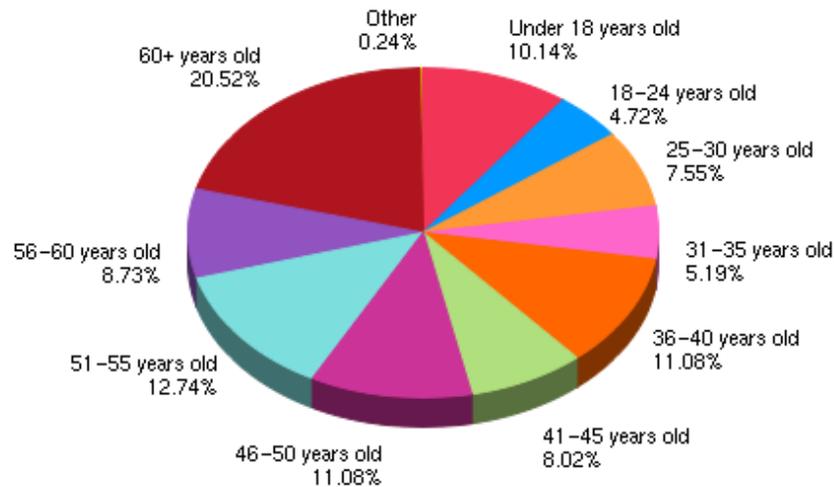


# Response Summary Report I

January 24, 2012

1. At what age did you first become aware of your erythromelalgia (EM) symptoms?



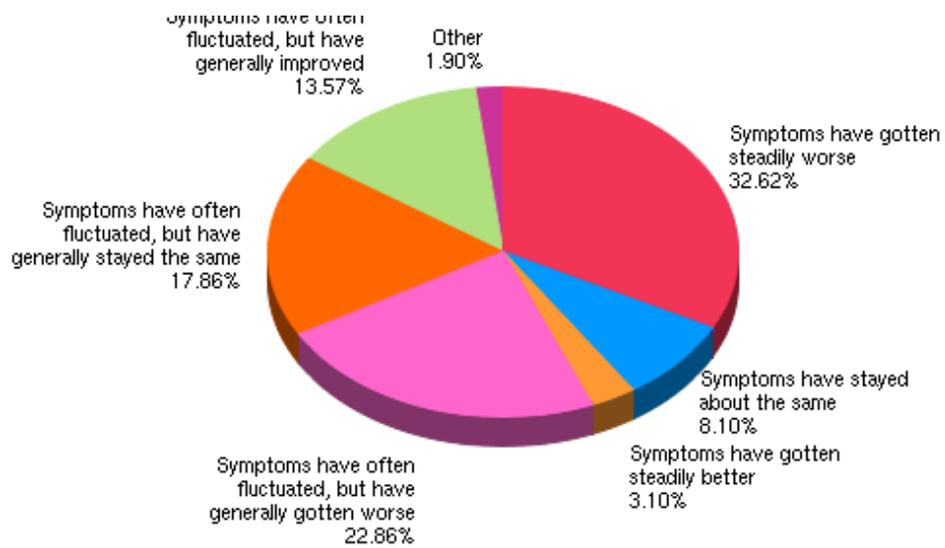
Item	Count	Percent %
Under 18 years old	43	10.14%
18-24 years old	20	4.72%
25-30 years old	32	7.55%
31-35 years old	22	5.19%
36-40 years old	47	11.08%
41-45 years old	34	8.02%
46-50 years old	47	11.08%
51-55 years old	54	12.74%
56-60 years old	37	8.73%
60+ years old	87	20.52%
Don't know / Can't remember	1	0.24%

2. Do you feel your symptoms started after some sort of defining event like trauma or change in your life?



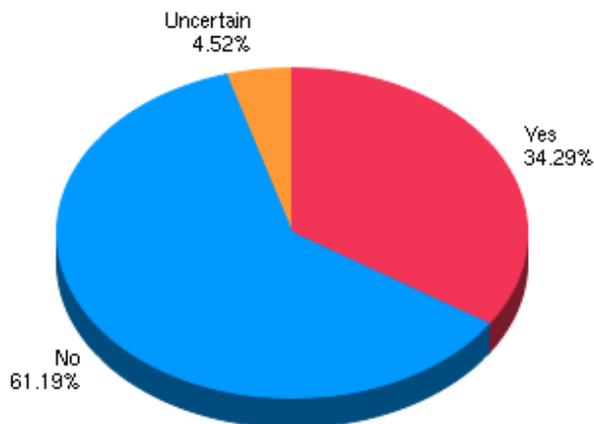
Item	Count	Percent %
Yes	117	27.66%
Sort of	79	18.68%
No	227	53.66%

## 3. How have your symptoms changed since you first became aware of them?



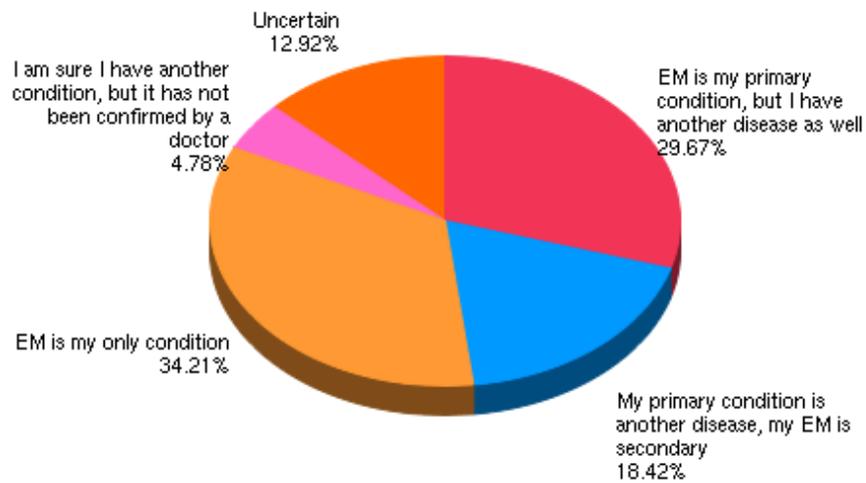
Item	Count	Percent %
Symptoms have gotten steadily worse	137	32.62%
Symptoms have stayed about the same	34	8.10%
Symptoms have gotten steadily better	13	3.10%
Symptoms have often fluctuated, but have generally gotten worse	96	22.86%
Symptoms have often fluctuated, but have generally stayed the same	75	17.86%
Symptoms have often fluctuated, but have generally improved	57	13.57%
Not sure	8	1.90%

4. Since your EM symptoms started have you had periods of more than a few days where you were symptom-free?



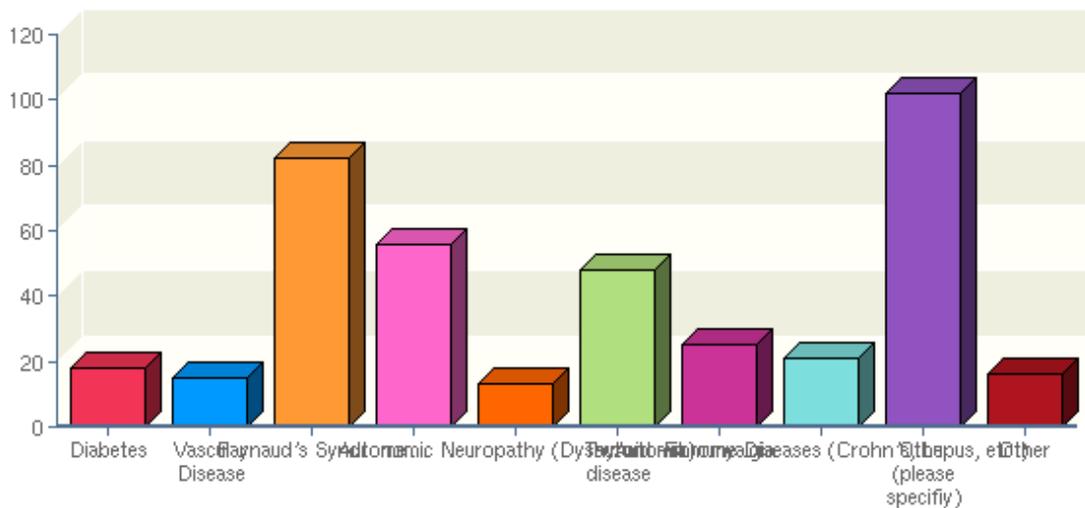
Item	Count	Percent %
Yes	144	34.29%
No	257	61.19%
Uncertain	19	4.52%

5. Other diseases can accompany EM, either in a primary role or a secondary role. Which of the following applies to you?



Item	Count	Percent %
EM is my primary condition, but I have another disease as well	124	29.67%
My primary condition is another disease, my EM is secondary	77	18.42%
EM is my only condition	143	34.21%
I am sure I have another condition, but it has not been confirmed by a doctor	20	4.78%
Uncertain	54	12.92%

## 6. What other diseases or conditions do you have that accompanies your EM? (Select all that apply)

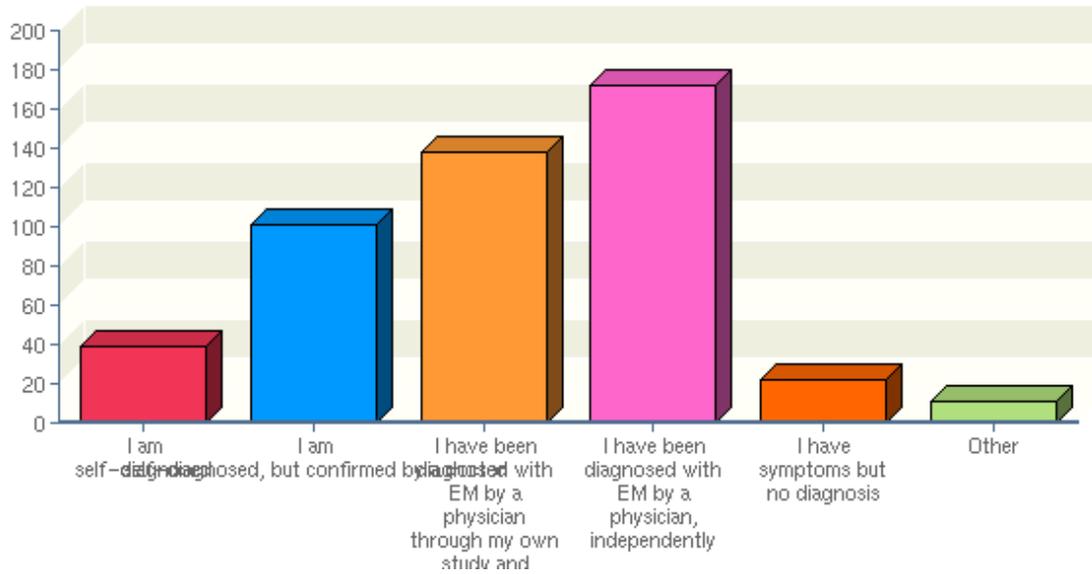


Item	Count	Percent %
Diabetes	18	9.18%
Multiple Sclerosis	5	2.55%
Myeloproliferative disorder	2	1.02%
Vascular Disease	15	7.65%
Raynaud's Syndrome	82	41.84%
...	56	28.57%
Peripheral Neuropathy	2	1.02%
Autonomic Neuropathy (Dysautonomia)	13	6.63%
Thyroid disease	48	24.49%
Fibromyalgia	25	12.76%
Reflex Sympathetic Dystrophy (aka CRPS)	7	3.57%
Auto-immune Diseases (Crohn's, Lupus, etc.)	21	10.71%
Other (please specify)	102	52.02%
Others: Other (please specify)		
Rosacea	3	1.53%
Breast Cancer	2	1.02%
osteoporosis	2	1.02%
Rheumatoid arthritis	2	1.02%
3 prostate ops (one with low "illegible" cancer)	1	0.51%
alcohol (also vinegar, mustard) total intolerance	1	0.51%
Antiphospholipid	1	0.51%
Anxiety, ADHD	1	0.51%
arthritis	1	0.51%
arthritis, dental	1	0.51%
ARTHRITIS	1	0.51%
atrial fibrillations, anxiety	1	0.51%
Auto-Immune runs in famil	1	0.51%
Benign brain tumour	1	0.51%
Bilat. Lumbar Radiculopathy s/p Hemilaminectomies	1	0.51%
Bowen's Disease	1	0.51%
Burning Mouth	1	0.51%
Carpel Tunnel Syndrome and may suffer from Raynaud's Syndrome	1	0.51%
Chronic back pain (possibly fibromyalgia or myofascial)	1	0.51%

Item	Count	Percent %
Chronic fatigue syndrome, asthma, macrocytic anemia, eczema	1	0.51%
Chronic Headache	1	0.51%
chronic renal failure / on dialysis	1	0.51%
Colitis	1	0.51%
Connective Tissue Disease	1	0.51%
CREST	1	0.51%
degenerative disk disease	1	0.51%
Depression	1	0.51%
dilated aorta	1	0.51%
Ehlers Danlos	1	0.51%
ELEVATED CHOLESTEROL EVEN UNDER MEDICATIONS...INHERITED. I DO NOT HAVE HIGH BLOOD PRESSURE NOR HAVE I HAD A HEART ATTACK OR NEEDED VASCULAR SURGERY	1	0.51%
Fibrosing Alveolitis	1	0.51%
food allergies	1	0.51%
heart bypass, prostate cancer healed	1	0.51%
heart condition	1	0.51%
Heart Disease/Dilated Aorta	1	0.51%
heart diseast	1	0.51%
Hep. C	1	0.51%
high blood pressure and cholesterol, thyroidectomy, GERD	1	0.51%
high blood pressure, high cholesterol, type 2 diabetes	1	0.51%
high lipids, high blood pressure	1	0.51%
hypercholesterolemia	1	0.51%
hypertension	1	0.51%
hypertension since age 18	1	0.51%
I get anti depression medicin	1	0.51%
IBS	1	0.51%
Interstitial Cystitis, Menieres	1	0.51%
lichen planus	1	0.51%
Liver disease from diabetes	1	0.51%
lumbar/sacral disc disease	1	0.51%
Lyphoplasmacytic Lymphoma (Waldenstroms Macroglobulinemia)	1	0.51%
M.E	1	0.51%
migraine	1	0.51%
Migraines, Anhidrosis	1	0.51%
mixed connective tissue disease	1	0.51%
Monoclonal gammopathy	1	0.51%
mononeuropathy multiplex vasculitis, sensory autonomic neuropathy, trigeminal neuralgia, cachetsia	1	0.51%
Morton's Neuroma	1	0.51%
MTFHR - Blood Clot Disorder	1	0.51%
muscle spasms of feet & calves	1	0.51%
nerve entrapment in foot	1	0.51%
Non-malignant Tumor on my pituitary gland so that the gland no longer functions. I rely on Hydrocortisone to address this situation.	1	0.51%
None that I know of	1	0.51%
Nothing confirmed yet, but I have had a very poor immune system for all of my 37 years.	1	0.51%
Obstructive Sleep Apnea	1	0.51%
onset of raynauds after onset of EM	1	0.51%
OPLL, ossification of the posterior longitudinal ligament (causes stenosis of the spinal canal & compression of the spinal cord)	1	0.51%
osteo arthritis	1	0.51%
osteo-arthritis	1	0.51%
osteoporosis at age 17	1	0.51%

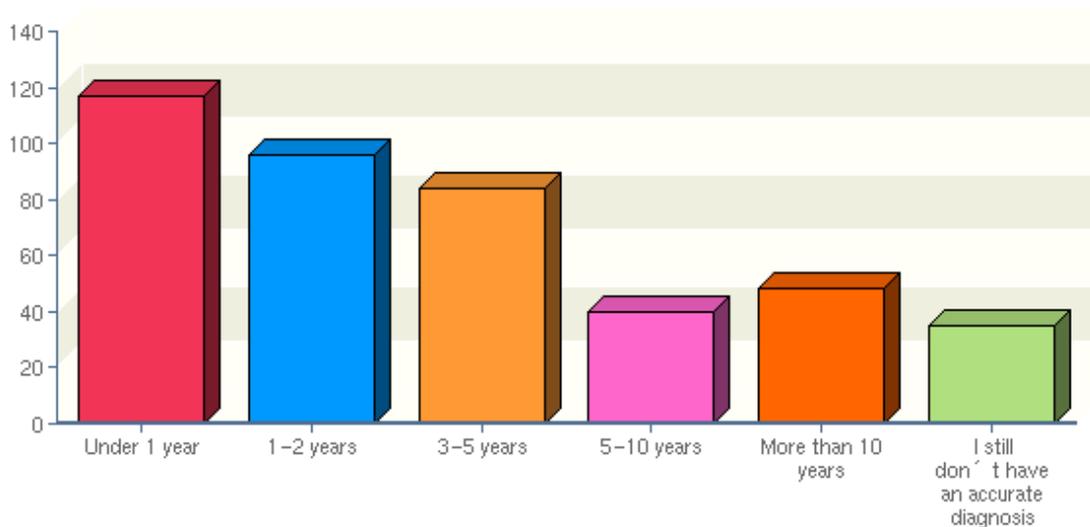
Item	Count	Percent %
osteoporosis, high blood pressure, high cholesterol	1	0.51%
Panic Disorder	1	0.51%
parkinson's (MSA?)	1	0.51%
periodic paralysis	1	0.51%
Perniosis	1	0.51%
Photosensitivity, HBP, Osteoarthritis	1	0.51%
Platelet count is high, cholesterol was very high	1	0.51%
Polycythemia Rubra Vera	1	0.51%
post-op.depression	1	0.51%
Postural orthostatic Tachycardia Syndrome (POTS)	1	0.51%
Pre-diabetes; lupus antibody positive once.	1	0.51%
premature ovarian failure (early menopause)	1	0.51%
primary is bronchiectasis	1	0.51%
Problems with blood clots	1	0.51%
pseudohypoparathyroidism and metatarsalgia	1	0.51%
reactive hypoglycemia	1	0.51%
reactive thrombocytosis	1	0.51%
Restless leg syndrome	1	0.51%
Rheumatoid arthritis	1	0.51%
rhuematoid arthritis	1	0.51%
scoliosis, osteoporosis, arthritis	1	0.51%
sleep disorder and psychiatric disorder	1	0.51%
small fiber neuropathy	1	0.51%
small fiber neuropathy	1	0.51%
small fibre neuropathy, interstitial cystitis, irritable bowel syndrome	1	0.51%
Temporal arteritis and polymyalgia	1	0.51%
thallesemia, von williambrands disease, profound deaf	1	0.51%
thyroid cancer, anti-phoslipid antibodies	1	0.51%

