

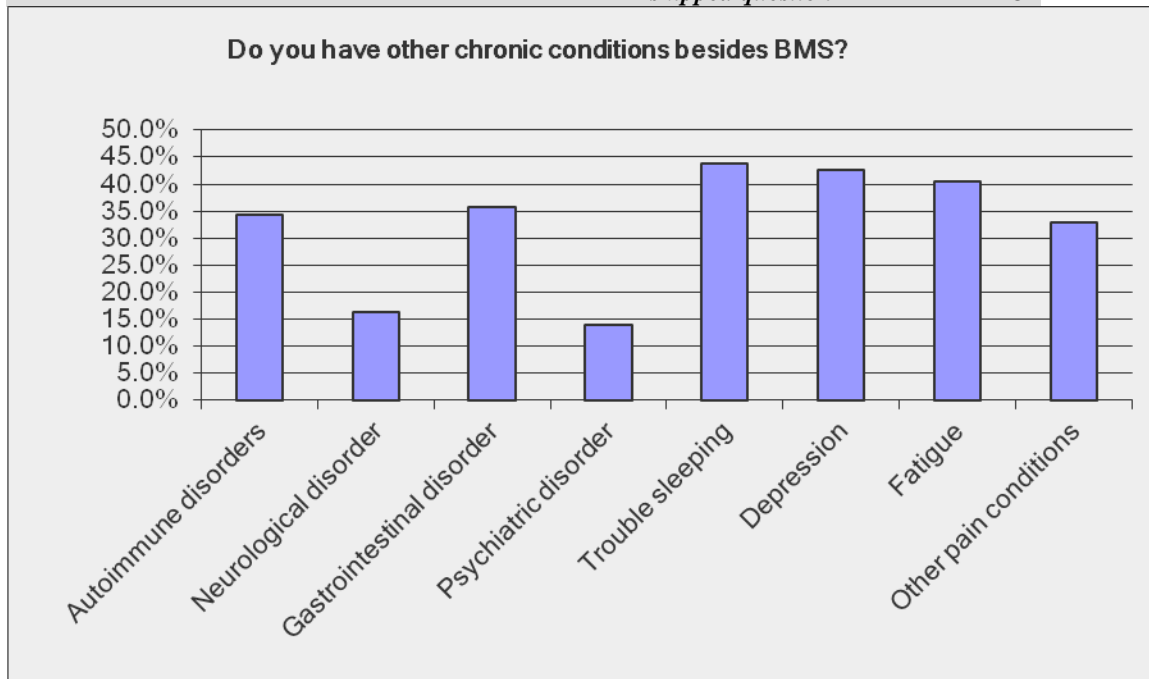
This report is on a survey study that was done within a face book support group that has 1400 plus members. During the two months the survey was posted 436 members were active, 347 members filled out the survey. People were asked not to fill out the survey if they were not diagnosed with Burning Mouth Syndrome (BMS).

The first question asked.

Do you have other chronic conditions besides BMS?

43.8 % of the people had trouble sleeping, 42.7 % had depression, 40.5% suffered from fatigue, 35.8 % have gastrointestinal disorder, while 34.3 % have autoimmune disorders, only 16.4 % have neurological disorders and 32.8 % of these (a little confusing is this 32.8 of the 16.4 % or 32.8% of the total) people have other pains.

