

**LIVING WITH EMS:  
NEMSN'S 1999 Survey of Patients**

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Paper Presented at the Workshop:

**THE EOSINOPHILIA-MYALGIA SYNDROME:**

**What We Learned; What We Should Do to Prevent Another Epidemic;  
What are the Most Promising Directions for Research?**

**October 22, 2004**

**Bethesda, MD**

**Sponsored by**

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**The National Institute of Allergy and Infectious Diseases (NIAID)**

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**1999 National Eosinophilia-Myalgia Syndrome Network Survey**  
**PHASE I: PRELIMINARY ANALYSIS OF MEDICAL SYMPTOMS<sup>1</sup>**  
**Karen L. Tonso, Ph.D.**

**INTRODUCTION**

In late 1998, National Eosinophilia-Myalgia Syndrome Network (NEMSN) developed and distributed a survey to its members. Almost 10 years had passed since the EMS "Outbreak" in 1989. There were among our membership a sense that many in the medical community had misunderstood EMS. We were still alive and many of us were not doing well, and believed that more could be done for those of us with EMS. Through this survey, NEMSN endeavored:

- To better understand the health status of those with EMS,
- To gauge the socioeconomic impact of EMS,
- To help those with EMS (and those not yet diagnosed) get the attention they deserve, and
- To stimulate the interest of the medical community and reinvigorate research into EMS.

The following preliminary analysis of medical symptoms reports the descriptive statistics for two items from the survey: Item 19, a comprehensive list of symptoms in body-system categories; and Item 23, a sense of how we are doing - better, the same, or worse - by body-system categories.

This was a grassroots effort of NEMSN and several people contributed to developing the survey. The survey grew out of NEMSN Board members' frustration trying to explain the effects of EMS. Don Hudson (Public Relations Director) and Faith Rumph (Newsletter Editor and now President) proposed that a survey of membership would give NEMSN some guidance on these issues. Don Hudson coordinated gathering symptoms listed in Item 19 from several sources: years of listening to those with EMS talk about their illness, email and surface mail lists solicited through the NEMSN Newsletter, doctors familiar with EMS, and published medical-journal articles describing EMS. Hudson organized the symptoms into nine broad categories related to various body systems and added a tenth for miscellaneous symptoms:

- Dental and Oral
- Gastrointestinal and Bladder
- Eyes and Vision
- Muscles, Nerves, Connective Tissues, and Joints
- Skin and Deep Tissue
- Immune System
- Respiratory and Circulatory
- Neurological and Cognitive
- Psychological
- Miscellaneous

Karen L. Tonso drafted a survey and elicited feedback from NEMSN Board members: Don Hudson, Faith Rumph, Jann Heston (Medical/Research Director), Sharron Lobaugh (Secretary), Betty Hoffing (Midwest Regional Vice President), Irma Goodman (Western Regional Vice President) and Jerry Goodman (Business Consultant). A revised survey was reviewed by Board members and doctors on the NEMSN Medical Advisory Council. Tonso revised the survey and Rumph distributed it to members. (Whatever errors remained in the survey are the responsibility of NEMSN.)

Though this was a grassroots effort affiliated with NEMSN, we have made every effort to maintain high standards for our research analysis. First, we guaranteed confidentiality. Respondents returned surveys to Jann Heston, who removed all identifying information and forwarded the surveys to Karen Tonso. Tonso assigned ID numbers to each survey and performed data input and analysis tasks. Thus, no one in NEMSN could link respondents' names and ID numbers.

Second, of the almost 900 NEMSN members with EMS, 295 completed the survey in time to be included in this analysis. This exceeded our expectations because the survey was long and complex, and because EMS is a disease characterized by pain, fatigue, and neurological difficulties - hardly conditions conducive to completing a survey. Many people wrote extensive (unsolicited) open-ended responses to augment their quantitative data. Others reported that the survey was physically, mentally, and emotionally taxing. That so many spent their limited energy and productive time completing the survey indicates the desire we have to understand our disease and improve our lives. Those of us working on the survey hope that we have done justice to survey respondents' trust in us.

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<sup>1</sup> The findings portion of this paper were first published in the *NEMSN Newsletter* in May 1999.