7. Please indicate which of the following statements applies to your EM diagnosis. (Select all that apply)



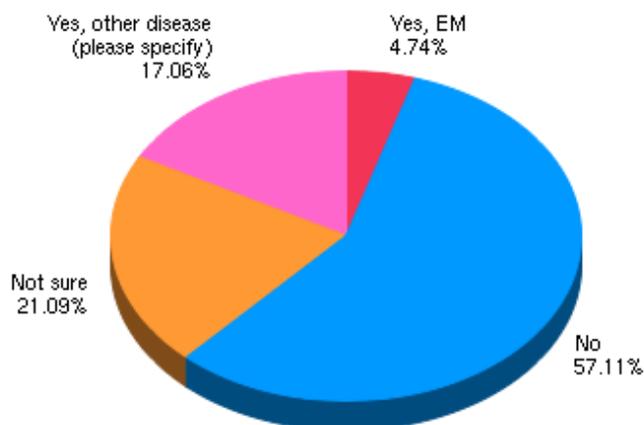
Item	Count	Percent %
I am self-diagnosed	39	9.24%
I am self-diagnosed, but confirmed by a doctor	101	23.93%
I have been diagnosed with EM by a physician through my own study and efforts	138	32.70%
I have been diagnosed with EM by a physician, independently	172	40.76%
My diagnosis has been supported by genetic testing.	7	1.66%
I have symptoms but no diagnosis	22	5.21%
None of these apply to me	4	0.95%

8. Approximately how long did it take you or the medical community from the time you first had EM symptoms until you had an accurate EM diagnosis?



Item	Count	Percent %
Under 1 year	117	27.86%
1-2 years	96	22.86%
3-5 years	84	20.00%
5-10 years	40	9.52%
More than 10 years	48	11.43%
I still don't have an accurate diagnosis	35	8.33%

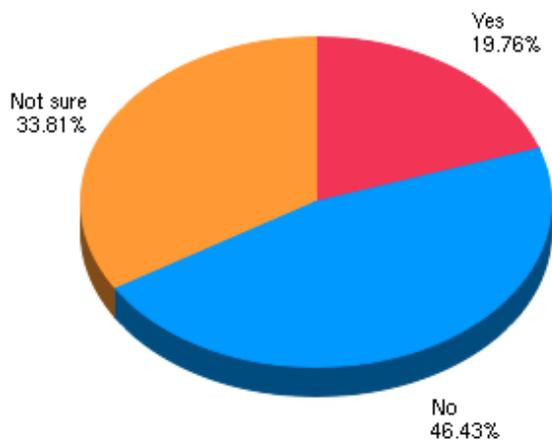
9. Do you have any blood relatives that have been diagnosed with EM (or any of the other diseases mentioned above)?



Item	Count	Percent %
Yes, EM	20	4.74%
No	241	57.11%
Not sure	89	21.09%
Yes, other disease (please specify)	72	17.23%
Others: Yes, other disease (please specify)		
Raynauds	3	0.71%
Thyroid disease	3	0.71%
Diabetes, Raynaud's	2	0.47%
Lupus	2	0.47%
Raynaud's	2	0.47%
Autonomic Neuropathy (Dysautonomia), Diabetes	1	0.24%
lumbar disc disease; rosacea	1	0.24%
(familial) CA of thyroid, MS	1	0.24%
A-typical R.S.D.	1	0.24%
Aunt has Lupus and Raynauds, Grandmother and aunt have diabetes	1	0.24%
auto-immune-fibro	1	0.24%
bvother, raynauds	1	0.24%
cant see list of diseases but blood relatives with hashimoto's thyroiditis, and gluten intolerance	1	0.24%
cardiac sarcoidosis (mother)	1	0.24%
daughter has raynauds in winter time, mother had cold feet alot of the time	1	0.24%
diabetes	1	0.24%
DIABETES AND VASCULAR DISEASE	1	0.24%
diabetes, vascular	1	0.24%
diabetes, vascular disease	1	0.24%
Diabetes, Vascular disease, Raynauds and Fibromyalgia	1	0.24%
Dysautonomia, thyroid disease,Lupus,Raynauds	1	0.24%
EM and diabetes	1	0.24%
Father - Diabetes, Mother - Thyroid Disease	1	0.24%
father diabetic/neuropathy	1	0.24%
father mature onset diabetes mother mild sarcoidosis lungs	1	0.24%
father, crps	1	0.24%
female cousin with raynauds and died of complications of Scleroderma	1	0.24%

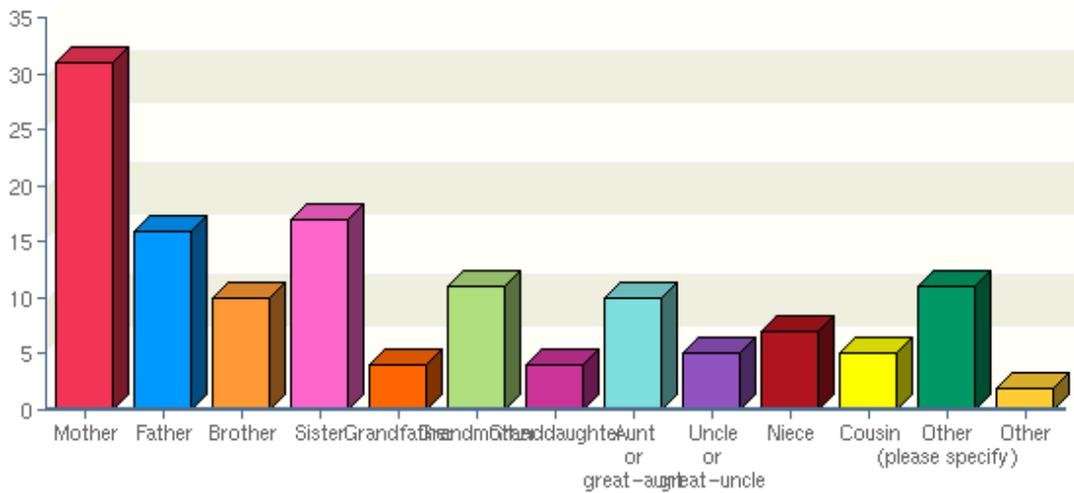
Item	Count	Percent %
Fibro, Crohn's, PN, Hypo Thyroid	1	0.24%
fibromyalgia	1	0.24%
Fibromyalgia,MS, Diabetes	1	0.24%
Fibromyalgia/RSD	1	0.24%
Hypo-hyperthyroidism, Fibromyalgia and Addisons Disease	1	0.24%
hypoglycemia	1	0.24%
Hypothyroidism, arthritis, osteoporosis	1	0.24%
hypothyroidism, diabetes	1	0.24%
hypothyroidism, maybe Raynaud's	1	0.24%
lupus, diabetes	1	0.24%
migraine	1	0.24%
Many that have symptoms, some gave names over the years to the other diseases but none that consider their em symptoms as the worst of their problems.	1	0.24%
Mother = lupus, father = rheumatoid arthritis	1	0.24%
mother died of lupus	1	0.24%
mother has fibromyalgia	1	0.24%
MS	1	0.24%
MS - brother	1	0.24%
Multiple Sclerosis	1	0.24%
my mother have the opposite Raynauds symphoms	1	0.24%
peripheral neuropathy, diabetes, lupus	1	0.24%
R.A.	1	0.24%
Raynads	1	0.24%
Raynaud	1	0.24%
raynaud's, dysautonomia	1	0.24%
Raynauds Syndrome	1	0.24%
raynauds, scleroderma, Marie Charcots Toothes Disease	1	0.24%
reflex sympathy disease	1	0.24%
Reynaud's syndrome	1	0.24%
reynauds	1	0.24%
Rheumatoid Arthritis and Diabetes	1	0.24%
rhuetoid arthritis	1	0.24%
scleroderma and raynaud's	1	0.24%
Sister -Fibramyalgial Father - Restless les syndrome; Uncle Possible EM	1	0.24%
thyroid	1	0.24%
Thyroid ( hypo )	1	0.24%
thyroid disease, als (auto-immune)	1	0.24%
vascular disease	1	0.24%
vascular disease, diabetes	1	0.24%

10. Do you think any of your blood relatives have EM symptoms but have not actually been diagnosed with EM?



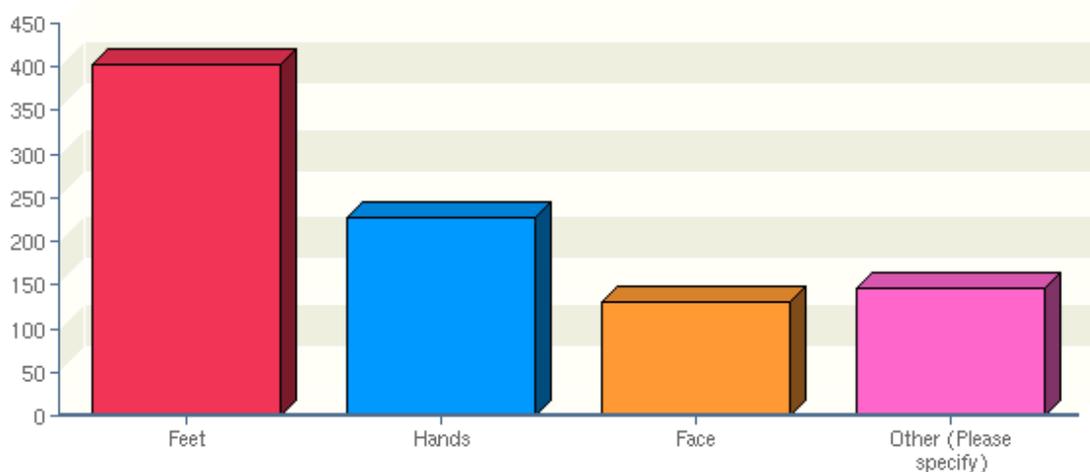
Item	Count	Percent %
Yes	83	19.76%
No	195	46.43%
Not sure	142	33.81%

## 11. List your relations that have been diagnosed with EM or who you think might have EM symptoms.



Item	Count	Percent %
Mother	31	37.80%
Father	16	19.51%
Brother	10	12.20%
Sister	17	20.73%
Grandfather	4	4.88%
Grandmother	11	13.41%
Grandson	1	1.22%
Granddaughter	4	4.88%
Aunt or great-aunt	10	12.20%
Uncle or great-uncle	5	6.10%
Niece	7	8.54%
Nephew	1	1.22%
Cousin	5	6.10%
Other (please specify)	11	13.42%
Others: Other (please specify)		
Daughter	3	3.66%
2 daughters	1	1.22%
2nd brother	1	1.22%
cousin's daughter	1	1.22%
Daughter	1	1.22%
great grandmother	1	1.22%
middle son	1	1.22%
my children	1	1.22%
son	1	1.22%

12. Please indicate in which of the following locations you experience painful flares which you attribute to your EM.  
(Select all that apply)

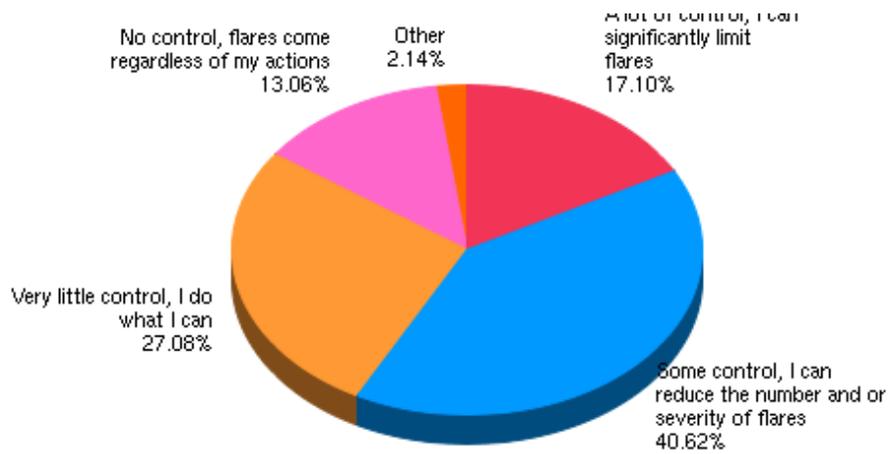


Item	Count	Percent %
Feet	403	95.27%
Hands	228	53.90%
Face	131	30.97%
Other (Please specify)	146	34.87%
Others: Other (Please specify)		
ears	22	5.20%
knees	7	1.65%
legs	5	1.18%
lower legs	4	0.95%
ankles	3	0.71%
legs and arms	3	0.71%
Head	2	0.47%
above knee	1	0.24%
Along my arms, but not on my hands (not too frequent though). Plus along my legs up to my knee.	1	0.24%
and lower legs	1	0.24%
ankles and knees	1	0.24%
Ankles and lower half of lower leg	1	0.24%
ankles and up a little	1	0.24%
Anterior Thighs	1	0.24%
arms up to elbows and legs up to knees	1	0.24%
Arms, lower legs	1	0.24%
at it's worst,shins more so than feet	1	0.24%
back	1	0.24%
back of arms, back of legs up to waist	1	0.24%
between thighs	1	0.24%
both knees	1	0.24%
both legs from feet to knees	1	0.24%
calves	1	0.24%
chest	1	0.24%
chest & back	1	0.24%
chest, ears, back	1	0.24%

Item	Count	Percent %
crotch	1	0.24%
ear	1	0.24%
ears and nose	1	0.24%
ears are worst for em, Hands and Nose is worse for raynaud's but can have both in all areas.	1	0.24%
ears occasionally	1	0.24%
Ears, & I think there is some related affect causing sensitivity to light and sound, and strange "dizziness," categorized as perhaps some kind of migrane, but headache is not the main sympton.	1	0.24%
ears, and sometimes nose	1	0.24%
ears, ankles	1	0.24%
ears, but not painful	1	0.24%
ears, lips	1	0.24%
ears, lower extremities to the knees	1	0.24%
ears, nose, knees	1	0.24%
ears,chest	1	0.24%
entire body	1	0.24%
entire legs up to trunk	1	0.24%
face is ears and nose (cheeks also but think is rosacea only)	1	0.24%
face with reddnes only without the heat and pain	1	0.24%
Feet to above knees	1	0.24%
Foot discomfort; not painful	1	0.24%
forearms	1	0.24%
front of legs up to knees1`	1	0.24%
genital area, left butt-cheek, lower legs	1	0.24%
Hand minor; face seldom	1	0.24%
I sometimes get a burning of the face	1	0.24%
In basic remission, but had it eventually over whole body	1	0.24%
it is not painful but the sweating is almost unbearable	1	0.24%
it sometimes travels up to my knees	1	0.24%
just left foot/hands	1	0.24%
knee	1	0.24%
knees and legs	1	0.24%
knees, ears	1	0.24%
knees, ears, and possibly in nasal sinus cavity	1	0.24%
Knees, ears, scalp, breast, eyelids	1	0.24%
knees,arms,ears,chest	1	0.24%
knees/all over body	1	0.24%
Legs including upper thighs	1	0.24%
legs midway to knees	1	0.24%
legs to knees, hands to elbow	1	0.24%
legs up to knees	1	0.24%
Legs, Arms & Ears	1	0.24%
legs, arms and ears	1	0.24%
Legs, arms, ears, back, etc - nearly everywhere	1	0.24%
legs, back	1	0.24%
legs, buttocks	1	0.24%
legs, knees to feet	1	0.24%
legs, knees, hips	1	0.24%
legs,and arms	1	0.24%
legs/arms	1	0.24%
lips	1	0.24%
lower arms and legs	1	0.24%
lower arms, lower legs	1	0.24%
lower legs, buttocks, scalp, ears	1	0.24%
lower legs, especially shins	1	0.24%

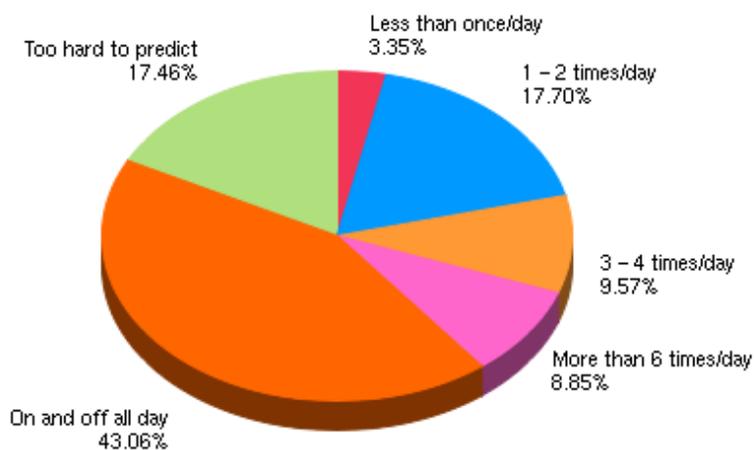
Item	Count	Percent %
lower legs, menstrual problems	1	0.24%
maybe just starting in hands	1	0.24%
mostly HANDS, some toes	1	0.24%
mouth	1	0.24%
neck	1	0.24%
neck, chest	1	0.24%
neck, shoulder and knees	1	0.24%
Nose	1	0.24%
nose knee	1	0.24%
Nose,	1	0.24%
Now my neck and back of head	1	0.24%
only toes	1	0.24%
outside thighs, sometimes there seems to be a flush all over	1	0.24%
pain behind knees	1	0.24%
She has problems with her feet, but we think this is actually due to the arthritis in her toes.	1	0.24%
some difficulty with arms but no flaring	1	0.24%
Sometimes "buzzing" sensations in face and throughout torso; sometimes interior buzzing.	1	0.24%
sometimes cheeks	1	0.24%
Sometimes entire body	1	0.24%
thigh	1	0.24%
throughout whole body	1	0.24%
Toes	1	0.24%
Top of head & buttocks	1	0.24%
torso,shoulders,legs,arms,all over	1	0.24%
up legs/calves	1	0.24%
upper back of legs and buttocks	1	0.24%
upper chest	1	0.24%
yes, burning and bloodshot	1	0.24%

13. Based on actions you take to control your environment, how much control do you have over the frequency of you EM flares?