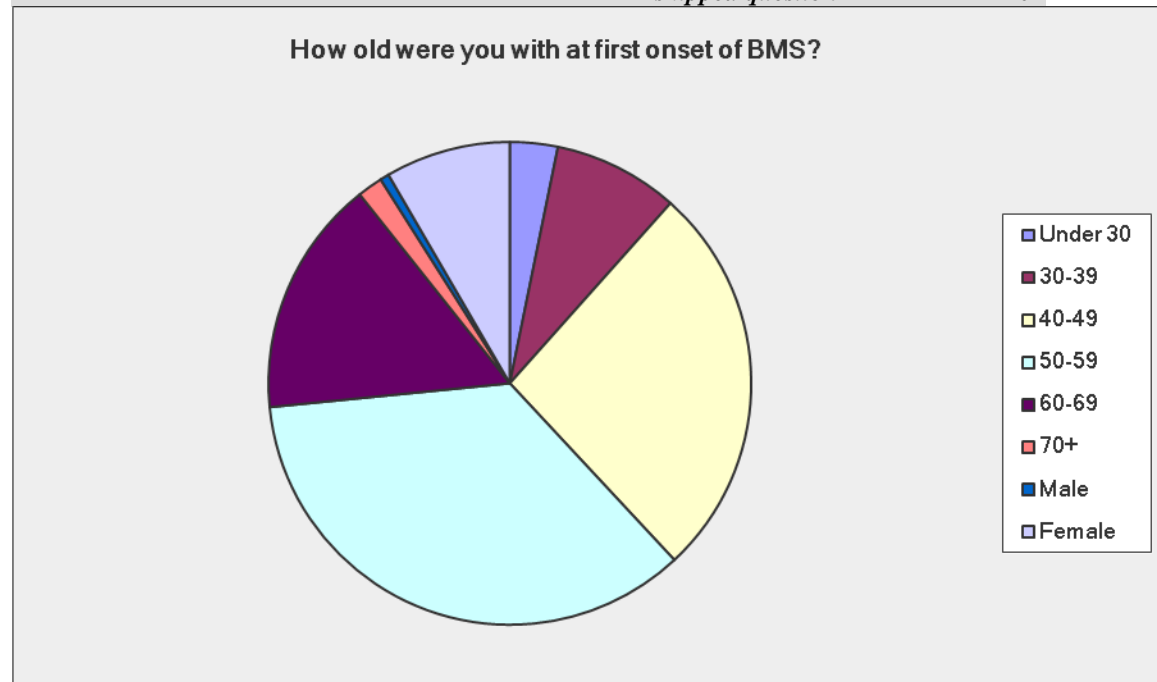
<b>Do you have other chronic conditions besides BMS?</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Autoimmune disorders	34.3%	94
Neurological disorder	16.4%	45
Gastrointestinal disorder	35.8%	98
Psychiatric disorder	13.9%	38
Trouble sleeping	43.8%	120
Depression	42.7%	117
Fatigue	40.5%	111
Other pain conditions	32.8%	90
<i>answered question</i>		<b>274</b>
<i>skipped question</i>		<b>73</b>



Second question, how old were you with at first onset of BMS?

The bulk of the people were between 40 and 60 years of age, the youngest under 30 years of age the oldest over 70 years of age.

How old were you with at first onset of BMS?		
Answer Options	Response Percent	Response Count
Under 30	3.2%	11
30-39	8.4%	29
40-49	26.5%	92
50-59	35.4%	123
60-69	15.9%	55
70+	1.7%	6
Male	0.6%	2
Female	8.4%	29
<i>answered question</i>		<b>347</b>
<i>skipped question</i>		<b>0</b>



Third question asked.

What type of BMS do you have?