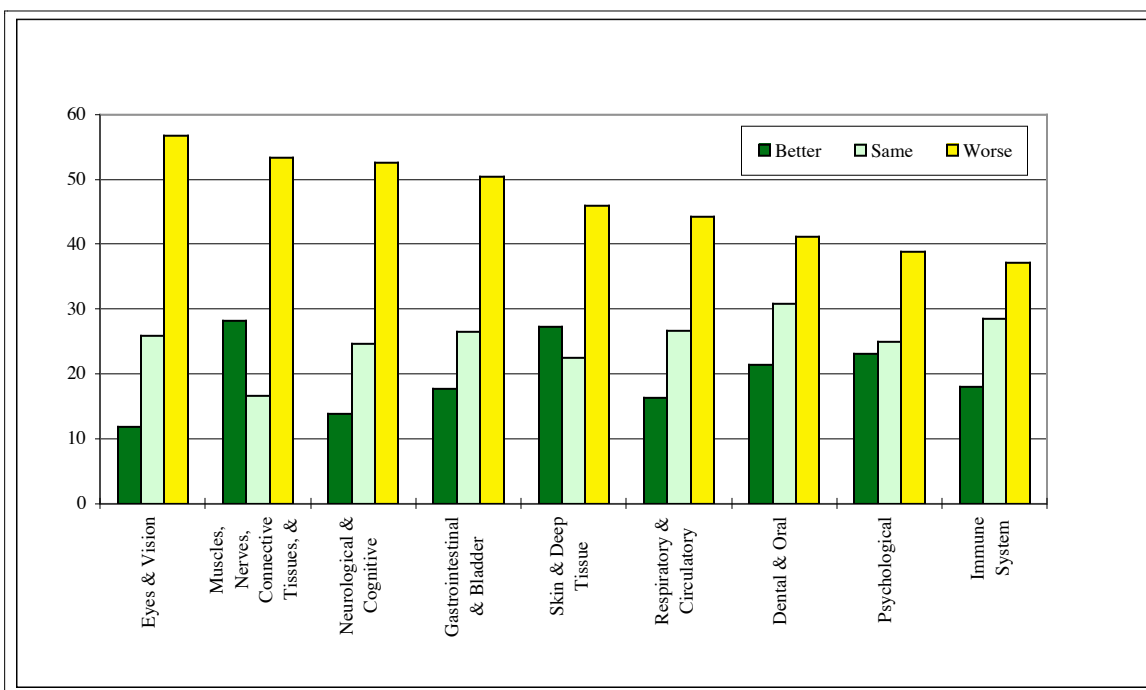
Third, no claims can be made, at least not yet, about the extent to which the survey respondents are representative of all people with EMS. In fact, those of us working on the survey suspect that two groups could be underrepresented: those who feel “well,” and those too ill to complete the survey. On the one hand, people with an illness who recover seem less likely to continue an affiliation with a support network focused on those with the illness. On the other hand, anecdotal evidence from regional support-group facilitators and others who speak often with EMS patients who are quite ill suggests that these people did not (and likely could not) participate in the survey.

Fourth, as with all research, the results reported here are necessarily “partial.” Because the survey analysis will proceed in modules, readers must exercise care not to intuit “causal” relations prematurely. This paper describes a portion of the “what” of EMS and cannot, at least not yet, comment on the extent to which changes in our symptoms over time are caused by various factors (such as EMS, aging, or other medical conditions). However, this in no way diminishes the importance of the findings. Overwhelmingly, people with EMS who responded to the survey reported an extraordinarily wide range of symptoms; and sadly, most are the same or worse 10 years after EMS onset.

### ITEMS 19 AND 23: COMPARING NOW WITH ONSET

What does EMS look like now? How has it changed since onset? Are people with EMS better, the same, or worse?

Figure 1: Respondents’ Health Changes (Item 23): Better, the Same, or Worse?



#### Item 23: Better, the Same, or Worse?

In Item 23 respondents gauged their progress for each of the nine body-system categories by checking one of three characterizations: better, same, or worse. When respondents checked only one of the three boxes, Tonso coded a “1” for that characterization. A few respondents (35) marked two or three of the characterizations - their thinking being that they were better for muscles, the same for nerves, but worse for joints (for example). When respondents checked more than one box per body system, the “1” was divided between the boxes marked, entering either 1/2 for two or 1/3 for three boxes.