Item	Count	Percent %
A lot of control, I can significantly limit flares	72	17.10%
Some control, I can reduce the number and or severity of flares	171	40.62%
Very little control, I do what I can	114	27.08%
No control, flares come regardless of my actions	55	13.06%
Not sure	9	2.14%

14. If you did NOTHING to control your EM flares, how often would you experience a flare-up?



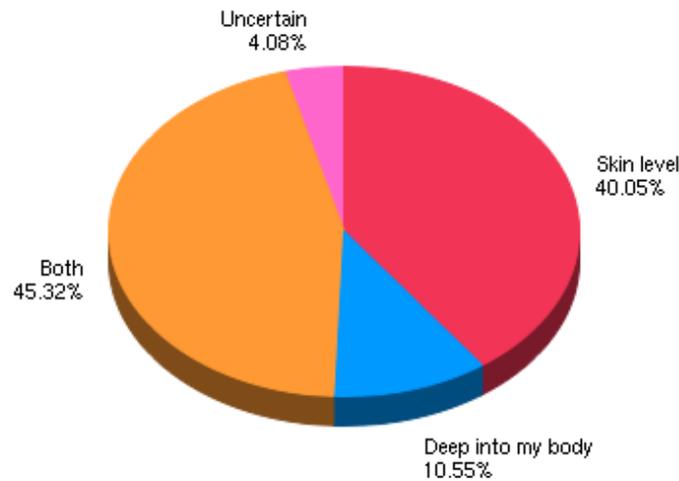
Item	Count	Percent %
Less than once/day	14	3.35%
1-2 times/day	74	17.70%
3-4 times/day	40	9.57%
More than 6 times/day	37	8.85%
On and off all day	180	43.06%
Too hard to predict	73	17.46%

15. Please indicate the worst degree of pain you might feel during a flare-up and the typical degree of pain you feel during a flare up.

Table 1 of 2	Item	No pain	Slight pain	Moderate pain	Intense pain
#0	Worst degree	1.2% 5	4.1% 17	15.6% 65	41.9% 175
	Typical degree	3.8% 16	13.4% 56	53.0% 221	26.6% 111
#2	Average %	2.5%	8.7%	34.3%	34.3%

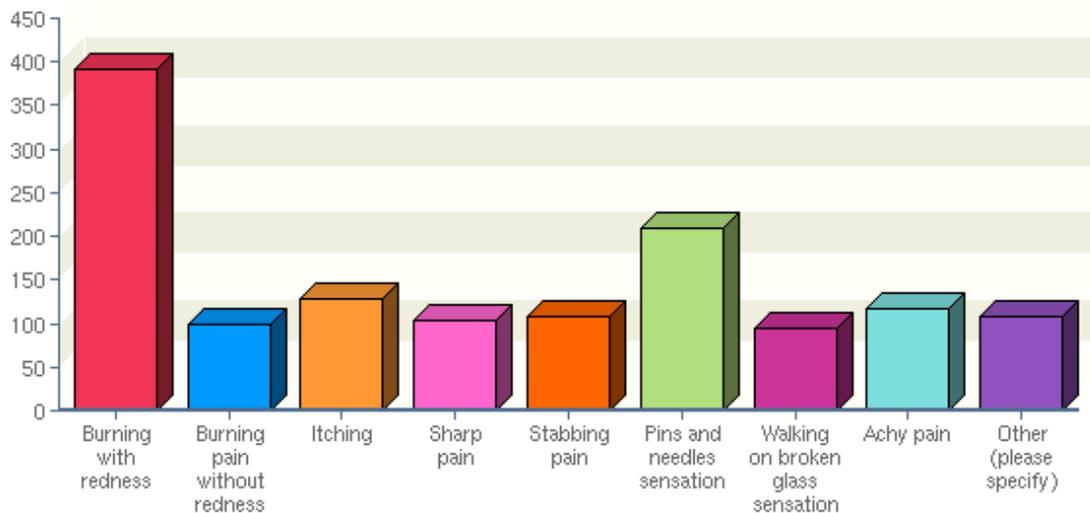
Table 2 of 2	Excrutiating pain	Uncertain	Total
#0	36.1% 151	1.2% 5	418
#1	2.2% 9	1.0% 4	417
#2	19.2%	1.1%	835.0

16. At what level would you say you experience your EM pain?



Item	Count	Percent %
Skin level	167	40.05%
Deep into my body	44	10.55%
Both	189	45.32%
Uncertain	17	4.08%

17. Please indicate the type of pain you experience with your EM flares. (Select all that apply)



Item	Count	Percent %
Burning with redness	391	92.43%
Burning pain without redness	99	23.40%
Itching	129	30.50%
Sharp pain	103	24.35%
Stabbing pain	109	25.77%
Pins and needles sensation	210	49.65%
Walking on broken glass sensation	94	22.22%
Achy pain	117	27.66%
Other (please specify)	107	25.64%
Others: Other (please specify)		
crushing Pain	2	0.47%
Pressure sensation	2	0.47%
Swelling	2	0.47%
throbbing pain	2	0.47%
carpet feels like sharp stones	1	0.24%
a swollen feeling, like the hands have too much blood in them.	1	0.24%
after blow torch is touched to gasoline drenched feet	1	0.24%
also I experience pain in the jaw bone still after 2 years removing teeth	1	0.24%
As long as my feet are cool and raised, there is only a slight throbbing. But, pressure from walking on them can be pretty intense.	1	0.24%
at it's worse, it feels as if the skin on the bottom of my feet has been peeled off and I am trying to walk on them	1	0.24%
At night in bed,when lying down	1	0.24%
bee-stings	1	0.24%
Boiling acid poured over feet	1	0.24%
bottom of feet incredibly sore	1	0.24%

Item	Count	Percent %
burning pain with redness, edema	1	0.24%
buzzing pain in toes and botton of feet.	1	0.24%
color of feet: blue	1	0.24%
constant "buzzing" as though electrical current is flowing	1	0.24%
cramping	1	0.24%
crawling sensations (sometimes)	1	0.24%
crushing sensation (in feet only)	1	0.24%
deep bone pain	1	0.24%
don't have flare ups anymore	1	0.24%
dull aching	1	0.24%
During an intense flare, walking feels as if the skin on the bottom of my feet has been peeled off.	1	0.24%
edema in my feet, very severe	1	0.24%
either a Freezing/Hot or Burning/Cold sensation	1	0.24%
Electric (like E-stim set too high)	1	0.24%
electric like shocks day or night	1	0.24%
electrical feeling	1	0.24%
Electrical Sensation in Feet	1	0.24%
emptiness	1	0.24%
excruciating deep pressure	1	0.24%
extreme heat (not pain)	1	0.24%
extreme skin sensitivity	1	0.24%
facial bone, teeth, and jaw pain	1	0.24%
feeling of being on fire	1	0.24%
feeling of large painful blisters on bottom of feet	1	0.24%
feeling of raw flesh, burnt, stinging nettle rash. Itching, burning; low back, arms, shoulder bone area, front stomach, hips.	1	0.24%
feels like a layer of skin has been ripped off & then salt rubbed into the open wounds.	1	0.24%
feels like I'm walking on metal nuts/bolts,skin feels like it's 3/4 sizes too small, burning sensation up legs if contacting a surface, toes feel like being crushed inside but have lost sense of touch on surface of toes.	1	0.24%
Feet and angles feel like they will burst.	1	0.24%
Feet are very sore and tender most of the time.	1	0.24%
Gritty/gravelly feeling in foot. Also, very unpleasant neurological sensations when foot goes cold.	1	0.24%
heavyness and aching in arms and/or legs	1	0.24%
Hot	1	0.24%
hot, swollen hands	1	0.24%
I have nerve pain all the time, the least being "buzzing." Flare-ups consistently occur when it's hot (so I use AC & fans almost always).	1	0.24%
inabilty to sleep	1	0.24%
It's like a bad toothache in my limbs sometimes	1	0.24%
like a vise grip around my legs	1	0.24%
like an asphalt burn on the bottoms of my feet	1	0.24%
looks like sunburn, shiny tight swollen skin, red as lobster	1	0.24%
My flares don't cause pain during the flare--just too much heat. If I have flares frequently it eventually leads to constant inflamation/swelling in my toes along with pain	1	0.24%
My pain in the neck is so bad that I am unable to turn my head at imes andthe back of my head will go numb. I have been doctoring forover a year and now finally my GP is going to have an MRI done of the brain. He doesn't feel it is neuro but understands it is not a normal thing. Dr. also is not familiar with EM.	1	0.24%
my skin on ankles feels tight and swollen feels stretched.	1	0.24%
neuropathy	1	0.24%
no relief -swelling, can't think of anything else	1	0.24%
oedema (feet)	1	0.24%

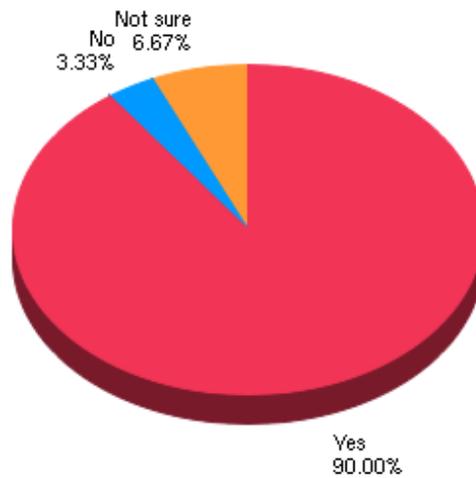
Item	Count	Percent %
often tightening of esophagus blurred vision and extreme forgetfulness, mind goes blank	1	0.24%
Pain from edema in feet and legs. Also sinus pain from EM on face	1	0.24%
Pain in ball of my right foot where it all started.	1	0.24%
pain like an electric shock on the tips of fingers and rarely a toe	1	0.24%
pain so severe feel like killing self	1	0.24%
pins and needles, plus burning and redness, sometimes sharp pain	1	0.24%
pulsing, neuropathy (although not necessarily at the time of flare)	1	0.24%
racing heart	1	0.24%
Redness, heat, discomfort except during summer	1	0.24%
rithing and crying, almost a state of shock and can experience 3rd degree burns on skin with blistering.	1	0.24%
see the above comments about migraines	1	0.24%
severe heat	1	0.24%
skin feels ready to split	1	0.24%
slight burning, no redness	1	0.24%
sometimes crawly sensations	1	0.24%
stinging and pressure from within	1	0.24%
Swelling - pressure	1	0.24%
swelling and difficulty walking	1	0.24%
swelling and stiffness, my whole day suddenly becomes miserable and intolerable, become short with people and things	1	0.24%
swelling of whole top of foot	1	0.24%
swelling pain	1	0.24%
Swelling tightness, warmth	1	0.24%
swelling w/redness and burning	1	0.24%
swelling, especially toes and fingers	1	0.24%
swelling, neurological sensations from feet to upper neck	1	0.24%
swelling, skin tightness, as if I will explode	1	0.24%
Swelling, veins stick out	1	0.24%
swelling, tight skin, like my body will explode,	1	0.24%
swollen toes the worst	1	0.24%
terrible sensitivity of the skin to air flow and water	1	0.24%
thobbing pain	1	0.24%
Throbbing	1	0.24%
throbbing like you get when something is swollen	1	0.24%
Throbbing pain from swelling	1	0.24%
tightness	1	0.24%
twitches	1	0.24%
unbearable pressure on veins	1	0.24%
uncomfortable hot skin (unrelated heel pain & ankle joint contractures)	1	0.24%
very hott, feet feel like intense pressure	1	0.24%
walking ankle-deep in burning hot sand	1	0.24%
walking on blisters	1	0.24%
walking on fire with burned off skin	1	0.24%
walking on rocks sensation	1	0.24%
when very intense tingling pain w/burning skin becomes very dry	1	0.24%

18. Which of these choices most closely describes your perspiration (sweating)?

Table 1 of 2	Item	Excessive	Normal	Less than normal	Very little, if at all
#0	During a flare-up	14.1% 59	31.7% 132	5.8% 24	41.0% 171
#1	Normally	4.0% 16	44.4% 179	12.4% 50	36.7% 148
#2	Average %	9.1%	37.9%	9.0%	38.9%

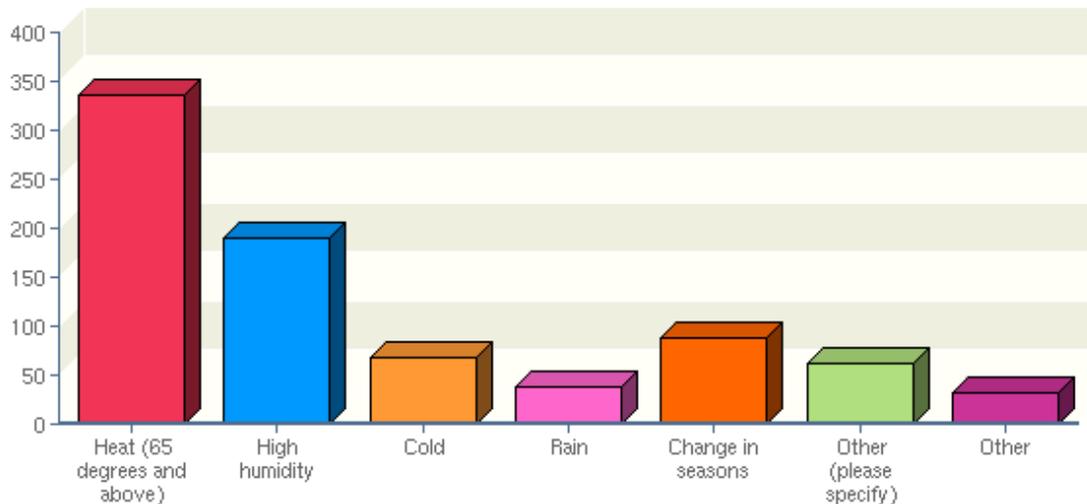
Table 2 of 2	Not sure	Total
#0	7.4% 31	417
#1	2.5% 10	403
#2	5.0%	820.0

19. Do particular weather conditions tend to exacerbate your EM symptoms?



Item	Count	Percent %
Yes	378	90.00%
No	14	3.33%
Not sure	28	6.67%

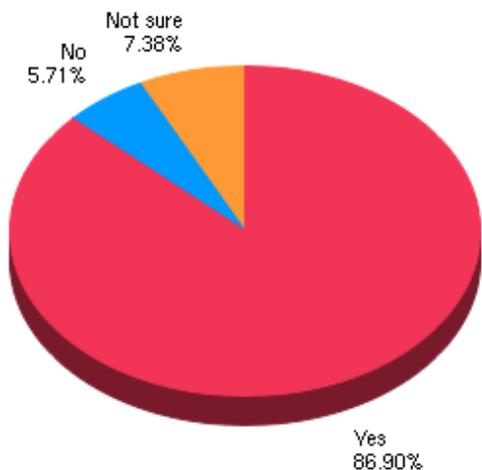
20. Which of the following weather conditions, if any, cause or exacerbate your EM flares? (Select all that apply)