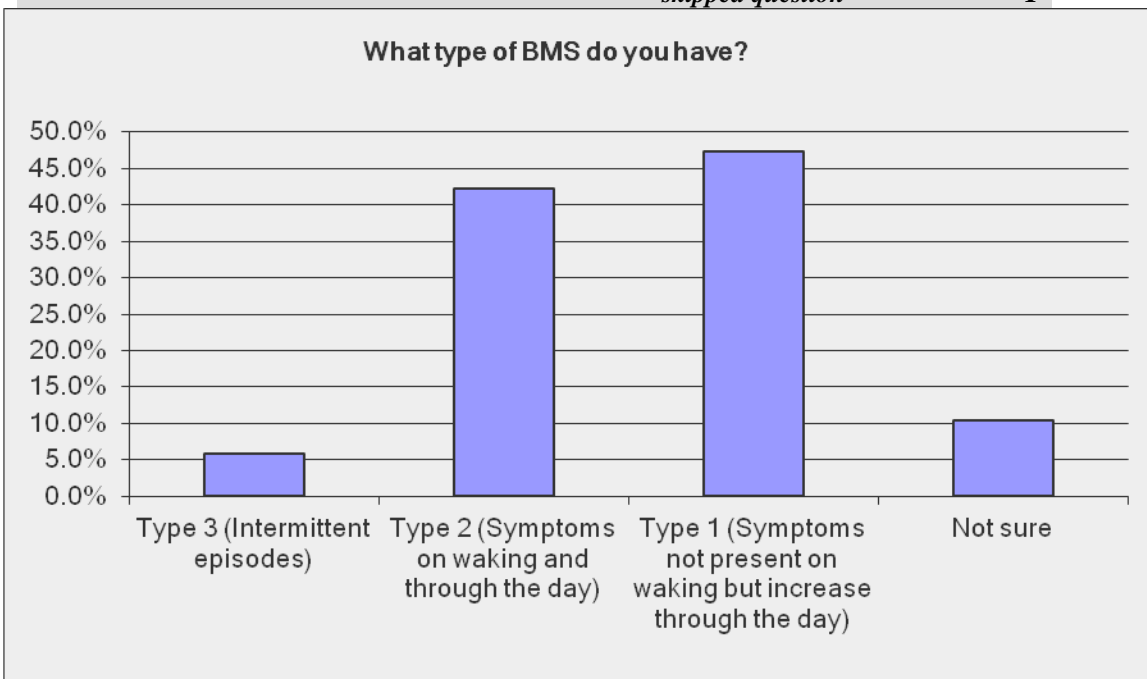
Type 1 (Symptoms not present on waking but increase through the day) 47.4%

Type 2 (Symptoms on waking and through the day) 42.2%

Type 3 (Intermittent episodes) 5.8%

Those not sure 10.4%

What type of BMS do you have?		
Answer Options	Response Percent	Response Count
Type 3 (Intermittent episodes)	5.8%	20
Type 2 (Symptoms on waking and through the day)	42.2%	146
Type 1 (Symptoms not present on waking but increase through the day)	47.4%	164
Not sure	10.4%	36
<i>answered question</i>		<b>346</b>
<i>skipped question</i>		<b>1</b>

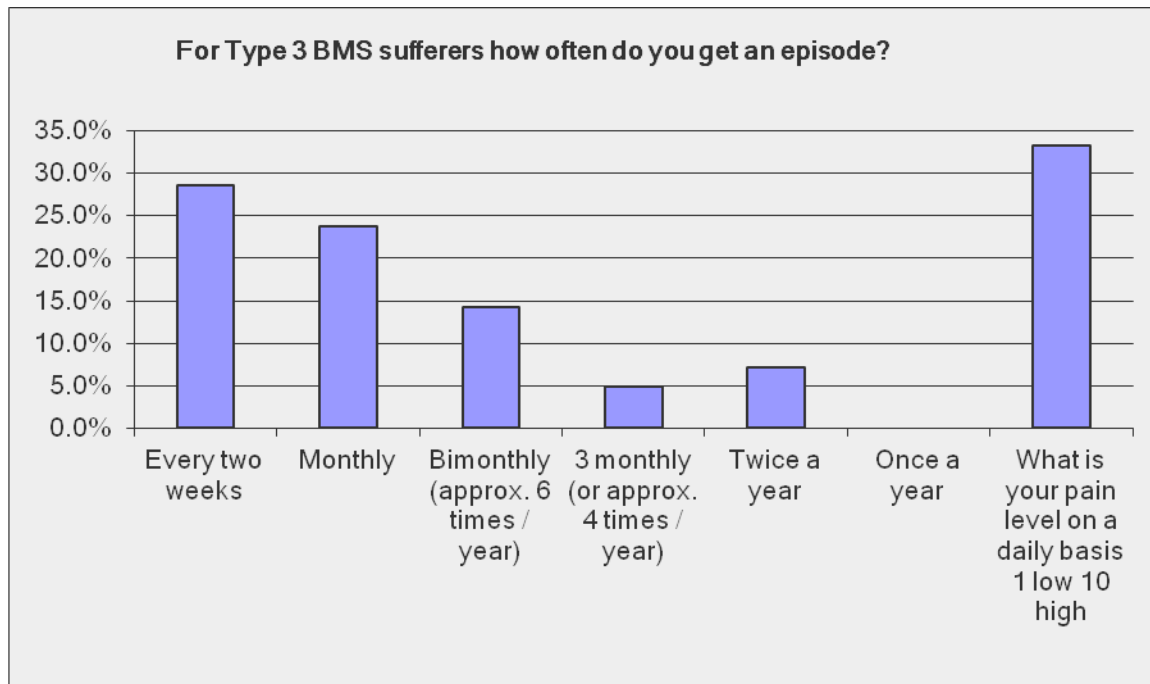


Fourth question.