Figure 1 summarizes Item 23 responses, ranked from left to right according to number of respondents characterizing a category as “worse.” Across the categories, from 12% to 28% respondents were better, 17% to 31% were the same, and 37% to 57% were worse. In other words, up to a fourth of those with EMS are doing better in some categories, about a fourth have stayed the same, and about half are doing worse. However, interpreting these responses is not a straightforward task. Doing “better” may not mean that someone is healthy enough, just as doing “worse” might not indicate that someone is in dire straits. Likewise, staying the same could send mixed messages. For someone with a milder case of EMS at onset, staying the

same poses fewer long-term health concerns. For someone who began with a more severe case of EMS, staying the same is hardly encouraging news.

Delineating these kinds of differences is best done using the fine-grained analysis possible from Item 19 - EMS symptoms. By gauging both the frequency of different symptoms among survey respondents and the changes in respondents' symptoms over the last decade, the survey results document the nature of EMS. The next section examines each of the body-system categories in turn, beginning with Eyes and Vision, working from left to right across Figure 1, and finishing with the Miscellaneous category.

**Item 19: Symptoms Now and Onset**

In Item 19, respondents indicated the presence of each symptom at three different points in time: onset, interim, and now. This section contains the analysis of the onset and now responses. For each symptom marked, Tonso coded a “1” (“0” for unmarked). To date, the analysis focused on descriptive statistics for each symptom (onset and now) and on comparing onset to now responses statistically.

The tables of results summarizing findings for each category share several key features. First, within each table, the symptoms are arranged in order of descending frequency reported in the “now” column. Second, columns show the portion of respondents (as a percent of total respondents) who reported having a symptom at onset, then now. Third, two statistical significance columns indicate the extent to which each symptom got better, worse, or (when blank) stayed the same.

Table 1. Statistical Significance Parameters

Term	Symbol	Statistical Significance Parameters
None	(blank)	$0.100 < p$ (greater than 10% probability of change occurring by chance)
Slightly	✓	$0.020 < p \leq 0.100$ (2-10% probability of change occurring by chance)
Moderately	✓✓	$0.002 < p \leq 0.020$ (0.2-2% probability of change occurring by chance)
Strongly	✓✓✓	$p \leq 0.002$ (less than 0.2% probability of change occurring by chance)

For those interested in the statistical particulars, two matters deserve explanation: the statistical test of differences between means (averages) and the choice of statistical significance levels. Tonso used a t-test for paired (or two-sample) means and a two-tailed test for significance. A paired t-test applies when two means are dependent, as in the case when the same individual's “score” is measured at two different times (onset and now). The two-tailed test for significance implies that the shift from onset to now could go either up or down (worse or better, respectively). Because the sample size is moderate (n=295), Tonso selected a 0.10 level of statistical significance. To say that the difference between two means is “slight” (at the 0.10 level) implies that the probability of the difference occurring by chance is less than 10%. Indicating four ranges of significance - none, slight, moderate, and strong - allows readers to judge the extent to which symptoms have become better (now is lower than onset) or worse (now is higher than onset) (Table 1). The following sections explain the frequency of, and changes in, symptoms, focusing on those symptoms reported by over 25% of respondents.

## Eyes and Vision

The statistical analysis bears out respondents' sense that their eyes and vision have become worse in the last 10 years (Table 2). For symptoms acknowledged by 25-50% of respondents, none were better or the same; and dry eye syndrome, sensitivity to light, blurred vision, dark circles under the eye, sensitivity to blowing air, dramatic vision changes, and inability to tolerate blinking lights worsened.

Table 2. Eyes and Vision

(n=295)	%	%	Statistical Significance	
			Better	Worse
<b>Eyes &amp; Vision</b>	Onset	Now		
dry eye syndrome	32.54	47.80		✓✓✓
sensitivity to light	30.85	45.76		✓✓✓
blurred vision	28.81	42.71		✓✓✓
dark circles under eyes	21.36	30.51		✓✓✓
sensitivity to blowing air	19.32	28.14		✓✓✓
dramatic vision changes	20.00	27.80		✓✓
inability to tolerate blinking lights	18.31	27.12		✓✓✓
redness in & around eyes	15.93	21.36		✓✓
runny eyes or over-productive tear ducts	10.17	18.64		✓✓✓
sensitivity to TV viewing	12.88	17.29		✓
tissue swelling around eyes	15.93	15.25		
other	7.12	11.53		✓✓
inflammation &/or hemorrhage on the eyeball itself	8.47	7.12		