Item	Count	Percent %
Heat (65 degrees and above)	337	89.63%
High humidity	190	50.53%
Cold	69	18.35%
Rain	38	10.11%
Dry conditions	17	4.52%
Windy conditions	14	3.72%
Change in seasons	89	23.67%
None of these	1	0.27%
Other (please specify)	62	16.71%
Others: Other (please specify)		
direct sunlight	2	0.53%
Sun exposure	2	0.53%
sunlight	2	0.53%
75 degrees and above	1	0.27%
above 20 degrees celcius	1	0.27%
above 70 I experience EM; below I have Raynauds	1	0.27%
all changes in weather	1	0.27%
any warm environment, worse in the evening, I need to stay cool	1	0.27%
Been typically in the winter months	1	0.27%
Bending over and squatting	1	0.27%
Change from cold to warm	1	0.27%
change in barametric pressures	1	0.27%
circulation	1	0.27%
clouds or fog that hold the heat in with no breeze	1	0.27%
cold affects hands only	1	0.27%
Cold causes raynauds as well	1	0.27%
cold feet at any temperature below 20 Centigrade	1	0.27%

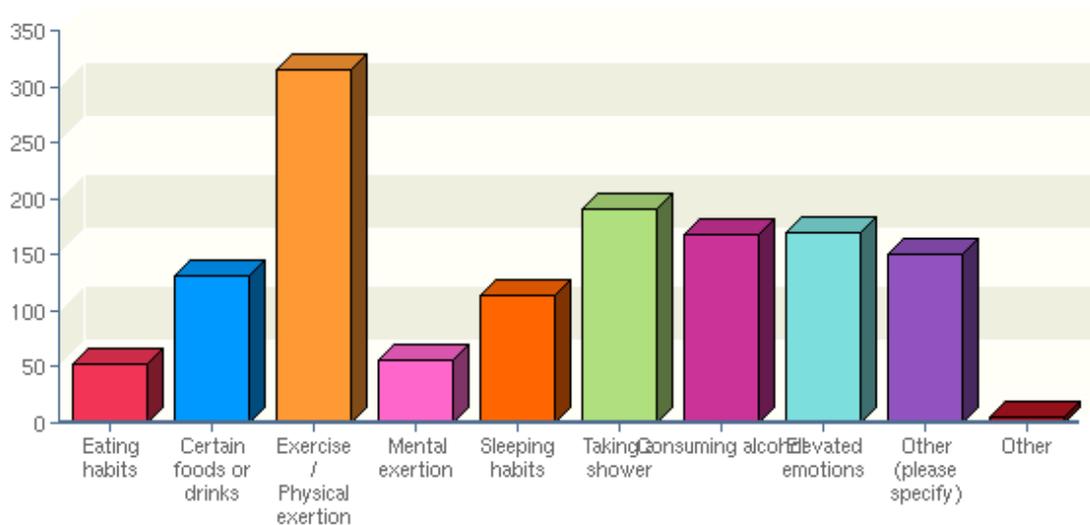
Item	Count	Percent %
cold(raynaud) leads to hot flare few hrs.later in day	1	0.27%
direct heat, sun, closed shoes, covers, etc.	1	0.27%
direct sunolight on my legs	1	0.27%
evenings	1	0.27%
extreme cold triggers a funny opposite respose, it takes severe cold but then extremeties go white and numb, and are very hard to warm, it is like there is no in between, like I have about 2 degress of temperature tolorange	1	0.27%
Heat (60 degrees and above)	1	0.27%
Heat (75 and above)	1	0.27%
Heat (75 degrees and above)	1	0.27%
Heat - over 70 - 72 degrees	1	0.27%
Heat about 72 and above	1	0.27%
heat above 55, any type of direct sun	1	0.27%
Heat above 75 degrees	1	0.27%
Heat above 78 degrees	1	0.27%
Heat in the above 80 degrees	1	0.27%
heat over 70 degrees	1	0.27%
heat, 75 degrees or above	1	0.27%
heat...75 and above; sunshine directly on me especially when it comes through car window	1	0.27%
Hot weather	1	0.27%
Hot weather - 90+	1	0.27%
I am not sure how much all this applies to me as I am in virtual remission if I watch myself.	1	0.27%
I have Raynaud's and hypothyroidism, too, so heat, cold, wind, and high humidity can leave me a hurting unit. Sometimes, just walking into a room with only a couple degrees cooler temp. will trigger neuropathic pain.	1	0.27%
Just plain heat, no matter the temp	1	0.27%
OK with heat & no humidity	1	0.27%
over 72-73 degrees	1	0.27%
prolonged sun exposure in heat	1	0.27%
rapid temperature changes	1	0.27%
Spontaneous flares happen mostly during cold months, though flares can be exercise induced at any time of year	1	0.27%
Stail stagnut air	1	0.27%
standing with no movement	1	0.27%
Stormy, high winds	1	0.27%
Sun shining	1	0.27%
sunlight hurts skin	1	0.27%
sunshine	1	0.27%
upward change in temperature	1	0.27%
Usually during the fall and winter, I have the most outbreaks. But, I think this is due to the excess time I am on my feet during hunting season when I walk a lot and have my feet restricted from layers of socks, hunting boots and waders.	1	0.27%
very hot days, 80 and above	1	0.27%
very hot temps	1	0.27%
very sensitive to sun/sunny days	1	0.27%
warm,styuffy rooms	1	0.27%
When Raynaud's is worse so is EM but at different times of the day	1	0.27%
winter	1	0.27%
Winter (only severe cold), sunlight	1	0.27%

21. Have you established that certain things you do can trigger your EM symptoms or make them worse?



Item	Count	Percent %
Yes	365	86.90%
No	24	5.71%
Not sure	31	7.38%

## 22. Which of the following do you feel might trigger your EM symptoms to occur? (Select all that apply)



Item	Count	Percent %
Eating habits	52	13.30%
Certain foods or drinks	131	33.50%
Exercise / Physical exertion	315	80.56%
Mental exertion	56	14.32%
Sleeping habits	114	29.16%
Taking a shower	191	48.85%
Consuming alcohol	168	42.97%
Elevated emotions	169	43.22%
None of these	5	1.28%
Other (please specify)	150	38.93%
Others: Other (please specify)		
stress	7	1.79%
heat	4	1.02%
walking	3	0.77%
standing for long periods	2	0.51%
standing in direct sunlight	1	0.26%
1. Stress. 2. Overuse of the eyes. 3. Hot spicy foods. 4. Feet in socks or shoes or under warm blankets	1	0.26%
30-45 minutes standing and walking long distances	1	0.26%
Allowing my hands or feet to get really cold - EM flares as they warm	1	0.26%
Also toes get warm/hot in the eveing time.	1	0.26%
ambient temp	1	0.26%
and speciall shoes	1	0.26%
anything that warms me up	1	0.26%
approaching weather fronts or changes in weather	1	0.26%
being in a warm place	1	0.26%
being in hot weather or warm interiors	1	0.26%
Being warmly dressed or under bed covers in cold weather	1	0.26%
Bending over, standing for more than a few minutes.	1	0.26%
Both exercise and lack of make symptoms worse	1	0.26%
carrying things	1	0.26%
Certain positions of my head, looking down for long periods. Hot food like soups and coffee, opening oven door, sun, flouresent lights	1	0.26%

Item	Count	Percent %
change in temperature	1	0.26%
closed footwear	1	0.26%
cold/ice compresses	1	0.26%
Contact with running water (handwashing); when sitting on softer surfaces	1	0.26%
covering feet (including use of rich creams)	1	0.26%
direct sun on my feet	1	0.26%
drinking caffeine related drinks	1	0.26%
drinking hot beverages, sitting for long periods of time	1	0.26%
eating to much salty food, getting too tired	1	0.26%
Elevated Body heat	1	0.26%
Elevation of limbs	1	0.26%
Exertion in high heat & humidity	1	0.26%
exposure to direct sunlight	1	0.26%
feet getting hot and standing a lot	1	0.26%
feet not elevated, heat	1	0.26%
feet on warm surface or covered	1	0.26%
Feet up with toes point up	1	0.26%
GENERALLY JUST BEING ON MY FEET FOR A PERIOD OF TIME	1	0.26%
getting too warm for any reason	1	0.26%
having feet lower than pelvis	1	0.26%
Heat,	1	0.26%
heat, sunlight	1	0.26%
heat; legs down/not elevated	1	0.26%
holding a warm object like a laptop or plate, when stressed like when giving a presentation	1	0.26%
hot bath	1	0.26%
hot flashes	1	0.26%
hot rooms, hot trains, hot buses	1	0.26%
hot shower or hot tub, closed shoes	1	0.26%
hottub/spa	1	0.26%
I cannot wear socks or closed shoes	1	0.26%
I don't take baths because of it (mental exertion just affects my face, 'foods and drinks' is just physically hot ones that I avoid not particular types of food which seem to make no difference)	1	0.26%
i used to fill bath tub with cold water then take hot shower	1	0.26%
I've eliminated caffeine and alcohol	1	0.26%
infection	1	0.26%
Insufficient or poor quality sleep exacerbates my pain; so does a diet too high in carbs (even good carbs).	1	0.26%
keeping my feet down	1	0.26%
lack of elevating daily or having legs down too long in the wheelchair or sitting chair	1	0.26%
letting myself get too overheated	1	0.26%
limbs hanging downward	1	0.26%
Long time in shoes	1	0.26%
Mental stress	1	0.26%
mostly the temperature	1	0.26%
msg	1	0.26%
MSG in particular	1	0.26%
MSG, food additives	1	0.26%
MSG?	1	0.26%
my 12 days of progesterone	1	0.26%
my EM will flare at night if I don't keep the air conditioner blowing as I sleep.	1	0.26%
need 12 hrs. of sleep daily	1	0.26%
not sure about food or drink...maybe	1	0.26%
Often occurs shortly after lying down and relaxing.	1	0.26%

Item	Count	Percent %
outdoor/indoor heat	1	0.26%
overtiredness	1	0.26%
physical activity in heat	1	0.26%
positional (eg: legs dependent, or lying on my side will always trigger EM flare)	1	0.26%
prolonged exposure to sun	1	0.26%
Raynaud's in my toes causes blanching, then I get EM if I warm up too quickly	1	0.26%
Resting; any change in heart rate	1	0.26%
room temperature above 69 degrees, sitting with feet down, lying in bed	1	0.26%
shoes and socks in afternoon	1	0.26%
simple carbohydrates	1	0.26%
sitting for a long time	1	0.26%
sitting or standing for extended time	1	0.26%
sitting with my feet down or standing still.	1	0.26%
Sleeping (anytime . . . not necessarily sleeping habits)	1	0.26%
smoking	1	0.26%
Spending too much time in the heat	1	0.26%
standing	1	0.26%
Standing for long periods.	1	0.26%
standing is of course bad, and the period during the night about 3 am, I think there is overall temperature patterns that people go through when they sleep, for those of use with this condition, we get way warm where others would not notice	1	0.26%
standing on my feet wearing closed shoes getting too hot	1	0.26%
Standing or sitting with feet and hands dependent for longer than 10 minutes. Consuming MSG, red wine, or items that also trigger migraines. Exposure to hot surfaces with the hands and feet.	1	0.26%
Standing or walking for long periods of time.	1	0.26%
standing still (in a line) rushing, or shopping over 20 minutes at a slow walk.	1	0.26%
standing!	1	0.26%
Standing, Walking, Cleaning, Cooking, etc	1	0.26%
Standing/Walking for any length of time; Using my hands for anything-writing, typing, gripping, pulling, holding, etc.	1	0.26%
stress & anxiety	1	0.26%
stress (work, and other), Must keep hands above covers while sleeping and in many past episodes it has been the same with feet	1	0.26%
stress and standing for long periods	1	0.26%
stress espically emotional stress	1	0.26%
stress, elevating my feet above heart level only increases my problem	1	0.26%
stress, sex	1	0.26%
stress,long sitting, standing,lifting heavier things, Raynaud attack	1	0.26%
Stress,possibly too much sugar?, sometimes afternoon naps	1	0.26%
Sunshine	1	0.26%
Taking a warm to hot shower; hot tub; being in the sun; standing e.g.cashier line, brushing teeth, kitchen counter work, picking out a greeting card, shopping in general	1	0.26%
temp above 70 degrees	1	0.26%
temperature changes (e.g. going from outside inside the house)	1	0.26%
temperature, hot tub	1	0.26%
Too many blankets in bed	1	0.26%
Too much sun; too much clothing	1	0.26%
too much walking,standing	1	0.26%
too much walking/certain shoes (croc's (latex??))	1	0.26%
type of footwear	1	0.26%
type of footwear	1	0.26%
vasodilatator drug or body cream	1	0.26%
walking and housework	1	0.26%
walking or being on feet too much	1	0.26%

Item	Count	Percent %
walking or standing for too long, shopping	1	0.26%
walking some distance & closed shoes	1	0.26%
Walking, standing	1	0.26%
walking, standing frequently	1	0.26%
Walking, standing, squatting for more than minimal amounts of time	1	0.26%
warm baths (avoided)too many clothes/bed clothes	1	0.26%
warmth, heat	1	0.26%
washing dishes, cleaning, water temp	1	0.26%
wearing boots (hunting)	1	0.26%
Wearing my shoes for more than 2 hours.	1	0.26%
wearing shoes	1	0.26%
wearing shoes and socks in the winter	1	0.26%
Wearing shoes that don't have a leather insole	1	0.26%
wearing shoes,too much clothing,the heat from cooking,my husband's body heat when we snuggle,blowdrying my hair	1	0.26%
wearing shoes/socks	1	0.26%
wearing socks or warm clothing	1	0.26%
wearing wrong sandals	1	0.26%
When first lying down to sleep	1	0.26%
whenever I elevate my legs (I seem different to everyone else)	1	0.26%

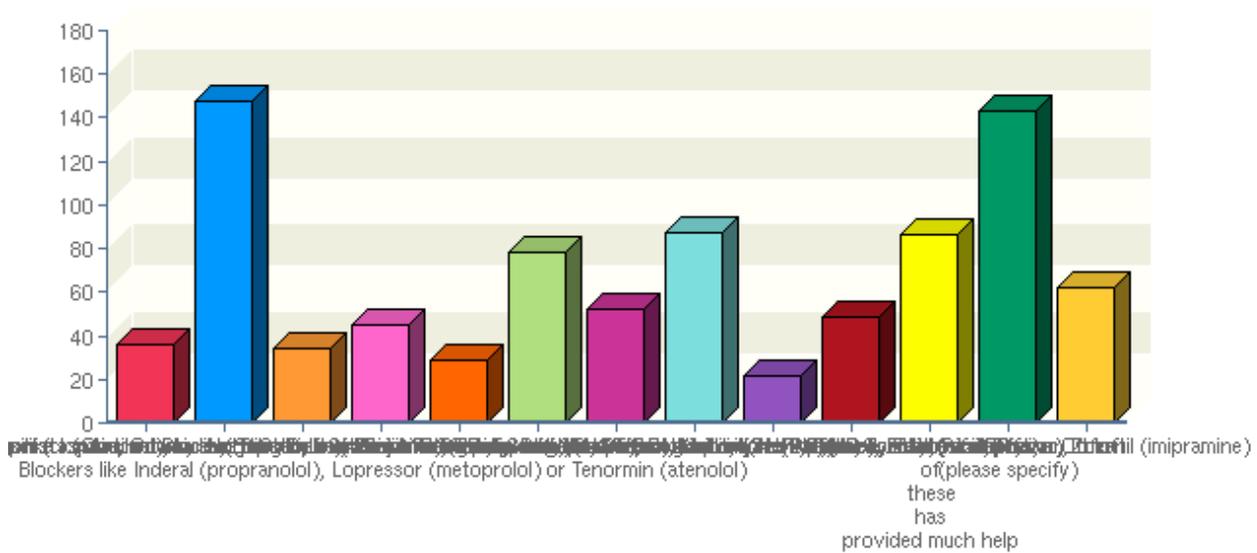
23. Please rate how aggressively you treat your EM condition or another primary condition that affects your EM.