For those who answered Type 3 BMS sufferers how often do you get an episode?

Every two weeks 28.6% responded while 23.8% had monthly episodes, 14.3% were bimonthly, 4.8% said four times a year and 7.1% only twice a year.

For Type 3 BMS sufferers how often do you get an episode?		
Answer Options	Response Percent	Response Count
Every two weeks	28.6%	12
Monthly	23.8%	10
Bimonthly (approx. 6 times / year)	14.3%	6
3 monthly (or approx. 4 times / year)	4.8%	2
Twice a year	7.1%	3
Once a year	0.0%	0
What is your pain level on a daily basis 1 low 10 high	33.3%	14
<i>answered question</i>		<b>42</b>
<i>skipped question</i>		<b>305</b>



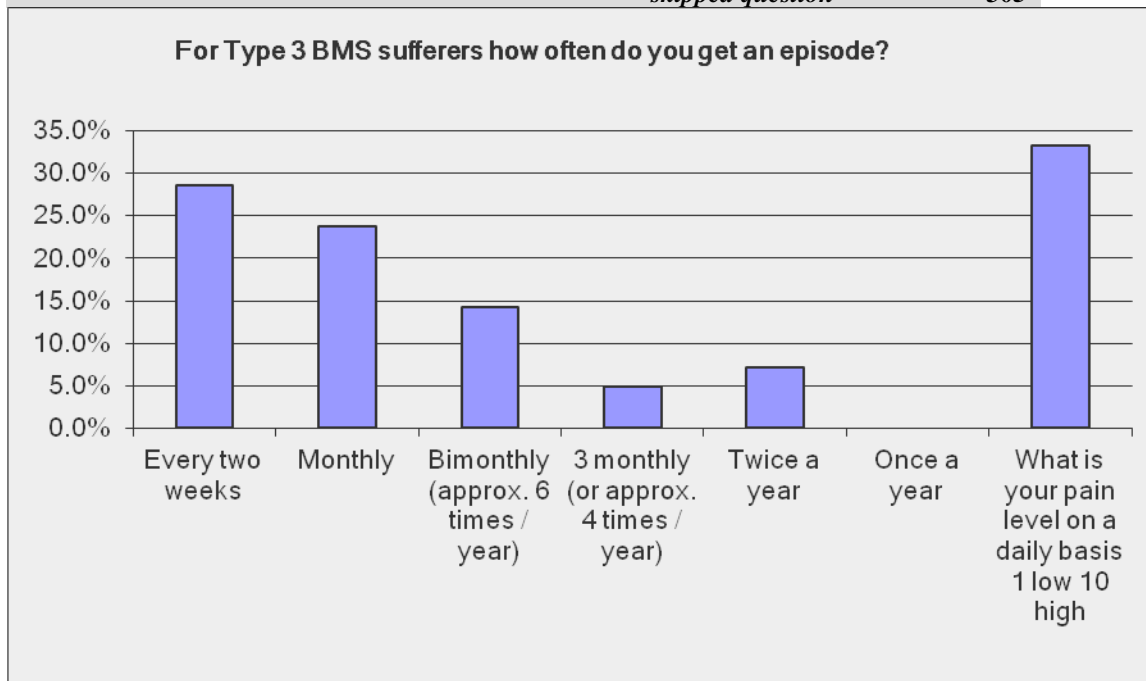
Question Five.

Which of the following do you do/ take to try to reduce your BMS?

Both Vitamin B-12 and Alpha-Lipoic Acid seem to help along with (SSRI's ?) and pain meds.