### Muscles, Nerves, Connective Tissues, and Joints

More than any other category, muscles, nerves, connective tissues, and joints remain among the most pervasive symptoms (Table 3). For symptoms reported by over 50% of respondents, only muscle pain improved, though 75% continue to report this symptom; muscle spasms or twitching, a sense of weakness, numbness, tingling, or loss of sensation, and chronic myalgias and arthralgias remained unchanged; and joint pain without redness or swelling got worse. For symptoms reported by from 25-50% of respondents, no symptoms improved; muscle atrophy and red or purplish lower legs, ankles, or feet after standing or showering remained unchanged; and sensitivity to cold, fibromyalgia, restless legs syndrome, sensitivity to heat, disc or lumbar problems, tendonitis, and rotator cuff injury or joint problems got worse.

Table 3. Muscles, Nerves, Connective Tissues, and Joints

(n=295)	%	%	Statistical	Significance
<b>Muscles, Nerves, Connective Tissues, Joints</b>	Onset	Now	Better	Worse
muscle spasms or twitching	74.24	75.59		
muscle pain	82.37	74.58	✓✓	
sense of weakness	74.24	69.83		
numbness, tingling, or loss of sensation	63.05	67.80		
joint pain without redness or swelling	51.19	63.39		✓✓✓
chronic myalgias & arthralgias	55.93	55.93		
sensitivity to cold	39.32	48.14		✓✓✓
fibromyalgia	33.90	45.42		✓✓✓
restless legs syndrome	33.56	41.02		✓✓
muscle atrophy	37.63	39.32		
sensitivity to heat	29.49	37.29		✓✓✓
disc or lumbar problems	21.36	37.29		✓✓✓
red or purplish lower legs, ankles, or feet after standing or showering	33.22	36.27		
tendonitis	21.69	27.46		✓✓
rotator cuff injury or joint problems	18.31	26.44		✓✓✓
joint contractures	25.42	23.73		
carpal tunnel syndrome	18.31	19.66		
abnormal nerve conduction tests	26.44	16.95	✓✓✓	
other	9.49	11.86		
myofascial localized syndrome	10.17	10.85		

## Neurological and Cognitive

Neurological and cognitive symptoms also worsened appreciably (Table 4). For symptoms reported by over 50% of respondents, no symptoms were better; insomnia remained the same, and loss of short-term memory, losing the train of thought in the middle of a sentence, and inability to concentrate worsened. For symptoms reported by 25-50% of respondents, no symptoms improved; difficulty writing and/or typing, dizziness while standing still, night sweats, becoming disoriented in familiar areas, and neurocognitive dysfunction remained the same; and inability to tolerate multiple sensory stimuli, sensitivity to light and/or sound, difficulty discriminating speakers from low-level background noise, cognitive disorders, ringing in the ears, headaches of a new type or severity, problems with speech, dyslexia and/or dyscalcula, and loss of long-term memory worsened.

Table 4. Neurological and Cognitive Symptoms - Comparing Onset to Now

(n=295)	% Onset	% Now	Statistical Better	Significance Worse
<b>Neurological &amp; Cognitive</b>				
loss of short term memory	47.12	67.80		✓✓✓
lose train of thought in the middle of a sentence	40.00	65.42		✓✓✓
inability to concentrate	51.86	61.02		✓✓
insomnia	54.24	54.92		
inability to tolerate multiple sensory stimuli (easily confused when several things require your attention)	33.22	48.81		✓✓✓
sensitivity to light and/or sound	28.14	44.07		✓✓✓
difficulty hearing speakers when low-level background noise is present	23.05	43.39		✓✓✓
cognitive disorders (“brain fog”)	32.54	37.63		✓
difficulty writing &/or typing	33.56	36.27		
ringing in the ears	21.36	33.90		✓✓✓
dizziness while standing still (such as waiting in a line)	29.49	33.22		
headaches of a new type or severity compared to before EMS onset	27.80	32.88		✓
night sweats	31.53	32.20		
problems with speech	24.41	31.53		✓✓
dyslexia and/or dyscalcula (mixing up letters and/or numbers)	19.32	30.51		✓✓✓
becoming disoriented in familiar area	25.08	27.12		
loss of long term memory	17.29	25.76		✓✓✓
neurocognitive dysfunction	23.05	25.42		
impaired ability to drive a vehicle	30.51	21.02	✓✓✓	
irrational thought and/or behavior	10.51	12.88		
loss of sense of taste &/or smell	12.20	11.19		
inability to get out of chair or bed without assistance	34.58	10.85	✓✓✓	
hypersomnia (excessive sleeping)	11.86	10.85		
tremor, myoclonus	10.17	10.51		
sudden loss of motor function	23.05	10.17	✓✓✓	
other	5.76	9.15		✓✓
white matter brain lesions	6.78	7.80		
axonal neuropathy	6.10	5.42		
seizures	3.05	2.37		
stroke	0.68	0.68		
paraplegia	2.37	0.00	✓✓	
quadriplegia	0.68	0.00		