Table 1 of 2	Item	Very aggressively	Aggressively	Somewhat aggressively	Passively
#0	Treating your EM symptoms	19.8% 81	26.8% 110	29.0% 119	14.9% 61
#1	Treating another primary condition	12.9% 40	18.1% 56	15.2% 47	11.0% 34
#2	Average %	16.8%	23.1%	23.1%	13.2%

Table 2 of 2	Not at all	Not sure or NA	Total
#0	5.6% 23	3.9% 16	410
#1	12.6% 39	30.3% 94	310
#2	8.6%	15.3%	720.0

24. With which of the following medications and/or treatments have you had the MOST SUCCESS in treating your EM or primary condition? (Select NO MORE THAN 5)

NOTE: Medications are listed by drug family; examples are given but not all brand names are listed



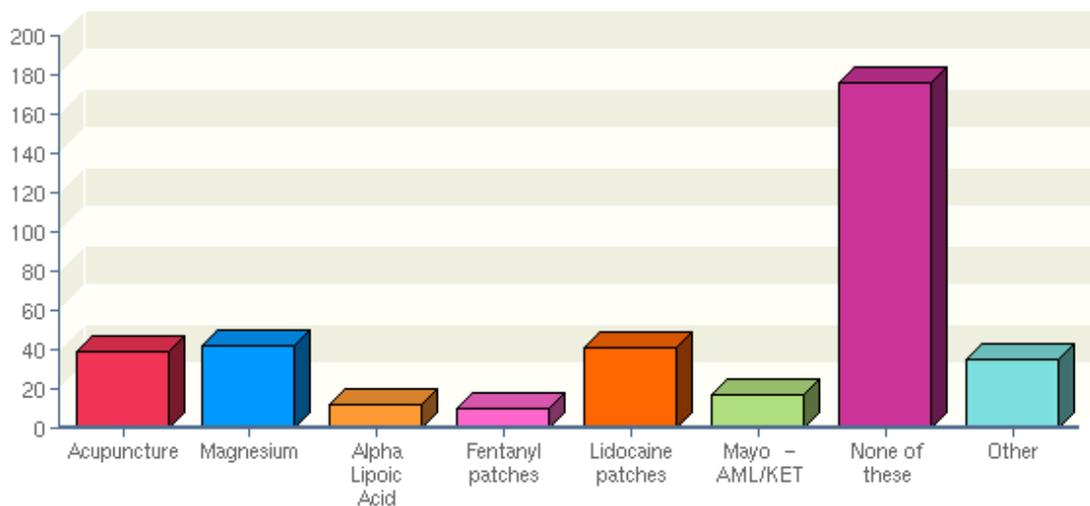
Item	Count	Percent %
Adrenergic receptor agonist: Clonidine for example.	10	2.53%
Antiarrhythmic Sodium Channel Blockers like Lidocaine or Mexilitine	20	5.06%
Anticoagulants like aspirin, Coumadin, Heparin, and Plavix	36	9.11%
Anticonvulsants like Klonopin (clonazepam), Lyrica (pregabalin), Neurontin (gabapentin), and Trental.	148	37.47%
Antihistamines (over the counter) Like Benadryl	34	8.61%
Antihistamines by prescription like Periactin.	11	2.78%
Antimigraine medications - Triptan medications: like Maxalt, Zomig.	3	0.76%
Alpha Blockers: like Dibenzyline	2	0.51%
Beta Blockers like Inderal (propranolol), Lopressor (metoprolol) or Tenormin (atenolol)	45	11.39%
Calcium Antagonists (Channel Blockers) like Calan (verapamil), Cardizem (diltiazem), magnesium, Norvasc, Procardia (nifedipine)	29	7.34%
Corticosteroid drugs like Prednisone.	11	2.78%
Dopamine Agonist (Parkinson or Restless Leg Syndrome medications) like Mirapex and Requip	3	0.76%
Immunosuppressive drugs like Cyclosporine and Interferon	2	0.51%
Non-Steriodal Anti-inflammatory drugs (NSAIDS): Aspirin, Advil, Tylenol	78	19.75%
Perscription Pain Medications: Dilaudid, Vidocin, Methadone, Morphine, Oxycodone	52	13.16%
Serotonin-norepinephrine Reuptake Inhibitor (SNRI's) like Cymbalta and Effexor	87	22.03%
Selective Serotonin Reuptake Inhibitors (SSRI's): Luvox, Paxil, Prozac, Zoloft	22	5.57%
Tricyclic Antidepressants: Aventyl (nortriptyline), Elavil (amitriptyline), Tofranil (imipramine)	49	12.41%
None of these has provided much help	86	21.77%
Other (please specify)	143	35.81%
Others: Other (please specify)		
Lyrica	3	0.76%
acupuncture	2	0.51%
adderall	2	0.51%
chinese herbs	2	0.51%
Have tried none	2	0.51%
Neurontin	2	0.51%
5-HTP, L-Tyrosine, Quercetin	1	0.25%
50mg Fentanyl patch w/2 750mg vicodin tabs	1	0.25%
ACE inhibitor - lisinopril	1	0.25%
alpha lipolic acid & magnesium	1	0.25%
already on neurontin for radiculopathy;NSAIDs made EM WORSE	1	0.25%
alternative methods	1	0.25%
ambin	1	0.25%
anti anxiety drugs	1	0.25%
Antihistamine in Drixoral that I take for allergy	1	0.25%
apo-amitriptyline	1	0.25%
ativan	1	0.25%
Benadryl: I think b/c helped me sleep	1	0.25%
benedryl and xanas help me sleep, but and that helps me overall, but does not touch the EM directly	1	0.25%
benedryl, xanax, cymbalta	1	0.25%
Benfotiamine, Magnesium Glycinate	1	0.25%
benzodiazapines (e.g. Ativan)	1	0.25%
cinnarizine	1	0.25%
citalopram	1	0.25%
Clonidine transdermal patch but only temporarily.	1	0.25%
cold water	1	0.25%
combination gel of 1% amitriptyline and 0.5% ketamine	1	0.25%
compounded gel of neurontin, amitriptyline, ketamine	1	0.25%

Item	Count	Percent %
Crestor and Imovane	1	0.25%
cytotec (a vasodiolater)	1	0.25%
Cytotec by Pfizer	1	0.25%
dark choc. with no milk	1	0.25%
diagnosed only 3 weeks ago. No time to try anything yet	1	0.25%
Diazepam	1	0.25%
Dihydrocodeine Tartrate	1	0.25%
Duragesic pain patch	1	0.25%
evening primrose, bilberry, milk thistle, magnesium, vitamin D, omega-3	1	0.25%
Fentanyl patches	1	0.25%
Fever Few, Quercetin, Propolis	1	0.25%
fish oils, lyprinol, petadolex (supplements) - but don't know if they are helpful!	1	0.25%
Gabapantin	1	0.25%
gabapentin	1	0.25%
Gabapentin + Oxycodone	1	0.25%
gabapetin	1	0.25%
Glyceryl Trinitrate patches	1	0.25%
have not tried any except aspirin did not know of these remedys	1	0.25%
have not tried any medical treatments	1	0.25%
have tried none of these	1	0.25%
Have tried several of above, but was told that it was pain due to MS. Nortriptyline stopped pain, but side effects horrible. Took 4 yrs. to stop Nortriptyline; now have SVT.	1	0.25%
Haven't tried a specific treatment, but when I take NSAIDs for arthritis, I seem to have less severe episodes.	1	0.25%
HRT	1	0.25%
hydroxyethylrutosides (Paroven)	1	0.25%
I also take Singular for allergies - don't know if it helps or not	1	0.25%
I am on Topamax for migraines and don't know if that helps, but it seems to be better since I've been on it and I noticed it mentioned in one of the articles on the EM website	1	0.25%
I am self diagnosed so I have not tried these medications. I know that if I have an outbreak coming, cold water and OTC aspirin and advil is all I take.	1	0.25%
I am taking or have tried several of these medications but nothing really relieves the EM.	1	0.25%
I have never taken anything.	1	0.25%
I have only tried a few, they did not help, I have Raynauds also which limits my options, you need to reword this one into a chart, those tried and level of success, as does not adequately measure the failures	1	0.25%
I have taken approx. 12 of the specified choices listed above throughout my life. (since age 18 months) Only one thing seemed to give me some relief and helped reduced the accompanying swelling and sensitivity that follows the next day. That was the Oxycodone.	1	0.25%
I HAVE TRIED A FEW OF THE ABOVE, SUCH AS NORVASC (WHICH DROVE ME CRAZY), NERUROTIN (COULDN'T STAND THE SIDE EFFECTS). I PLAN TO WORK WITH MY PHYSICIAN TO TRY SOME OTHER TREATMENTS BASED ON THE LAST ARTICAL BY DR. COHEN	1	0.25%
I haven't taken any of these for symptoms	1	0.25%
I haven't tried any of these	1	0.25%
I no longer take meds, but control symptoms by environment and diet only.	1	0.25%
I really haven't tried anything specifically to treat this	1	0.25%
i sarterd with aspirin without suces	1	0.25%
I use a prescription compounded cream containing several pain reducers and this gives me some relief (but not much)	1	0.25%
I was put on Nurotin for about 6 months. that is all the meds I have been offered.	1	0.25%
iloprost infussion & a spinle cord simulator	1	0.25%
Ketamine infusions	1	0.25%
Ketamine/Amitriptyline oint. 3%/3%	1	0.25%

Item	Count	Percent %
ketamine/amytriptiline compound cream	1	0.25%
Lamictal (25mg 2 x a day)	1	0.25%
lidocaine patches	1	0.25%
Lorazepam #1 most effective. 2. Vicodin	1	0.25%
lyrica/gabapentiin	1	0.25%
Magnesium 400 mg	1	0.25%
Magnesium over 1000mg/day; IVIG	1	0.25%
Magnesium supplements, roughly 1000 mg a day.	1	0.25%
magnesiumcitrate	1	0.25%
majuana	1	0.25%
Medtronic pump with morphine	1	0.25%
Mistletoe Extract, dandelion root tea and phlebotomy	1	0.25%
Morphine ER and IR morphine	1	0.25%
Most of my pain is from the neuropathy which is helped at night by neurontin 900-1000 mg nightly	1	0.25%
mostly work with magnesium & potassium	1	0.25%
mouthwash- listerene	1	0.25%
Naftdrofuryl	1	0.25%
naftidrofuryl oxalate +zydol	1	0.25%
natural blood thinners, boswellia, bromelain, quercetin, curcumin, devils claw root, yucca root, alfalfa leaf	1	0.25%
Neurontin, Calcium with magnesium and vitamin D , Ambien, Celexa	1	0.25%
niacin has saved my life, vasodialator with no side effects	1	0.25%
Nitrazepam	1	0.25%
No medication so far	1	0.25%
no medications - history of Stevens-Johnson	1	0.25%
No Medications work for me	1	0.25%
none of the above	1	0.25%
None. Few of above tried	1	0.25%
not tried any	1	0.25%
nothing helped more than 3 months now trying acupuncture and chinese herbs	1	0.25%
only gabapentin -made worse	1	0.25%
Pain Buster 2	1	0.25%
paracetamol	1	0.25%
prednisone	1	0.25%
Pregablin (Lyrica)	1	0.25%
Prescription Topical jel of 1% amittriptiline/ .5% Ketamine	1	0.25%
Propranolol	1	0.25%
Quinapril 20mg, Coreg 12.5mg & Clonidine .05mg for emergencies	1	0.25%
quinapril and fish oil	1	0.25%
sarna-cortisone creme	1	0.25%
Simvastatin, Propranolol	1	0.25%
sleeping pills (a lot)	1	0.25%
sleeping pills, to get some sort of relief, even if it's just to sleep. (Zolpidem)	1	0.25%
sulfate of magnesium	1	0.25%
The doctors have not given her oral medications because they wanted to see if her thyroid was part of the problem.	1	0.25%
Topalgic	1	0.25%
Toprol	1	0.25%
Tramadol	1	0.25%
Tramadol/cool raps/bok flowers	1	0.25%
tramedol	1	0.25%
Tried aspirin--no help at all; tried mirapex--seemed to work for a couple weeks then positive effects tapered off and side-effects were too unpleasant to continue	1	0.25%
Triest	1	0.25%
trileptal and neurontin help at night	1	0.25%

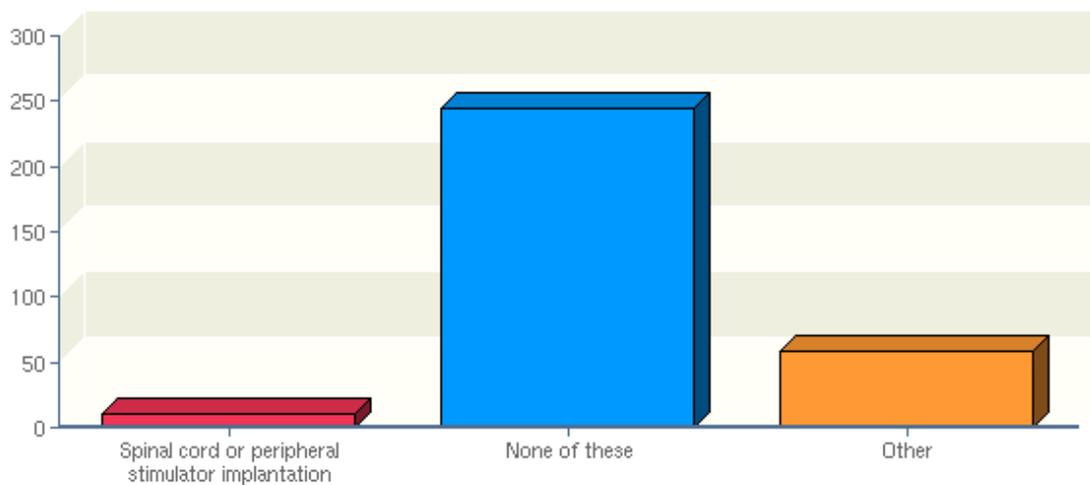
Item	Count	Percent %
Trileptal works better than the neurontin	1	0.25%
Ultra Musles Powder, Magnesium with vitamin E, B6, B12, Vitimin C	1	0.25%
Ultram	1	0.25%
use super blue on bottom of feet morn + eve	1	0.25%
valerian root, extreme foot elevation (almost strait up)	1	0.25%
Vitamin D	1	0.25%
vitamin d, ultrom, ambian/xanax	1	0.25%
Walking exercise has helped tremendously; it helped desensitize my feet. My EM got much better after I started to walk regularly and now my symptoms are fewer. I use thin socks and shoes with mesh to reduce heat.	1	0.25%
Wearing shoes with leathe insole	1	0.25%
wellbutrin XR	1	0.25%
Zonegran, Ultracet	1	0.25%
zyflamend 1 daily in a.m.	1	0.25%
Zyflammend, all natural anti-inflammatory soft gel, 2 dy	1	0.25%
Zyrtec a Rx antihistamine give me total control for 5 to 8 days and then I use Calomine lotion to stop itching for another week (use it twice a day) and then back to Zyrtec	1	0.25%

25. With which of the following topical creams, dietary supplements and or regimens have you had the MOST success in treating your EM symptoms or your primary condition? (Select NO MORE THAN 4)



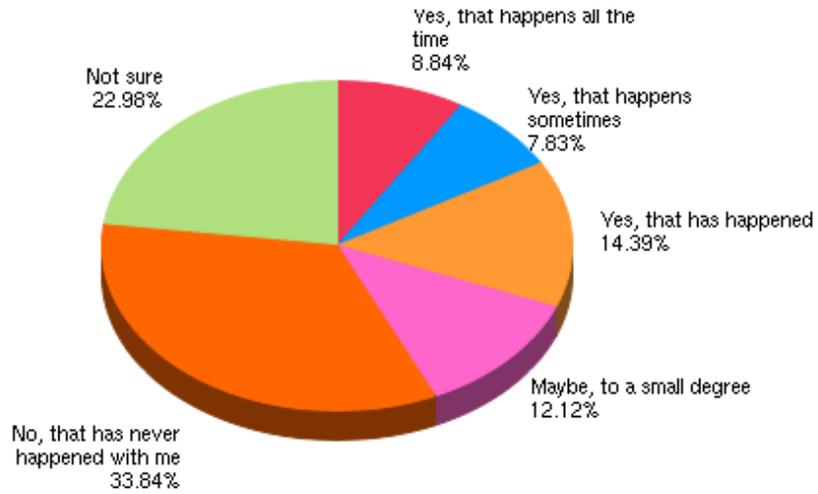
Item	Count	Percent %
Acupuncture	39	12.62%
Biofeedback	7	2.27%
Hypnosis	1	0.32%
Magnets	3	0.97%
Magnesium	42	13.59%
Alpha Lipoic Acid	12	3.88%
Fentanyl patches	10	3.24%
OTC capsaicin cream	9	2.91%
Prescription capsaicin cream	6	1.94%
Lidocaine patches	41	13.27%
Doxepin cream	2	0.65%
EMLA cream	1	0.32%
Mayo - AML/KET	17	5.50%
External stimulation unit like TENS	6	1.94%
None of these	176	56.96%
Not applicable	2	(N/A)

26. With which of the following invasive treatments have you had the MOST success in treating your EM or primary condition symptoms? (Select NO MORE THAN 3)



Item	Count	Percent %
Lidocaine infusions	7	2.39%
Morphine or pain pump implant	6	2.05%
Spinal cord or peripheral stimulator implantation	10	3.41%
10% capsaicin application	5	1.71%
Intravenous immunoglobulin (IVIG) infusions	1	0.34%
Radio frequency lesioning	1	0.34%
Sympathectomy	1	0.34%
None of these	244	83.28%
iloprost infusion	2	0.68%
Blood thinner ,Plavix	1	0.34%
can't find a Dr that doesn't think I made it up	1	0.34%
cervical spinal steroid injection	1	0.34%
cold water	1	0.34%
did not know of these treatments	1	0.34%
didn't try any of these	1	0.34%
doctors have not prescribed these	1	0.34%
epidural nerve blocks	1	0.34%
Feet up and keeping cool	1	0.34%
had a temporary spinal block	1	0.34%
Have never had any of these	1	0.34%
have not tried any	1	0.34%
Have not used any of these	1	0.34%
Have tried none	1	0.34%
hydromorphone	1	0.34%
I already had a pain pump for back problems.	1	0.34%
I could never get them to give me many but always try if i am in for anything, as I think it helps to somehow calm the overactive nerveswo	1	0.34%
i have don e all of these except capsaisin with no long term benefit	1	0.34%
I tried Lidocaine patches on the bottom of my feet but didn't do much.	1	0.34%
Ketamine infusions	1	0.34%
lumbar sympathetic blocks	1	0.34%
magnesium IV after giving birth.	1	0.34%
marijuana	1	0.34%
maybe magnesium, not sure	1	0.34%
Medtronic pump	1	0.34%
none helped	1	0.34%
not had any of these done	1	0.34%
not tried any	1	0.34%
Phenol	1	0.34%
previously listed prescriptions: effexor, trental, loproesser, sudafed XR. advil liqui gels	1	0.34%
remacaide	1	0.34%
REMICADE 700mg every 8 weeks, and blook pressure controls	1	0.34%
Should have option to pick haven't tried any of these.	1	0.34%
The key for me has been shoe selection. An absolute must is leather insoles. But not all shoes with leather insoles actually work. I certainly can't wear gym shoes, except outside in cold weather. Temperature seems to be the critical factor. The new edition of the Merck Manual lists a trigger temperature of 84 degrees, and that seems to apply to my case. I have a closet full of shoes that haven't worked. I might try the GEOX breathable sole shoes that I've seen advertized. Right now I'm wearing Sperry Topsiders 0197640. Very mysterious...	1	0.34%
Touch Therapy	1	0.34%
v beam light treatment	1	0.34%
Not applicable	3	(N/A)

27. Have you found that some treatments are effective at reducing symptoms for a period of time, only to lose their effectiveness over time?