Some folks find relief though Stress- management along with meditation, hypnosis, yoga, Qi Gong and or Bio-feed back. **For Type 3 BMS sufferers how often do you get an episode?**

Answer Options	Response Percent	Response Count
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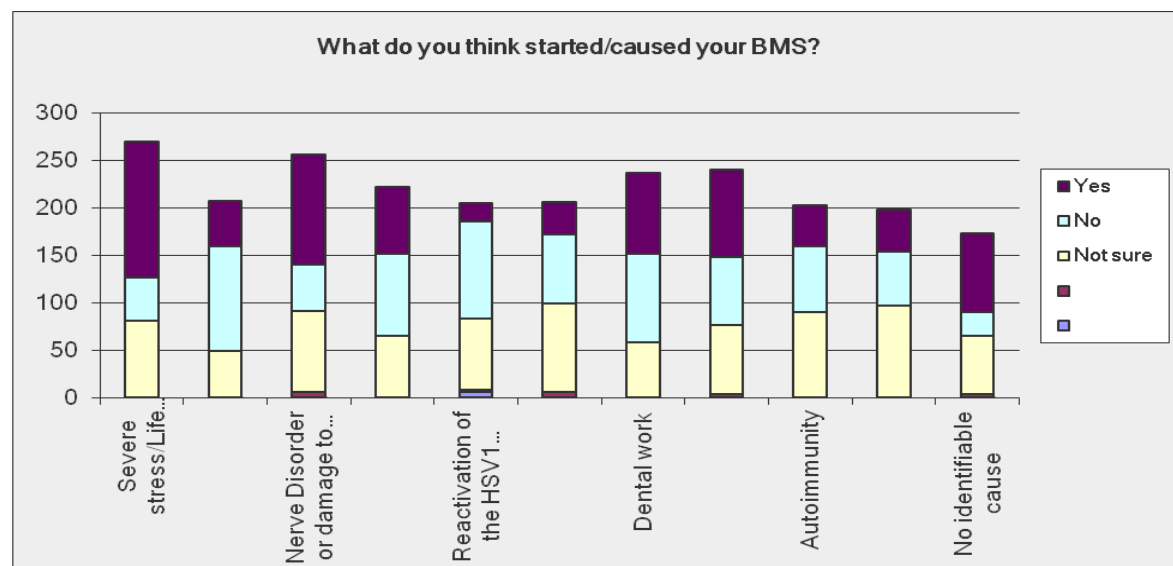


Question Six.

What do you think started/caused your BMS?

Because there is no known cause people were asked to best guess what caused them to get BMS. Many think that stress and nerve damage were a factor. Some thought that dry mouth, dental or menopause was a factor. Few thought that trauma, allergies or HSV1 had anything to do with their BMS. 83 out of the 347 had no identifiable causes. Autoimmunity and neurological issues were split.

What do you think started/caused your BMS?				
Answer Options	Yes	No	Not sure	
Severe stress/Life change	143	46	79	0
Trauma	48	111	46	2
Nerve Disorder or damage to nerves in mouth	117	48	86	3
Dry Mouth Syndrome	70	87	64	0
Reactivation of the HSV1 (herpes cold sore virus) in the Trigeminal nerve	19	102	76	2
Allergies to certain substances	34	72	94	3
Dental work	85	93	56	2
Menopause	92	72	73	3
Autoimmunity	43	70	87	1
Neurological	44	57	95	1
No identifiable cause	83	25	61	2