## Gastrointestinal and Bladder

Gastrointestinal and bladder symptoms tended to worsen (Table 5). For symptoms reported by 25-50% of respondents, no symptoms improved; problems swallowing, unexplained weight gain, and diarrhea remained the same; and constipation, irritable bowel or spastic colitis, gastro-esophageal reflux, intestinal spasms, incontinence, and sensitivity to food additives, spices, MSG, sweeteners, etc. worsened.

Table 5. Gastrointestinal and Bladder Symptoms - Comparing Onset to Now

(n=295)	% Onset	% Now	Statistical Significance	
			Better	Worse
<b>Gastrointestinal &amp; Bladder</b>				
problems swallowing	34.24	36.27		
constipation	20.68	34.92		✓✓✓
irritable bowel, spastic colonitis	26.78	34.58		✓✓✓
gastro-esophageal reflux disease	18.98	33.56		✓✓✓
intestinal spasms	26.10	31.53		✓
unexplained weight gain	32.20	30.17		
incontinence	13.90	28.47		✓✓✓
diarrhea	24.41	27.80		
sensitivity to food additives, spices, MSG, sweeteners, etc.	12.54	25.76		✓✓✓
nausea	24.75	23.73		
sore throat	27.80	20.34	✓✓✓	
food allergies	9.15	18.31		✓✓✓
hiatal hernia	11.19	16.61		✓✓
frequent urinary infection	9.49	16.61		✓✓✓
inability (or markedly reduced ability) to tolerate alcohol, where intolerance was not present before	9.83	14.92		✓✓
unexplained weight loss	24.07	8.47	✓✓✓	
other	5.08	8.47		✓✓



## Skin and Deep Tissue

Some of the more prevalent skin and deep tissue symptoms improved, while others worsened (Table 6). Both symptoms reported by over 50% of respondents worsened: excessive dry skin and easy bruising or bruises that do not fade. For symptoms reported by 25-50% of respondents, rashes, scleroderma-like skin thickening or tightness, burning sensation on or in the skin, swelling (water retention or edema), and hair loss (alopecia) improved (though 30-38% still have these); rosacea (redness of the skin, neck, or face) remained the same; and dry flaky skin, sensitivity to sunlight, purple spots under the skin that fade to brown, skin that tears easily or bleeds freely, and sensitivities to soaps and other ordinary skin-care products worsened.

Table 6. Skin and Deep Tissue Symptoms - Comparing Onset to Now

Skin & Deep Tissue (n=295)	% Onset	% Now	Statistical Significance	
			Better	Worse
excessive dry skin	45.08	60.34		✓✓✓
easy bruising or bruises don't fade	43.05	56.27		✓✓✓
dry flaky skin	32.20	48.14		✓✓✓
sensitivity to sunlight	33.56	42.71		✓✓✓
rashes	63.05	37.97	✓✓✓	
scleroderma-like skin thickening or tightness	48.81	37.97	✓✓✓	
burning sensation on or in the skin	43.73	36.95	✓✓	
swelling, water retention (edema)	43.05	36.27	✓	
hair loss (alopecia)	65.76	30.85	✓✓✓	
purple spots under skin that fade to brown	19.66	29.83		✓✓✓
skin tears easily or bleeds freely	18.31	27.80		✓✓✓
sensitivities to ordinary products, such as deodorants, soaps, or lotions	15.25	25.76		✓✓✓
redness of skin - neck and face (rosacea)	22.03	25.08		
cysts or non-malignant fatty tumors (granulomas)	10.51	22.71		✓✓✓
collagen deposits under the skin	15.25	22.03		✓✓✓
skin lesions	23.73	19.66		
skin allergies	10.85	15.59		✓✓
hives	16.61	11.53	✓✓	
other	10.51	11.19		
acne	5.76	8.14		✓
desmoid tumor	0.00	0.68		
malignant fibrous histiocytoma	0.00	0.34		

## Respiratory and Circulatory

Respiratory and circulatory symptoms tended to worsen (Table 7). For symptoms reported by over 50% of respondents, shortness of breath *with* exertion worsened. For symptoms reported by 25-50% of respondents, only shortness of breath *without* exertion improved; no symptoms remained the same; and high cholesterol, rapid, irregular, or abnormal heartbeat, dry, unproductive cough, lightheadedness after standing, and high blood pressure worsened.