Item	Count	Percent %
Yes, that happens all the time	35	8.84%
Yes, that happens sometimes	31	7.83%
Yes, that has happened	57	14.39%
Maybe, to a small degree	48	12.12%
No, that has never happened with me	134	33.84%
Not sure	91	22.98%

28. Now please RATE each medication or treatment's effectiveness for treating your EM symptoms. [Use the scale provided.]

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#0	Adrenergic receptor agonist	37.5% 3	37.5% 3	12.5% 1	
#1	Antiarrhythmic Sodium Channel Blockers		42.9% 6	42.9% 6	7.1% 1
#2	Anticoagulants	17.9% 5	28.6% 8	28.6% 8	14.3% 4
#3	Anticonvulsants	28.1% 36	46.1% 59	14.8% 19	3.9% 5
#4	Antihistamines over the counter	15.6% 5	34.4% 11	37.5% 12	3.1% 1
#5	Antihistamines by prescription	27.3% 3	18.2% 2	36.4% 4	18.2% 2
#6	Antimigraine medications - Triptan medications			66.7% 2	
#7	Alpha Blockers		50.0% 1	50.0% 1	
#8	Beta Blockers	13.2% 5	26.3% 10	36.8% 14	13.2% 5
#9	Calcium Antagonists	27.3% 6	50.0% 11	13.6% 3	4.5% 1
#10	Corticosteroid drugs	11.1% 1	44.4% 4	22.2% 2	22.2% 2
#11	Dopamine Agonist		50.0% 1	50.0% 1	
#12	Immunosuppressive drugs	50.0% 1	50.0% 1		
#13	Non-Steriodal Anti-inflammatory drugs (NSAIDS)	17.5% 11	38.1% 24	20.6% 13	12.7% 8
#14	Perscription Pain Medications	22.7% 10	50.0% 22	22.7% 10	
#15	Serotonin-norepinephrine Reuptake Inhibitor (SNRI's)	26.3% 20	43.4% 33	15.8% 12	6.6% 5
#16	Selective Serotonin Reuptake Inhibitors (SSRI's)	16.7% 3	50.0% 9	11.1% 2	11.1% 2
#17	Tricyclic Antidepressants	13.3% 6	31.1% 14	37.8% 17	6.7% 3
#18	None of these		8.3% 1	8.3% 1	58.3% 7
#19	Lorazepam #1 most effective. 2. Vicodin		100.0% 1		
#20	benzodiazapines (e. g. Ativan)		100.0% 1		
#21	Triest	100.0% 1			

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#22	no medications - history of Stevens-Johnson				
#23	Prescription Topical gel of 1% amitriptyline/ .5% Ketamine	100.0% 1			
#24	I really haven't tried anything specifically to treat this				
#25	Have tried none	50.0% 1			50.0% 1
#26	Have tried none	50.0% 1			50.0% 1
#27	Antihistamine in Drixoral that I take for allergy	100.0% 1			
#28	Magnesium 400 mg				
#29	Clonidine transdermal patch but only temporarily.				
#30	sleeping pills (a lot)			100.0% 1	
#31	I haven't taken any of these for symptoms				
#32	alternative methods		100.0% 1		
#33	prednisone	100.0% 1			
#34	majuana		100.0% 1		
#35	HRT				
#36	Crestor and Imovane	100.0% 1			
#37	alpha lipolic acid & magnesium	100.0% 1			
#38	none of the above				

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#39	Haven't tried a specific treatment, but when I take NSAIDs for arthritis, I seem to have less severe episodes.				
#40	acupuncture				
#41	acupuncture				
#42	have tried none of these				
#43	evening primrose, bilberry, milk thistle, magnesium, vitamin D, omega-3	100.0% 1			
#44	Dihydrocodeine Tartrate		100.0% 1		
#45	Benadryl: I think b/c helped me sleep		100.0% 1		
#46	I am on Topamax for migraines and don't know if that helps, but it seems to be better since I've been on it and I noticed it mentioned in one of the articles on the EM website		100.0% 1		
#47	Zonegran, Ultracet		100.0% 1		
#48	quinapril and fish oil				100.0% 1
#49	compounded gel of neurontin, amitriptyline, ketamine				
#50	paracetamol	100.0% 1			
#51	ativan		100.0% 1		

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#52	I HAVE TRIED A FEW OF THE ABOVE, SUCH AS NORVASC (WHICH DROVE ME CRAZY), NERUROTIN (COULDN'T STAND THE SIDE EFFECTS). I PLAN TO WORK WITH MY PHYSICIAN TO TRY SOME OTHER TREATMENTS BASED ON THE LAST ARTICAL BY DR. COHEN				100.0% 1
#53	cinnarizine	100.0% 1			
#54	sarna-cortisone creme	100.0% 1			
#55	valerian root, extreme foot elevation (almost strait up)		100.0% 1		
#56	Ketamine/ Amitriptyline oint. 3%/3%			100.0% 1	
#57	Fentanyl patches				
#58	lyrica/gabapentiin				
#59	diagnosed only 3 weeks ago. No time to try anything yet				
#60	magnesiumcitrate		100.0% 1		
#61	I also take Singular for allergies - don't know if it helps or not				
#62	No medication so far				
#63	mouthwash- listerene	100.0% 1			

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#64	Fever Few, Quercetin, Propolis		100.0% 1		
#65	anti anxiety drugs			100.0% 1	
#66	Vitamin D		100.0% 1		
#67	trileptal and neurontin help at night		100.0% 1		
#68	fish oils, lyprinol, petadolex (supplements) - but don't know if they are helpful!				
#69	Lyrica	66.7% 2	33.3% 1		
#70	Lyrica	66.7% 2	33.3% 1		
#71	Lyrica	66.7% 2	33.3% 1		
#72	Tried aspirin--no help at all; tried mirapex--seemed to work for a couple weeks then positive effects tapered off and side-effects were too unpleasant to continue			100.0% 1	
#73	Nitrazepam			100.0% 1	
#74	I no longer take meds, but control symptoms by environment and diet only.	100.0% 1			
#75	I was put on Nurotin for about 6 months. that is all the meds I have been offered.			100.0% 1	
#76	Pregablin (Lyrica)			100.0% 1	

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#77	50mg Fentanyl patch w/2 750mg vicodin tabs		100.0% 1		
#78	sleeping pills, to get some sort of relief, even if it's just to sleep. (Zolpidem)		100.0% 1		
#79	Medtronic pump with morphine		100.0% 1		
#80	I haven't tried any of these				
#81	Topalgic	100.0% 1			
#82	Glyceryl Trinitrate patches			100.0% 1	
#83	not tried any				
#84	I have taken approx. 12 of the specified choices listed above throughout my life. (since age 18 months) Only one thing seemed to give me some relief and helped reduced the accompanying swelling and sensitivity that follows the next day. That was the Oxyc				
#85	hydroxyethylrutosides (Paroven)		100.0% 1		
#86	I have never taken anything.				
#87	have not tried any medical treatments				
#88	Magnesium over 1000mg/day; IVIG		100.0% 1		

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#89	The doctors have not given her oral medications because they wanted to see if her thyroid was part of the problem.				100.0% 1
#90	Benfotiamine, Magnesium Glycinate		100.0% 1		
#91	Wearing shoes with leathe insole		100.0% 1		
#92	Have tried several of above, but was told that it was pain due to MS. Nortriptyline stopped pain, but side effects horrible. Took 4 yrs. to stop Nortriptyline; now have SVT.				
#93	lidocaine patches		100.0% 1		
#94	Toprol	100.0% 1			
#95	Mistletoe Extract, dandylion root tea and phlebotomy	100.0% 1			
#96	Ultram	100.0% 1			
#97	iloprost infussion & a spinle cord simulater		100.0% 1		
#98	Walking exercise has helped tremendously; it helped desensitize my feet. My EM got much better after I started to walk regularly and now my symptoms are fewer. I use thin socks and shoes with mesh to reduce heat.	100.0% 1			

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#99	Gabapentin + Oxycodone				
#100	I use a prescription compounded cream containing several pain reducers and this gives me some relief (but not much)			100.0% 1	
#101	None. Few of above tried				
#102	already on neurontin for radiculopathy; NSAIDs made EM WORSE			100.0% 1	
#103	I am self diagnosed so I have not tried these medications. I know that if I have an outbreak coming, cold water and OTC aspirin and advil is all I take.		100.0% 1		
#104	cold water	100.0% 1			
#105	Neurontin		100.0% 2		
#106	Neurontin		100.0% 2		
#107	Morphine ER and IR morphine	100.0% 1			
#108	zyflamend 1 daily in a.m.		100.0% 1		
#109	benedryl and xanas help me sleep, but and that helps me overall, but does not touch the EM directly				
#110	benedryl, xanax, cymbalta		100.0% 1		
#111	apo-amitripyline			100.0% 1	
#112	chinese herbs	50.0% 1			50.0% 1

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#113	chinese herbs	50.0% 1			50.0% 1
#114	Simvastatin, Propranolol				
#115	Zyrtec a Rx antihistamine give me total control for 5 to 8 days and then I use Calomine lotion to stop itching for another week (use it twice a day) and then back to Zyrtec	100.0% 1			
#116	i sarterd with aspirin without sucess				100.0% 1
#117	Gabapantin	100.0% 1			
#118	Magnesium supplements, roughly 1000 mg a day.	100.0% 1			
#119	Diazepam			100.0% 1	
#120	No Medications work for me				100.0% 1
#121	naftidrofuryl oxalate +zydol		100.0% 1		
#122	Propranerol	100.0% 1			
#123	Quinapril 20mg, Coreg 12.5mg & Clonidine .05mg for emergencies	100.0% 1			
#124	Tramadol/cool raps/ bok flowers		100.0% 1		
#125	combination gel of 1% amitriptyline and 0.5% ketamine		100.0% 1		
#126	Most of my pain is from the neuropathy which is helped at night by neurontin 900-1000 mg nightly		100.0% 1		

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#127	nothing helped more than 3 months now trying acupuncture and chinese herbs				
#128	ambin	100.0% 1			
#129	sulfate of magnesium				100.0% 1
#130	gabapetin		100.0% 1		
#131	adderall	50.0% 1	50.0% 1		
#132	adderall	50.0% 1	50.0% 1		
#133	ketamine/ amytriptiline compound cream	100.0% 1			
#134	I have only tried a few, they did not help, I have Raynauds also which limits my options, you need to reword this one into a chart, those tried and level of success, as does not adequately measure the failures				
#135	gabapentin	100.0% 1			
#136	use super blue on bottom of feet morn + eve		100.0% 1		
#137	5-HTP, L-Tyrosine, Quercetin	100.0% 1			
#138	Trileptal works better than the neurontin	100.0% 1			
#139	mostly work with magnesium & potassium		100.0% 1		
#140	wellbutrin XR				

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#141	Cytotec by Pfizer		100.0% 1		
#142	have not tried any except aspirin did not know of these remedies				
#143	Zyflammend, all natural anti-inflammatory soft gel, 2 dy	100.0% 1			
#144	Tramadol		100.0% 1		
#145	Neurontin, Calcium with magnesium and vitamin D , Ambien, Celexa		100.0% 1		
#146	ACE inhibitor - lisinopril			100.0% 1	
#147	Pain Buster 2	100.0% 1			
#148	only gabapentin - made worse				
#149	citalopram		100.0% 1		
#150	Lamictal (25mg 2 x a day)		100.0% 1		
#151	I am taking or have tried several of these medications but nothing really relieves the EM.				
#152	Naftdrofuryl		100.0% 1		
#153	Ketamine infusions		100.0% 1		
#154	dark choc. with no milk	100.0% 1			
#155	niacin has saved my life, vasodialator with no side effects	100.0% 1			

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#156	natural blood thinners, boswellia, bromelain, quercetin, curcumin, devils claw root, yucca root, alfalfa leaf				
#157	tramedol	100.0% 1			
#158	vitamin d, ultrom, ambian/xanax		100.0% 1		
#159	cytotec (a vasodiolater)	100.0% 1			
#160	Duragesic pain patch	100.0% 1			
#161	Ultra Musles Powder, Magnesium with vitamin E, B6, B12, Vitimin C	100.0% 1			
#162	Average %	23.7%	39.1%	20.4%	8.1%

Table 2 of 2	Uncertain, it varies	Total
#0	12.5% 1	8
#1	7.1% 1	14
#2	10.7% 3	28
#3	7.0% 9	128
#4	9.4% 3	32
#5		11
#6	33.3% 1	3
#7		2
#8	10.5% 4	38
#9	4.5% 1	22
#10		9
#11		2
#12		2
#13	11.1% 7	63
#14	4.5% 2	44
#15	7.9% 6	76

Table 2 of 2	Uncertain, it varies	Total
#16	11.1% 2	18
#17	11.1% 5	45
#18	25.0% 3	12
#19		1
#20		1
#21		1
#22		0
#23		1
#24	100.0% 1	1
#25		2
#26		2
#27		1
#28	100.0% 1	1
#29		0
#30		1
#31		0
#32		1
#33		1
#34		1
#35		0
#36		1
#37		1
#38		0
#39	100.0% 1	1
#40	100.0% 1	1
#41	100.0% 1	1
#42		0
#43		1
#44		1
#45		1
#46		1
#47		1
#48		1
#49	100.0% 1	1
#50		1
#51		1
#52		1
#53		1
#54		1
#55		1
#56		1
#57		0

Table 2 of 2	Uncertain, it varies	Total
#58	100.0% 1	1
#59		0
#60		1
#61	100.0% 1	1
#62		0
#63		1
#64		1
#65		1
#66		1
#67		1
#68	100.0% 1	1
#69		3
#70		3
#71		3
#72		1
#73		1
#74		1
#75		1
#76		1
#77		1
#78		1
#79		1
#80		0
#81		1
#82		1
#83		0
#84		0
#85		1
#86		0
#87		0
#88		1
#89		1
#90		1
#91		1
#92	100.0% 1	1
#93		1
#94		1
#95		1
#96		1
#97		1
#98		1
#99		0
#100		1
#101		0
#102		1
#103		1

Table 2 of 2	Uncertain, it varies	Total
#104		1
#105		2
#106		2
#107		1
#108		1
#109		0
#110		1
#111		1
#112		2
#113		2
#114	100.0% 1	1
#115		1
#116		1
#117		1
#118		1
#119		1
#120		1
#121		1
#122		1
#123		1
#124		1
#125		1
#126		1
#127		0
#128		1
#129		1
#130		1
#131		2
#132		2
#133		1
#134		0
#135		1
#136		1
#137		1
#138		1
#139		1
#140		0
#141		1
#142	100.0% 1	1
#143		1
#144		1
#145		1
#146		1
#147		1
#148		0
#149		1
#150		1

Table 2 of 2	Uncertain, it varies	Total
#151		0
#152		1
#153		1
#154		1
#155		1
#156		0
#157		1
#158		1
#159		1
#160		1
#161		1
#162	8.7%	691.0

29. Now please RATE each topical cream, dietary supplement or regimen's effectiveness for treating your EM symptoms.

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#0	Acupuncture	20.6% 7	41.2% 14	17.6% 6	14.7% 5
#1	Biofeedback	42.9% 3	28.6% 2	28.6% 2	
#2	Hypnosis				100.0% 1
#3	Magnets				100.0% 2
#4	Magnesium	20.5% 8	38.5% 15	15.4% 6	12.8% 5
#5	Alpha Lipoic		18.2% 2	36.4% 4	18.2% 2
#6	Fentanyl patches	12.5% 1	50.0% 4	25.0% 2	12.5% 1
#7	OTC capsaicin cream		28.6% 2	28.6% 2	42.9% 3
#8	Prescription capsaicin cream		20.0% 1	60.0% 3	20.0% 1
#9	Lidocaine patches	17.9% 7	20.5% 8	43.6% 17	17.9% 7
#10	Doxepin cream		50.0% 1		50.0% 1
#11	EMLA cream		100.0% 1		
#12	Mayo - AML/KET	31.3% 5	37.5% 6	31.3% 5	
#13	External stimulation unit like TENS		20.0% 1		60.0% 3
#14	None of these	11.5% 3	15.4% 4	23.1% 6	26.9% 7
#15	NA				
#16	Average %	16.7%	30.0%	26.1%	18.7%

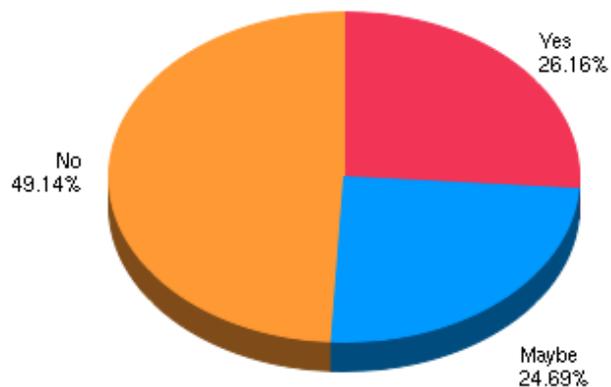
Table 2 of 2	Uncertain, it varies	Total
#0	5.9% 2	34
#1		7
#2		1
#3		2
#4	12.8% 5	39
#5	27.3% 3	11
#6		8
#7		7
#8		5
#9		39
#10		2
#11		1
#12		16
#13	20.0% 1	5
#14	23.1% 6	26
#15		0
#16	8.4%	203.0

30. Finally, please RATE the effectiveness for treating your EM symptoms of each invasive therapy you selected previously.