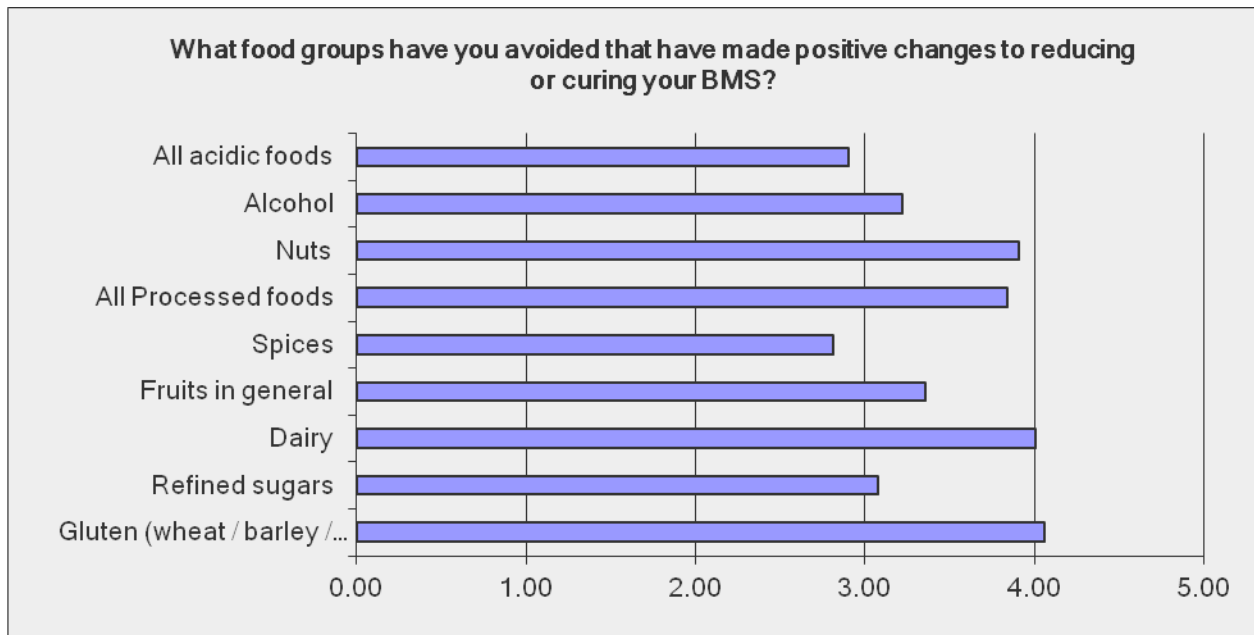
Question seven.

What food groups have you avoided that have made positive changes to reducing or curing your BMS?

Most folks definitely thought spices, acidic foods, Alcohol and refined sugars triggered more pain in their mouths.

**What food groups have you avoided that have made positive changes to reducing or curing your BMS?**

Answer Options	Definitely a trigger always	A medium trigger	A mild trigger	Definitely NOT a trigger
Gluten (wheat / barley / rye)	22	17	22	61
Refined sugars	76	51	24	30
Dairy	17	18	22	81
Fruits in general	48	31	44	53
Spices	94	47	25	35
All Processed foods	32	25	17	44
Nuts	18	22	22	85
Alcohol	67	37	23	46
All acidic foods	93	41	35	28



Question Eight.

What country do you live in?

Our group represents 53 different countries in the world. Those in the USA had filled out the survey the most with Australia, UK, and Canada having and good representation. USA 74.70%. Australia 8.23 5, UK 7.3% and Canada 4.75%.

What country do you live in?					
Answer Options	I Live Here				
USA	245	0	0	0	0
Canada	17	0	0	0	0
United Kingdom	24	0	0	0	0
Denmark	3	0	0	0	1
Sweden	4	0	0	0	0
Netherlands	4	0	0	0	0
Italy	1	0	0	0	0
Belgian	0	0	0	1	0
Australia	27	0	0	0	0
Other					



Question Nine.

What medications have you tried?

Until the mechanism for BMS is found it looks like Klonopin is the number one choice for helping 90% of those that filled out the survey.

**What medications have you tried?**

Answer Options	Definitely Helped	Definitely Did Not Help	I Am Not Sure Either Way	
Magic Mouthwash recipe	43	81	39	2
Neurontin/Gabapentin medication	38	77	47	4
Lyrice (a medication for nerve pain)	15	59	27	5
Klonopin	90	33	37	3
A tranquilizer/antiolytic other than Klonopin	33	17	37	3
Hydrocodone	27	18	29	3
Tylenol with Codeine	15	26	32	5
Oxycodone or other strong pain medication	20	22	30	7
Antidepressant (any kind, Cymbalta, Wellbutrin, etc.)	47	75	50	6
Duloxetine	8	19	31	5
Hormone Replacement Therapy (medication and natural)	2	42	41	6
Antifungal medications	22	87	36	5