Table 7. Respiratory and Circulatory Symptoms - Comparing Onset to Now

(n=295)	%		Statistical Significance	
	Onset	Now	Better	Worse
<b>Respiratory &amp; Circulatory</b>				
shortness of breath with exertion	50.51	60.00		✓✓
shortness of breath without exertion	42.71	37.29	✓	
high cholesterol	16.61	34.24		✓✓✓
rapid, irregular, or abnormal heartbeat	26.44	32.88		✓✓
dry, unproductive cough	25.76	31.86		✓
lightheadedness after standing	23.05	30.17		✓✓
high blood pressure	17.63	28.47		✓✓✓
excess mucous in the lungs	15.93	22.37		✓✓
varicose veins	10.51	20.00		✓✓✓
blue-purple patches on the hands or feet in cold weather (Raynaud's)	12.88	18.98		✓✓✓
chronic respiratory infections	18.64	18.31		
sharp chest pains (angina)	12.88	17.63		✓
viral respiratory infections	10.51	12.20		
bacterial respiratory infections	10.51	11.19		
other	6.44	9.49		✓
pulmonary hypertension	5.76	6.78		
low blood pressure	9.49	6.78	✓	
eosinophilic infiltration	16.61	5.42	✓✓✓	
abnormal chest x-rays	11.53	5.08	✓✓✓	
arteriosclerosis	3.05	5.08		✓
interstitial fibrosis	4.41	4.41		
pleurisy	4.41	4.07		
cardiomyopathy	2.03	2.71		
heart attack	0.68	1.69		
heart failure	2.03	1.02		

## Dental and Oral

Dental and oral symptoms are growing (Table 8). For symptoms reported by 25-50% of respondents, no symptoms improved; dry mouth syndrome (reported by almost half of those with EMS) and chronic, occasional mouth sores and ulcers remained the same; and gum-line tissue loss, and increased sensitivity to hot and cold worsened.

Table 8. Dental and Oral Symptoms - Comparing Onset to Now

(n=295)	%		Statistical Significance	
	Onset	Now	Better	Worse
<b>Dental &amp; Oral</b>				
dry mouth syndrome	41.36	46.44		
gum-line tissue loss	17.29	31.86		✓✓✓
increased oral sensitivity to hot & cold	21.69	30.51		✓✓✓
chronic/occasional mouth sores, ulcers	28.81	28.81		
rapid tooth decay	13.56	21.36		✓✓
TMJ	17.63	18.64		
failure of local anesthetics to “numb” during dental work	11.19	16.27		✓
tooth nerve &/or bone infections	8.14	12.20		✓
overactive saliva & mucous glands	7.12	10.17		✓
other	3.39	6.10		✓

## Psychological

Most psychological symptoms remained the same (Table 9). Half of respondents reported feeling overwhelmed by everyday activities and this has not changed. For symptoms reported by 25-50% of respondents, no symptoms improved; being easily angered or irritated, low or sad mood (or crying for no reason), excessive worry (and panic feelings), secondary (not present before EMS) depression, loss of self worth, and rapid mood changes remained the same; and loss of patience worsened.

Table 9. Psychological Symptoms - Comparing Onset to Now

(n=295)	%		Statistical Significance	
	Onset	Now	Better	Worse
<b>Psychological</b>				
feeling overwhelmed by everyday activities	45.76	50.17		
easily angered or irritated	34.24	34.92		
loss of patience	27.46	34.58		✓✓
low or sad mood, or crying for no reason	32.54	31.86		
excessive or unrealistic worry, or sudden panic feelings	27.46	31.53		
secondary (not present before onset) depression	25.08	29.15		
loss of self worth	30.51	27.12		
rapid or unexpected changes in mood	23.73	26.10		
sense of failure	20.68	24.75		✓
hopelessness	30.85	22.71	✓✓	
strange dreams or nightmares	21.69	22.37		
thoughts of suicide	20.68	10.17	✓✓✓	
other	3.73	6.10		✓