Table 1 of 2	Item	Good relief	Moderate relief	Minimal relief	No relief
#0	Lidocaine infusions	16.7% 1	83.3% 5		
#1	Morphine or pain pump implant	75.0% 3	25.0% 1		
#2	Spinal cord or peripheral stimulator implantation	12.5% 1	50.0% 4	25.0% 2	12.5% 1
#3	10% capsaicin application	66.7% 2	33.3% 1		
#4	Intravenous immunoglobulin (IVIG) infusions	100.0% 1			
#5	Plasmapheresis				
#6	Radio frequency lesioning		100.0% 1		
#7	Sympathectomy		100.0% 1		
#8	None of these	14.5% 8	20.0% 11	9.1% 5	25.5% 14
#9	NA				
#10	Average %	20.3%	30.4%	8.9%	19.0%

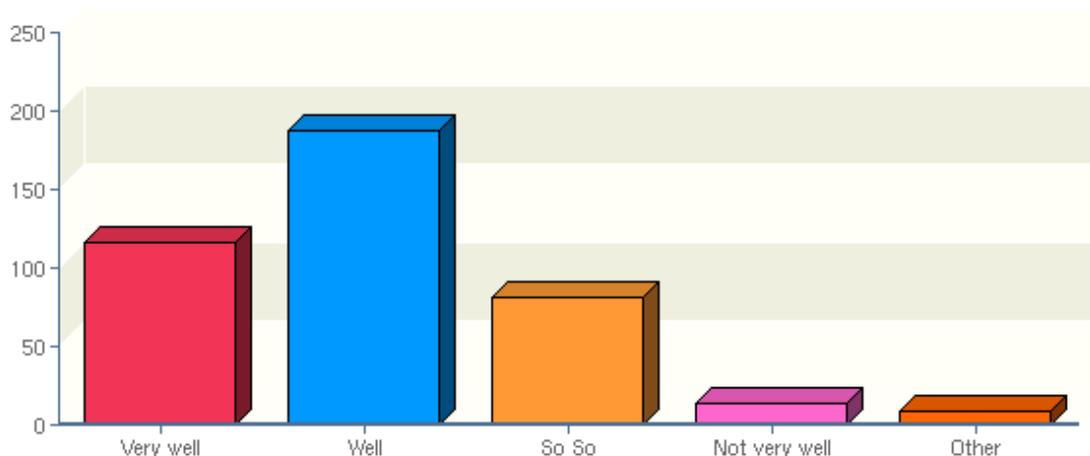
Table 2 of 2	Uncertain	Total
#0		6
#1		4
#2		8
#3		3
#4		1
#5		0
#6		1
#7		1
#8	30.9% 17	55
#9		0
#10	21.5%	79.0

31. Do you think your doctor is educated enough to diagnose and treat others that may have EM?



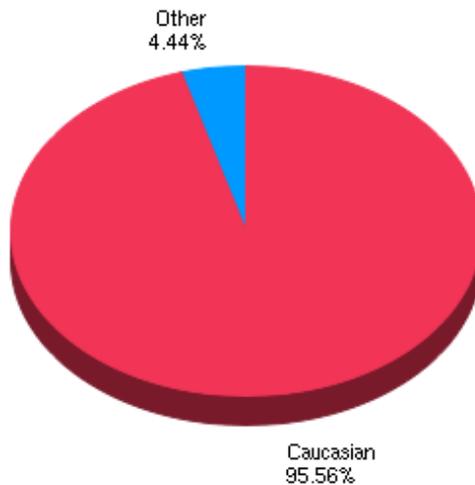
Item	Count	Percent %
Yes	107	26.16%
Maybe	101	24.69%
No	201	49.14%

32. Please rate how well you feel this questionnaire provided you the opportunity to characterize your EM experience?



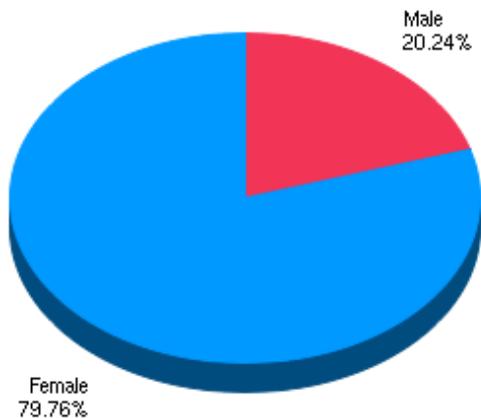
Item	Count	Percent %
Very well	116	28.50%
Well	187	45.95%
So So	81	19.90%
Not very well	14	3.44%
Not at all	2	0.49%
Uncertain	7	1.72%

33. Your Ethnic Background



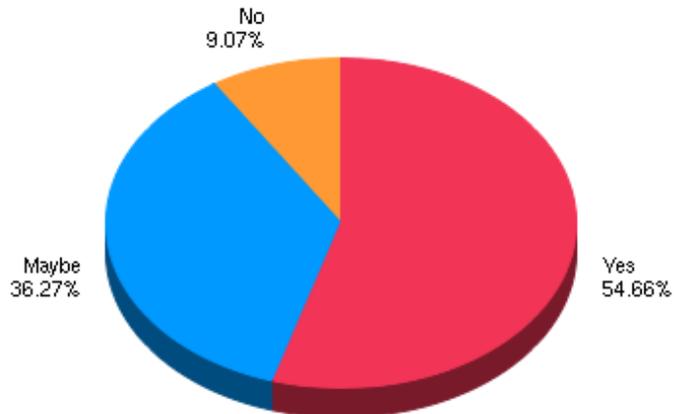
Item	Count	Percent %
Asian/Pacific Islander	4	0.99%
Black/African-American	3	0.74%
Caucasian	387	95.56%
Hispanic	2	0.49%
Native American/Alaska Native	1	0.25%
Other/Multi-Racial	5	1.23%
Decline to Respond	3	0.74%

34. Your Gender



Item	Count	Percent %
Male	83	20.24%
Female	327	79.76%

35. Would you be willing to participate in medical research concerning EM if the opportunity presented itself?



Item	Count	Percent %
Yes	223	54.66%
Maybe	148	36.27%
No	37	9.07%

## Appendix 2: Final Comments/Suggestions/Requests

## Open Text Responses:

Would be very interested/willing to take part in any research. It has a huge effect on my life, and anything that could help me I would like to pursue. Also I would like to be able to find out what other people with similar EM (i.e. primary, idiopathic, onset in teenage years, stable, raynauds) have tried or had success with. I enjoyed this survey, it was well structured (except for the sweating question).

Kind regards, Sam

There are many questions I wish you had asked. Your concept of "episodes" does not apply to me. My EM has a daily cycle (worse from 6:p.m. to wakeup) and a yearly cycle (worse from May to Sept). You missed MANY key details / tricks I've learned to manage EM to make it less painful and burdensome. You totally missed attitudes about this affliction. You missed one key detail: Lowering my feet always relieves my EM; raising them to horizontal (as when sleeping) aggravates my EM. I think there may be 4-5 major classes of EM - a KEY concept! Either my EM is quite different from those you have seen or you have come to believe there is only one basic type. I think the newsletter should focus on two things: (1) A survey of a key, broad question in each issue; (2) Ideas for helping people to manage EM and live more normal lives. I believe EM is WELL KNOWN to competent acupuncturists; four different practitioners have all diagnosed and treated me successfully in the same way - for Liver Fire. Bill Shurtleff

Can confirm dosage of current medications on a subsequent survey. Did not have all the info with me.

I think it is an excellent idea to conduct a survey such as this and I hope it proves useful to EM research. I am always willing to participate in anything that could shed light on EM. Thank you TEA!

I am so glad TEA is doing this. I will be anxious to receive the results.

I would have asked a lot more about weight and exercise, and injuries, and quality of life issues (level of stress on a day to day basis; job satisfaction, etc...). I'm convinced that victims of this disease are perhaps more sedentary than others and we literally lose our ability to function normally....

My symptoms are more of a damned nuisance than a disease, but I would be glad to know how to alleviate them. They've ruined many a night's sleep and bothered me at events and dinners out. Curiously, they abate in June and return in October.

I also have Raynaud's Disease & see a rheumatologist-Dr. Julian Ambrus-Buffalo

My face has turned bright red and burned when I was warm or hot my entire life--also, when I ate certain foods, drank alcohol, got emotionally aroused, etc. Also, I have had burning and "hot feet" all of my life. I always hated wearing shoes because my feet were so hot and uncomfortable though my mom made me wear them as a kid. I just thought that this is "the way I am"--I did not know that this was any medical condition at all until a clerk at a shoe store reacted so strongly to the redness of my feet and made such a fuss about it that I went to the internet and did some research on this--and learned of EM. I have not done a lot to try to treat this other than just trying to minimize the times that I am too hot, don't wear shoes if I can help it, not eat the foods I find to be triggers, etc., and I believe my case might not be as severe as some as I am not particularly debilitated by my symptoms though I am also extremely stubborn, and I refuse to slow down a lot for this. I am going to experiment with some of the meds, etc., that I hear help other people, and I appreciate everything that is being done to help to diagnose and treat this illness. Thanks very much---

I have a 97 year old Mother and a 68 year old Husband that I take care of, not mentioning, I am the chief cook and bottle washer... and they both walk better than I do...I need something to kill the pain permanently without side effects and get back to the rest of my Life.

I've been on Nexium for acid reflux for 3 years, I've wondered if there was any connection between that and EM.

p.s. my ex-dermatologist said what I had was athlete' foot.

I take magnesium, 400 mg divided into 3 doses a day. I have no idea if this has helped me. Now that I take my shoes and socks off and rest when my toes bother me I am doing better. Maybe the magnesium is helping.

I work at the Cleveland Clinic and am seen at the Cleveland Clinic. The physicians there seem to know close to nothing regarding this disease. It would be great to do a talk or meeting on this at large institutions such as this one. Thank you.

I responded that I was diagnosed within a year of symptoms, but I did not seek a diagnosis the 1st 2 years I had symptoms. Once I went to a doctor, he suspected what it was and sent me on to a neurologist to rule out other diseases. Fortunately, he had heard Dr. Richard Layzer, from UCSF; speak on it a couple of months before I saw him. Because I had free flights, and could easily travel to San Francisco, he asked Dr. Layzer to see me. Dr. Layzer said he had seen 35 people with EM at that time, around 2001.

It's very frustrating, just don't think I'm getting much relief from EM and have no idea what to do. I read through the posts from the Yahoo Group of EM patients and it just adds to the confusion.

If there was a defining event, no opportunity to state what it was. Question re drugs should have allowed one to identify all drugs which had been tried and their success if any (permanent or temporary). This would have allowed for a table to be produced as for previous survey. No ability to identify that just one foot involved (unilateral). Also, no provision for describing degree of impact on life or types of specialists who have been best able to help. I live in Wellington, New Zealand where I have been unable to get any useful help for the condition, despite more than 20 consultations with various doctors and specialists over a period of 7 years. Most doctors totally ignorant of condition, i.e. 'Google' it during consultation. Thank you for the opportunity to participate.

## Open Text Responses:

I filled this out for my daughter. She has EM. My name is Karen Gingrich, and I'm the one that joined TEA on her behalf. Thanks for all you do!

Great survey. Very easy to read and use. I would like to see more questions about how others control their EM or environment to reduce flares so myself and others could benefit from these methods. Thank you!

thank you for your consideration in constructing this study

Dr Novella is recommended as an expert in the News letter; he doesn't seem to have any treatment. I have been handed off to a NPRN. This is a puzzlement.

AFTER A FEW YEARS OF TRYING TO FIGURE OUT WHAT I HAD, MY GP SENT ME TO A DERMATOLOGIST WHO WAS ABLE TO DIAGNOSE ME IN 5 MINUTES. I WAS VERY LUCKY IN THAT THE SECOND TREATMENT OFFERED TO ME WORKED QUITE WELL AND HAS REMAINED MY ONLY TREATMENT. I HAVE PROVIDED MY GP WITH ALL THE INFORMATION I GOT FROM TEA AND MY GP IS NOW WELL EDUCATED ON THIS SUBJECT.

I suggest that instead of asking for birth date that you ask only for birth year (or year and month, if necessary) to reduce the possibility of identity theft.

I answered these questions on behalf of my 14 year old son, Luke, who is the one with EM. He first noticed the pain in 2006. We have seen over 10 different doctors in 4 different fields with no correct diagnosis and no relief with what they prescribed. Basically right now he is just living with the pain. He mainly has pain in his hands, and also has the typical "red cheeks" that go along with EM. His feet rarely bother him.

Re medications - it may be useful to ask which are currently being taken, and if some that had some good effects on EM have been stopped, why this was, e.g. I once used to take a small dose of a tricyclic antidepressant but did not continue it because of side effects. I have very recently swapped from gabapentin to pregabalin for a trial period.

If my Raynaud's is bad in the earlier part of the day it is very likely that my EM will be more marked in the evening. Re symptoms, it might be good to ask about severity before treatment and while on treatment - I answered with respect to my current symptoms, i.e. while on anticonvulsants.

I feel very strongly that my EM is related to a thermoregulatory disorder and that my lack of sweating when I am too warm/hot is a significant contributory factor.

Since Internal medicine doctors send patients to various specialists, it would be good if this organization could pass along information on this disease to that organization and the medical schools.

thank you for your time and dedication

I wish to share my experience with Sudafed 12HR extended release. It is a vasoconstrictor as well and I think it is quite beneficial for me. It also gives me a bit of energy.

I have tried to follow the protocol of Dr. Jay Cohen. His symptoms seem very similar to mine. The Ca channel

blockers seriously aggravated my condition. I do take several vitamin supplements also. Lab tests confirmed my vitamin D was very low.

Thank you for this opportunity to share and vent. I'll share anything I can to help you glean further data that I possibly can. Now I must dash and get the fan on my swollen, tingling, burning, and cyanotic looking feet which are truly a vexing and frustrating condition which I so wish I knew more about and hence could control it better...

Sincerely,  
Sandra E. Yaremko

I'm doing the best I've done the last month in a long time. Ever since I started Zyflamend I've been doing 70% better. I actually worked outside this weekend in 90 degree heat for 2 hours. I had a flare and some pain, but I was able to complete my yard work. It was GREAT! This is the first positive news I've had in the year+ I have had EM.

I'm pretty sure that I have the primary type of EM. I just happened to read about it in the Merck Manual while reading about Reynaud's syndrome. It is directly after Reynaud's. I couldn't believe it but it described my weird feet perfectly. I have never wanted my feet to be warm because it always made them sting and burn. Not really severely, but uncomfortably so. I have never worn socks or tennis shoes. It seems to get worse as I get older. I live in Houston, and for the last three or four summers, my feet have been bright red all the time unless I'm in a very cold building, like a hospital, for some time. Anything cold relieves the pain instantly. I wear sandals all the time except in the very coldest weather and then only stockings, never socks. Sometimes in the winters I can have a lot of pain when in a warm room for an extended period of time, even without shoes. Elevating my feet helps, but it has to be really elevated, above my heart, to have any effect. Usually I resort to cold tile, chilled lotion, or when it's really painful, ice packs.

While the medications and treatments I currently do only provide minimal relief, minimal relief is still better than no relief when it comes to the severe pain of facial EM.

I have tried many pharmaceutical and alternative therapies but to no avail. The survey didn't present an opportunity to say what I had TRIED that had failed only what worked. None of the treatments I have had have worked

## Open Text Responses:

I'm sorry if my survey is not very clear.

I've had many diagnosis (EM, RSD, possible fibromyalgia, 'neurovascular instability syndrome', etc.) and I'm not sure I fit into this group of well defined EM patients.

I am currently having flares after almost 6 years of minimal to non-existent activity. I think life stressors have triggered the return and I'm back to sleeping less than 4 hours per night. That's with the Magnesium.

I have been to see my endocrinologist who discovered my genetic coagulation problems (PAI G4/G4 and MFTHR heterozygous with Factor VIII issues) I am hypercoagulable because of hypofibrinolysis and thrombo.....something which causes the clotting.

