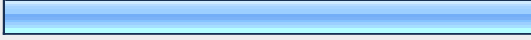
25. Diet is considered an important measure in order to help curb the symptoms of gastroparesis. Did your doctor mention dietary measures to you?

		Response Percent	Response Count
Yes		74.6%	457
No		25.4%	156
		<b>answered question</b>	<b>613</b>
		<b>skipped question</b>	<b>130</b>

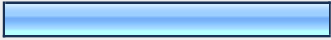

26. If your doctor advised you regarding what to eat for helping to control symptoms, how satisfied were you with this information he or she provided.

		Response Percent	Response Count
Unsatisfied, I had to find information on my own.		58.6%	330
Satisfied		31.4%	177
Very satisfied		5.3%	30
Excellent information with written instructions.		4.6%	26
		<b>answered question</b>	<b>563</b>
		<b>skipped question</b>	<b>180</b>

27. Often patients are told, or it is implied, that your symptoms are related to stress, depression or other psychological problems as the cause for your digestive distress. Do you feel that a doctor turned you away or declined any further medical follow-up due to an implied "psychological label"?

		Response Percent	Response Count
Yes		41.7%	255
No		58.3%	357
		<b>answered question</b>	<b>612</b>
		<b>skipped question</b>	<b>131</b>

28. If you answered yes to the above question, did your doctor refer you to a psychologist for treatment of your digestive symptoms?

		Response Percent	Response Count
Yes		35.9%	126
No		64.1%	225
		<b>answered question</b>	<b>351</b>
		<b>skipped question</b>	<b>392</b>

29. If you did go for psychological counselling, did this help decrease your digestive symptoms?			Response Percent	Response Count
yes			3.9%	11
no			96.1%	272
			<b>answered question</b>	<b>283</b>
			<b>skipped question</b>	<b>460</b>

30. Do you feel that your care has been handled with a team approach: utilizing some, or all of the professions of a: psychologist (to help you to cope), a nutritionist, pain specialists and others?			Response Percent	Response Count
Yes			25.4%	146
no			74.6%	429
			<b>answered question</b>	<b>575</b>
			<b>skipped question</b>	<b>168</b>

31. Thank you for your help. Please feel free to add any comments that you would like. Also, feel free to provide suggestions for other survey questions			Response Count
			182
			<b>answered question</b>
			<b>182</b>
			<b>skipped question</b>
			<b>561</b>