## Immune System

Respondents seemed to be less aware of immune-system issues than other body systems. In Item 19, 67 left it blank, 4 wrote in “?,” 5 wrote “unknown;” and in Item 23, 65 left it blank, 7 wrote “?,” 5 wrote in “unknown.” Also, based on informal evidence from email, telephone, and personal conversations, few people with EMS have had immune-system tests done by their doctors. Because EMS appears to be an autoimmune disease, it seems paradoxical that some people with EMS (and possibly their doctors) are unaware of recent medical research about the immune system. Thus, these data may be somewhat less informative than results from the other eight body systems. Nonetheless, in symptoms reported by 25-50% of respondents, colds, flu, and viruses lasted longer and seemed easier to catch (worsened).

Table 10. Immune System Symptoms - Comparing Onset to Now

(n=295)	%	%	Statistical	Significance
Immune System	Onset	Now	Better	Worse
colds, flu, viruses seem to last longer than pre-EMS	24.07	38.98		✓✓✓
seem to catch colds, flu, viruses easily	26.10	31.86		✓
low grade (mild) fever	32.88	20.00	✓✓✓	
tender lymph nodes	21.02	19.32		
hyperactive immune system	21.36	15.93	✓✓	
underactive immune system	12.54	13.90		
abnormal immune system tests	13.22	7.12	✓✓✓	
other	4.75	5.76		
low T-cell count	5.42	2.37	✓✓	

## Miscellaneous

Symptoms that did not seem to fit in any of the eight body-system categories were accumulated in the miscellaneous category. Here, things are worse (Table 11). Both symptoms reported by over 50% of respondents - substantial exhaustion after physical exertion and unrefreshing sleep - were unchanged. In two symptoms reported by 25-50% of respondents, severe, persistent, or relapsing fatigue for six months or more improved (though 50% of respondents continue to suffer from this symptom) and sexual dysfunction worsened. Since so many of those with EMS took l-tryptophan for sleep difficulties, it is ironic that fatigue-related symptoms remain so pervasive.

Table 11. Miscellaneous Symptoms - Comparing Onset to Now

(n=295)	%	%	Statistical	Significance
Miscellaneous	Onset	Now	Better	Worse
substantial exhaustion after physical exertion	56.27	58.31		
unrefreshing sleep	53.56	55.25		
severe, persistent or relapsing fatigue for six months or more	60.68	49.15	✓✓✓	
sexual dysfunction	26.44	31.19		✓
chronic fatigue syndrome	20.68	24.07		✓
below normal temperature	12.20	20.34		✓✓✓
hypothyroid (low thyroid output)	12.88	19.32		✓✓✓
female/male problems (such as cervical or prostate issues)	5.08	12.88		✓✓✓
other	5.76	8.47		✓
chronic liver disease, cirrhosis	1.36	2.03		
hyperthyroid (high thyroid output)	1.02	1.02		

## DISCUSSION OF FINDINGS

With the results in, it was more than a little depressing, frustrating, and infuriating to find just how little progress seemed to have been made treating this illness. On the bright side, in spite of a decade of living with EMS, respondents seem to be handling the psychological burdens of a chronic disease with aplomb. What can we say about the illness itself? These results strongly suggest that for many of those responding to the survey EMS is a systemic, progressive, and autoimmune illness.

EMS ranges across all systems of the body and many respondents had symptoms in several body systems. This suggests that EMS is a systemic illness. Though muscle, nerve, connective tissue, and joint symptoms are experienced in the greatest frequencies, neurological and cognitive symptoms were a close second, with eyes and vision, skin and deep tissue, gastrointestinal, and respiratory and circulatory symptoms close behind. That EMS appears to be progressive is supported by respondents' sense that their illness is worsening and by the extent to which individual symptoms are worse. Because anecdotal evidence suggests that health care varies dramatically for EMS patients, some portion of this worsening could be due to inadequate health care. The survey findings cannot elaborate on this issue. However, more than inadequate health care seems to be a factor since anecdotal evidence also suggests that many of those with the best health care are "coping with" EMS as it worsens. If this is the case, it strengthens claims about EMS being progressive. Finally, the comprehensive list of symptoms, paralleling in many ways other autoimmune diseases (such as lupus, arthritis, multiple sclerosis, and scleroderma), strongly suggests inflammation and tissue degradation of the sort associated with autoimmune diseases. Also, the increasing tendency of respondents to report skin and food allergies and sensitivities suggests that other immune-system changes may be occurring.

