

## Constant Contact Survey Results

**Survey Name:** Feb 04 2008 Survey

**Response Status:** Partial & Completed

**Filter:** None

Feb 21, 2008 6:07:31 PM

### TextBlock:

Two of the main Survey questions gave us skewed results on Oct 2007. The two questions pertained to present quality of life and activities of daily living.

All the responses (no=182 people ) showed that people with dystonia had no difficulties with grooming, cooking, driving, which I found rather amazing. The results are not being collected for any Social Security Disability Firm ; but is intended to provide us, at Care4Dystonia,Inc, with the tools you need to live a quality decent life with dystonia. Thus, we , kindly , ask that you answer the following questions as truthfully as possible. The survey is the property of Care4Dystonia, Inc. with content lifting prohibited.

We ask that you consider forwarding this mail to other people with dystonia and support group leaders. Everyones' input is valuable. We'll be be happy to post the results in future newsletters. With the help of Tom from Florida, we have corrected typo errors in this survey. I do apologize.

~ beka RN, MS, NP

[www.care4dystonia.org](http://www.care4dystonia.org)

### \* What type for KEY form of Dystonia have you been diagnosed with ?

Answer	0%	100%	Number of Response(s)	Response Ratio
Dyt1 General Early Onset Childhood Dystonia			8	2 %
Non Idiopathic Generalized Dystonia			12	3 %
Cervical dystonia ( ST = Torticollis + Spasmodic torticollis )			153	48 %
Hemidystonia ( affecting half the body )			5	1 %
Focal dystonia such as writer's cramp, limb dystonia, lingual dystonia			23	7 %
Paroxysmal Dystonia			6	1 %
Oromandibular Dystonia			23	7 %
Vocal Cord Dysphonia			9	2 %
Blepharospasm			25	7 %
Segmental dystonia ( dystonia with two or more focal forms such as ST, jaw)			19	5 %
Other			35	11 %
<b>Totals</b>			<b>318</b>	<b>100%</b>



\* Have You undergone DYT1 Gene Testing as part of your work-up in diagnosing your initial symptoms of dystonia by a neurologist ?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			26	10 %
No			204	81 %
Don't know- Never been asked			20	7 %
No Response(s)			1	<1 %
<b>Totals</b>			<b>251</b>	<b>100%</b>




Have you had trouble performing ONE of the activities of daily living since your diagnosis with dystonia  
\* regardless of form ? Choose the most important activity that applies to you. In other words, what is the one activity you find most difficult regardless of treatment- based just on your dystonia.

Answer	0%	100%	Number of Response(s)	Response Ratio
Dressing			4	1 %
Grooming- placing on make-up, shaving			13	5 %
Walking free of sensory tricks			34	13 %
Eating in a Public Setting			14	5 %
Cooking			4	1 %
Writing ( lists, checks etc. )			22	8 %
Driving a vehicle free of sensory tricks or use of cervical collars etc.			42	16 %
Riding a bicycle, completing other hobbies such as gardening			7	2 %
Exercising on a daily basis			19	7 %
Shopping			7	2 %
Getting to the Doctor for appointments			3	1 %
Speaking verbally			25	9 %
Attending a Support Group for Dystonia			4	1 %
Other			45	17 %
No Response(s)			8	3 %
<b>Totals</b>			<b>251</b>	<b>100%</b>







**\* What is Your Gender ?**

Answer	0%	100%	Number of Response(s)	Response Ratio
Male			60	23 %
Female			190	75 %
No Response(s)			1	<1 %
<b>Totals</b>			<b>251</b>	<b>100%</b>

**\* Do You feel depressed about your dystonia and treatments ?**

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			127	50 %
No			70	27 %
Other			51	20 %
No Response(s)			3	1 %
<b>Totals</b>			<b>251</b>	<b>100%</b>

**\* What is your present Age Group ?**

Answer	0%	100%	Number of Response(s)	Response Ratio
Under age 20			4	1 %
Age 21 to 30			9	3 %
Age 31 to 40			21	8 %
Age 41 to 50			60	23 %
Age 51 to 60			96	38 %
Age 61 to 70			41	16 %
Age over 71			19	7 %
No Response(s)			1	<1 %
<b>Totals</b>			<b>251</b>	<b>100%</b>

\* What is your current treatment for your dystonia ?

Answer	0%	100%	Number of Response(s)	Response Ratio
Oral Medications			65	19 %
Botox only			51	15 %
Myobloc only			7	2 %
Botox and Oral medications			74	22 %
MyoBloc and Oral medications			8	2 %
Selective denervation			12	3 %
Deep Brain Stimulation			11	3 %
Alternative Therapy ONLY			2	<1 %
Physical Therapy			29	8 %
Deep Brain Stimulation with the use of oral medications/botulinum toxin			10	3 %
No Therapy at this time.			23	6 %
Other			40	12 %
<b>Totals</b>			<b>332</b>	<b>100%</b>

\* Please rate your satisfaction with our newsletter ? Awareness Efforts ?

Answer	0%	100%	Number of Response(s)	Response Ratio
Extremely Satisfied			121	48 %
Somewhat Satisfied			76	30 %
Neutral			34	13 %
Somewhat Dissatisfied			3	1 %
Extremely Dissatisfied			1	<1 %
Other			10	3 %
No Response(s)			6	2 %
<b>Totals</b>			<b>251</b>	<b>100%</b>

**TextBlock:**

We hope this 10 question survey will help clarify some things. Don't be afraid to share your thoughts or concerns. They are not being shared with any governmental agency. Results will be posted on our "survey " webpage on our website. My intent is to make Dystonia as best as it can be in the area of care. You matter as does Dystonia.

So, please participate in this very short survey. 10 minutes of your time - 10 questions !

Thanks, in advance ,

Beka, RN, MS, NP  
www.care4dystonia.org