In spite of the substantive improvement of some people for some symptoms, far too many people continue to have debilitating conditions. Subsequent analysis will attempt to ascertain the extent to which aging contributes to health decline for those with EMS. However, in the long run, it makes little difference whether EMS, aging, or other illnesses cause these symptoms. People with EMS deserve better health care.

## LOOKING AHEAD

Two central issues deserve comment: clinical care issues during the last 15 years and recognizing the next toxic event.

### Clinical Care Issues

Virtually without exception, those with chronic EMS feel their medical care has been deficient. Did terms like "epidemic" and "outbreak" give the impression that EMS was an "infectious" disease, and the characteristics used to identify EMS early on gain a life of their own that miscast the disease and misguided front-line caregivers? Because the words "eosinophilia" and "myalgia" and "syndrome" name the disease, there may have been a tendency to believe that these define it. Thus, many with EMS recount experiences where more serious health limitations were dismissed as not a part of EMS, because doctors were sadly misinformed. This was exacerbated due to a lack of a widely-distributed, carefully-developed definition of the disease. It is important to note that in our survey only 16.6% of respondents reported eosinophilic infiltration at onset, with a decline to 5.4% after 10 years. For us, eosinophilia was a marker of a much deeper malady, which highlights a potential to take more seriously what can be quantified easily and to downplay other aspects of the disease that plague those with EMS. Furthermore, our doctors could not cope with the systemic nature of the illness, or with the massive fatigue and associated pain. If these wide-ranging symptoms had been systematically monitored, then we suspect that careful doctors would have been able to connect the dots, but few did either. (See Kaufman "Chronicity of the eosinophilia-myalgia syndrome. A reassessment after three years," *Arthritis & Rheumatism*, 37(1):84-7, 1994 Jan., for such a call from medical researchers.) The lack of systematically distributed information and advice about monitoring patients – at the levels that characterized the "outbreak" communication strategies – compounded these tendencies. Finally, the health-care industry's shift to "managed care" deepened the inadequate care given to those with EMS. Often specialists – especially rheumatologists with both clinical and research practices – ceased to be available to the general public, and primary care physicians became less likely to refer to specialists. But even patients with access to great rheumatologists, for instance, report the tendency to parse EMS in terms of another autoimmune disease, even when features of two or more may be present, and not to monitor each patient's unique situation. Thus, with awareness to the possibility that the medical community may not know enough about EMS yet, we recommend:

- Developing a definition for EMS that highlights its chronic, systemic nature
- Distributing this definition and advice about monitoring and caring for EMS patients to doctors

- Organizing a board of medical researchers and clinicians who can provide consultation about EMS and about care for EMS patients, which would go a long way not only to helping primary care doctors sort out EMS from other issues, but also to having the most knowledgeable medical researchers in the loop and aware of changing circumstances that would likely influence medical research

### **Recognizing and Responding to the Next Toxic Event**

Of course, those with EMS remain concerned that another such an event could occur and go undetected. Many recognized that silicon disease and Gulf War syndrome symptoms paralleled EMS, and felt at times quite fortunate that EMS was noticed without the acrimonious denial that surrounded the other two events. As will become clear in Janet Vaught's remarks, cases with similar toxic-event features fly under the CDC radar on a regular basis. Without meaning to diminish threats to U.S. sovereignty, concern exists about the real possibility that toxic events will come from manufacturing errors and lack of appreciation for unintended consequences to decisions about manufacturing, especially with foods and food additives less likely to undergo rigorous pre-distribution testing. Also, there is only a partial understanding of how the toxins in l-tryptophan were produced and knowing more would provide advice about food production and processing. In addition, to do a thorough job of understanding EMS itself suggests the need for considerably more research about those with EMS. With all due respect to medical researchers like yourselves who have worked to understand this disease, studying a cohort of persons with EMS longitudinally should be an important part of understanding the full range of EMS. Thus, in addition to fine-grained research intended to explain how toxicity, allergy, and autoimmunity interacted to produce EMS, we recommend:

- Organizing a clearinghouse for unexplained cases similar to EMS, because this is where the early warning signs will appear
- Saving and archiving as much as possible of the Showa Denko information now stored in Denver
- Analyzing the remainder of the EMS survey and expanding on it by studying those with EMS