Now I find out I have Stomolysin 5/5 and am being evaluated for Buerger's disease.

I have since become amenorrheic since Feb. and all hormones are being checked. Perhaps this has caused the return.

I hope this helps you determine if my situation should be included in your date.

The list of possible treatments was an eye-opener; I didn't know there were so many possible ones--and, by extension, that others have symptoms much worse than mine. Also, just having TEA is a great help--to know there are others with this and steps are being taken. I would like to know specifics on what others do to reduce symptoms. Thanks for doing the survey.

Thank you for allowing me to participate in this survey. I hope it helps.

I have been blessed in that with proper diet, exercise, weight loss(45 lbs) and gabapentin, I now have my EM under control. A low sodium lifestyle are a must for me. My exercise began as 10 min per day and now, 5 years later, I am amazed at the amount of time I can be on my feet. For the first time in 9 years I am able to wear socks-- not all day but for a few hours each day. Small increments of progress worked for me but only after several years of struggling with no progress while trying to find the medication that provided at least some relief.

Most of the time, I feel so alone with my illness. Although my doctor listens to me, I don't feel he really understands what I deal with on an emotional level with my symptoms. Your organization has saved me from going insane, and it also gives me a website that I can refer my family and friends to when they have questions about my illness.

I also take 10 mg of Crestor each day. My siblings all have/had heart disease (not my parents, this was documented). One brother died at 49, sister died at 53 cancer and heart, 2 brothers had heart attack before 55. I am not a physician; however, sometimes I think stress is a factor. I also think that taking all the medication I take interacts and confuses my body functions. I believe that only a face to face interview with patients will suffice for a true study. Our lay observations are not always reliable. I actually don't know WHAT is wearing me down . . . this condition, heart blood pressure, attitude or just age. Thank you, Rita

Thank you for lets continue to fight this disease process and get doctors educated to treat us

Thanks so much for all that work so hard to bring information to us and who work tirelessly to keep us updated on research, medicines etc. Thanks also for providing contacts and most importantly for a network that helped me learn that I was not alone with this condition.

Would there ever be a chance to have a bulletin board forum like the neuropathy.org provides? I did contact many people when given the opportunity to connect with others through the directory. But it seemed after initial connection, communication sort of dropped off. I think most of us are looking, hoping for some help and answers and there just really aren't any. I know that the neuropathy association has a lot more money, help and awareness for their cause. And I realize a bulletin board would take a lot of work and knowledge which I for one do not have. I know that all of you who are involved are working hard and giving of your time while dealing with this awful condition and life itself.

I would also like to know what benefit it is to actually be diagnosed by a physician? It seems there is really not much they can do. As long as you have a doctor at hand who is willing to work with you by prescribing what one might need for pain, what else can a doctor actually do for us?

Thanks again for this survey and all that you do to help all of us.

Perhaps I haven't understand everything because my native language is french and not english, but I've made my best to answer your questionnaire.

If I hadn't discovered the TEA website by chance about 10 years ago, I would probably never have found out what's wrong with my feet. In Germany there seem to be very few medical professionals who are familiar with this disease.

It might have been helpful to list treatments or drugs that were tried and/or made EM worse.

It would be wonderful if TEA could provide a list of Doctors across the US that are knowledgeable of this disease. I live in Seattle and have found no Doctor who is really up on Erythromelalgia.....everyone is just guessing. It is truly hard not finding answers. Thank you.

Had to discontinue Lidoderm Patches because I became allergic to them. Their help was fairly minimal. The problem is to stop the flaring at the inception.

## Open Text Responses:

A rheumatologist diagnosed my EM about 15 years ago, but he has since retired. I have trouble finding doctors who are familiar with EM. Most of them say they have heard of EM, but then it turns out they don't have a clue (they just want my money). Doctors need to be educated about EM. Most doctors seem to be familiar with Renaulds Phenomenon, but not with EM (which I describe as the opposite of Renaulds). Many doctors have told me I have peripheral neuropathy not EM, but a neurologist ruled that out. I have very bad osteoarthritis and tendonitis in my left foot from an accident, but I get the EM in BOTH feet, so there doesn't seem to be any correlation. As I stated earlier in the survey, I used to soak my feet in icewater for tendonitis and I think that may have damaged my blood vessels and caused the EM. My Aunt has MS but doctors have never found anything like that with me (I have primary EM). I have learned to live with EM but I can never go anywhere or plan anything for fear of having an attack (not much of a life). Thank you.

I am missing the opportunity to show in this questionnaire with what kind of handling I can find some relief, e.g. cooling with cooling packages, walking barefoot, some relief by nordic walking in spite of being followed by a flare afterwards. I was missing PLO-Gel with Ketamine and Amitriptylin which I used in conc. of 10% and 4% for 1 1/2 years, feeling that it gave me some dumbness in the feet, but nor preventing flares. After stopping the gel now there was no change so there has not really been an effect after all.

I would have liked to mark which treatments I tried and did not work. In the questionnaire you asked for those treatments which worked and unfortunately none of them worked. Some made a things worse, some I had to stop because the side effects were worse long before an effect of EM could show up. I would have liked to specify my experiences with all the meds I tried, but this was obviously not the point you wanted to know. The first part of the questionnaire I found ok. Thank you.

I appreciate this attempt, but felt many of the questions or answers limited me in my responses, so that you won't get a true picture of my EM or all the things we tried that subsequently didn't help or made me worse.

I have my name in to see Dr. Mark Davis and the Mayo Clinic in MN. (for 5 months now). I wish there was a way to not feel so alone with this. I am gradually getting worse and my pain is very frightening. I wish their were some way to get funding for this disease, a way to plead to the researchers and drug companines.

I find that most EM treatment is aimed at controlling pain, understandably. But for me having mild EM is STILL a great hindrance to a normal lifestyle and has caused me more problems and challenges than my lymphedema. Little has been written on the challenges of even mild EM though I realize that with every increase in symptoms, EM becomes more difficult to bear.

The most difficult part of my EM besides the terrible pain, has been the long period it took to be diagnosed. I basically diagnosed myself and then was confirmed by my GP and a Physician. However, It was me who provided them with medical information on the condition, from journals etc, so that them could confirm a diagnosis. I hope that somehow in the future, even though this disease is rare, that perhaps doctors worldwide could learn about this condition in college. It would perhaps save others some of their pain. Because I was unaware of exactly what it was for years, I lived in constant flare up because I wore closed shoes. Once I understood that this contributed to my condition, I was able to reduce some of my flares by always wearing open shoes and sitting as much as I can.

What percentage of the population suffers from this disease?

Medication probably helps but unless I terminate the meds. how would I really know? I do know that cooling my feet by water or fan is more effective for immediate relief so I do this periodically daily.

Dr. Burke diagnosed EM immediately. My primary physician had no idea what it was. I'd highly recommend him to anyone. 773-296-3636

Mine is a minor case, but the symptoms have lasted longer this year as compared to last year. I fear that it is just going to get worst. First I thought it was related to pre-menopause, but after reading other cases on your website, that's obviously not the case. I started seeing slight symptoms in my finger tips as well this year.

I only was diagnosed with EM in hospital where the doctor in her more than 30 years work had only seen EM 1 time before. But they immediately knew what it was - lucky me :- ) - so I could receive the right treatment.

I would like to know if others found similar remedies.

I've never had the redness that seems so typical of EM but I've always believed the specialist who diagnosed it! A month ago I broke a bone in my foot and the x ray shows that my veins are heavily calcified (a by product of blood thinners I believe) or could this have been the original problem? I'm waiting to see another "Specialist" to discuss this latest finding. P.S. Four Doctors at UCG Hospital Galway have never heard of EM !!!!

Thanks for all your work that is involved in this study, Heidi

3 generation have EM, Mother, I myself, my sister, and my 3 children have EM. But symptoms are different. 2 have restless legs, 3 have burning pain, 2 have it always cold.

I have provided this information on behalf of my mother (Olive McGill), who is the one suffering from EM.

Wendy Macdonald

Vasal dilators such as HCTZ has really made the symptoms worse. When I told the doctor I quit he put me on a combo of triemterine and HCTZ. ????? Go figure they just don't get it. When I showed him pictures of the EM he said he had seen that before but there's nothing that can be done. I Asked to see a specialist, he said what for???? I called all specialist in the HMO none had ever heard of or treated EM. I think more people have it than we realize and the doc are just like mine. You should survey the docs and ask them if they have seen patients with these symptoms.

The antihistamine cyproheptadine, which was recommended to me by a Dr in USA, has made my EM so much worse that I am 90% housebound. No improvement even after stopping the drug. Am very depressed.

## Open Text Responses:

Hopefully, this survey will help to find a UNIVERSAL treatment for all EM sufferer. Although I have a good Dr., I must be my own advocate and keep as current as possible with new research findings.

Grace's Neurologist does not think that she has EM, Her rhuemitologist says maybe and her GP says likely. Her immunologist says it's an immune disease, her other neurologist says she thought is was autonomic periferal neuropothy but now says she was mistaken but won't say what made her change her mind. I really would love to see doctors given information to help them get it straight.

the disease seems to be nerve related and temperature sensitive.

I am so thankful for the TEA website for providing updated information I could never find elsewhere and the aggressive pursuits in helping to find a cure for EM. Also, what does anyone say of know about glematax, meoltab, or melgatin? I just stumbled upon these and the website Erythromelalgia-options.com recently. Thank you for this opportunity.

I found that this survey didn't allow me to say this: I've been to Mayo Clinic with these symptoms (my symptoms also include patches of red, inflammed areas on my fingers that come and go following a Raynaud's outbreak). They said I DID NOT have Eyrthramalagia because my hands and feet weren't red ALL the time. So, I really don't know if I have it.

It seemed to my doctor and me that when I was on Nortriptyline it made my symptoms worse and also caused other neurological problems. I've been off of it for almost a year and I don't have as many flares except when I'm quite warm. I tend to be very chemically sensitive and cannot tolerate most drugs and certainly not normal dosages.

Other symptoms caused by EM: recession of the nailbed and nails in fingernails & toenails. Callouses and dry, peeling skin on toes.

The survey lacks personal historical depth --- the treatments tried and abandonned, the ups and downs of the condition itself; but I realize it would be difficult to incorporate rich data into survey format.

Dr. Michael Ferrante at the UCLA Pain And Spine Care Center, Santa Monica, CA is capable of diagnosing and treating EM.

I'm glad somebody is finally doing something about this debilitating ailment. Until my rheumatologist diagnosed me with EM, almost as an afterthought, I had never heard of it. He didn't seem to think it warranted much attention. Told me to take an aspirin when I go to bed. I received this diagnosis during the same visit in which he diagnosed fibromyalgia.

Thanks everyone! Keep up the good work.

It's good to hear from you, ...thought I was forgotten.

I have had EM that I try very hard to live with it. I feel my pain tolarence is high but would do anything to beable to treat with a Dr. that knows anything about this disease.

My G.P. Has no knowledge of this disease and seems not to be interested however my consultant a rheumatologist diagnosed with out hesitation and tried many different treatments, I have also been seen by a second rheumatologist whose speciality is C.R.P. S. and been advised by a third consultant whose speciality is EM These are the only available sources unfortunately in the U.K.

I would be very happy to find some relief for this discomfort, I have gained weight since taking the medications and am very sad because of it..

My first symptom was a degree of weakness in my legs which limits my ability to stand still, ie in a queue; this has not got worse, neurological tests excluded MS but did not explain it, tingling and later burning came on some years later; I think that all these symptoms have remained somewhat similar for years but are less troublesome thanks to learning how to live with them and/or avoiding aggravating factors. I think that what I take to be EM symptoms are fortunately not nearly as severe in my case as in many others; I do however panic if I find myself in too hot an environment and have to get out of it, I really feel very unwell and thirsty when this overheating occurs, it can be rather more troublesome than the pain. I do experience some needle like sharp pains almost anywhere, they are sudden and of brief duration, (normally less than 1 minute,) these seem much less frequent since taking magnesium, I don't know whether they are in any way associated with EM?

Please connect with me. I need more help and am willing to go anywhere and do anything. Thanks for this opportunity.

A list of Doctors by state that are familiar with this would be nice.

This was good though so much of it didn't apply to me. No medications ever worked for me and we tried many, many over time, so settled on the pump to just help with the pain. I mostly have it only when I try to do too much and most things you do, you need to be up on your feet. I can't.

Would be nice to have a list of doctors that have knowledge of EM.

Old address: 206 John Thomas, Georgetown, Texas 78628

## Open Text Responses:

The first doctor I told about my symptoms just laughed at me and told me he'd never heard of such a thing. I didn't bring it up again. A few years later I got a job where wearing sandals was questionable and I felt I just had to get a medical opinion because I knew I couldn't stand to wear regular shoes at work. I wear sandals no matter how cold it is. My son went online and he was the one who figured out what I probably had. I went to a different doctor (my insurance had changed) armed with the information my son had found. She had never heard of my symptoms, either, but she referred me to a podiatrist based on the information I gave her. The podiatrist knew what it was immediately. I didn't have any tests or anything, he just diagnosed me based on my symptoms. And he wrote notes to my job so that I have been allowed to wear sandals all the time. I am very grateful that my symptoms are as mild as they are. I do tend to want to be home in the evenings because that is when it is always the worst, but it is still nothing compared to what many people with EM suffer, and I can certainly deal with it. It's not bad enough that I want to try medication for it, since medication always comes with its own set of problems. I certainly have appreciated TEA. I took part in the telephone conference a couple years ago and I always enjoy Footsteps. Thank you for everything you do.

For me, my defining improvement has been the use of Cymbalta. I started with 30 mg and after a year increased to 60 mg. When I do get a flare, my feet are still quite red and swollen, but the pain is minimal. I still have some flares that are painful, but they are not very often. Usually, the problems happen in the late evening and at bedtime.

Request - Can I send this to my cousin's daughter to fill out?

She is suffering from something similar.

My EM has been extremely serious during winter 2006 and the year that followed. Now, I'm fine, I don't even take my medicine anymore. Nodody can understand this miracle.

Due to finding no dramatic relief from any medications, I have stopped using all but the occasional use of over the counter antihistamines. My pre-bed shower appears to be the most effective way to reduce night flares.

I feel that the EM assoc has helped me to cope with E M. I have enjoyed all the newsletters and articles from other people who have the same condition.

ticked "maybe" for my G.P. Dr. Park to diagnose E M .Prior to me being diagnosed by a Cardiologist he had no knowledge of this condition.

I have been taking tablets to improve my circulation,these have helped,I get them from Dr Teo Ah Choo in melbourne.

I actually went to a EM specialist in New Haven (Yale) and he indicated that I did not have EM - but Neurothopy as originally diagnosed - I still have the burning feet as they have not come up with a solution. I am still interested in hearing from people with EM - I did a lot of research on it and so did my arthritis doctor.

It might be useful to have included certain treatments that have been tried and have failed.

Such as high dose Mg (it failed for me)

Vascular specialist tried stockings and a blood pressure pill

Flare ups started only at night but are now day and night

At some point in my life I have used/taken Lidocane spray I think (child 4-5yrs. old)--No effect, maybe made it worse.

Clonidine (late 20's)-Saw no amazing changes. I was doing pretty well at that time.

Neurontin, Trental, Tenormin, Procardia, Aspirin, Elavil, Inderal. (during 20's and early 30's). Never could tell any significant changes.

I've always had periods of time (weeks, months) where I'm surprised at what I can tolerate. (maybe watching my little boys' baseball games in 90degree heat. After which I would have trouble at night, but at least I could stand it long enough to watch. I would always have to prepare properly by staying in a cool house all day prior to the game --doing nothing that would aggravate my hands, making sure I had a cold water bottle to hold onto while I watched the game.)

Then I would have periods of time I felt like just the friction of holding a book in my hands caused my hands to burn.

I've always said there is day to day burning that is always there (short episodes during the day and of course the burning while trying to sleep. But the next day all is back to usual.)

Then there's the more severe burning, where all activity for me has to stop. (Can't even wash my hair) All I can do is sit and try to keep the affected area in a place with a steady and comfortable temperature. These times last for hours, through the night (of which is a very uncomfortable and painful time) often the next day and maybe even a few days. During this time I put wet cloths on my hands/area to soothe them, or a cool fan (light airflow) for relief. During this time I can't even walk outside my house because it's painful.

Then there is the excruciating painful times where all I want to do is scream. These times were usually caused by my continually putting myself in a situation (outside, or in the heat) for several times/days. For these times when I was younger I did not have Oxycodone. I would put my feet/hands in water. As soon as I would take them out or the water would start to warm, the excruciating pain would resume. These usually last for several days.

My first week of college I had one of the most severe that I remember in my life. I was trying to

walk over the campus in Aug. in 90 and 100 degree heat.

Oddly enough, I had had a pretty good summer in the months just prior.

It seems that I never know where the limits are and they seem to change. One time I can tolerate something, the next time it causes a severe flare-up.

I am now trying to moderate my overall autoimmune problems with the parasite Necator Americanus- as is being done for Athsma and Crohn's.

## Open Text Responses:

I went to around 15 doctors before my husband diagnosed me by finding the EM web site. I tried everything from acupuncture, to removing mercury fillings, to intravenous chelation, to homeopathy. I found Dr. Laine just a week ago when I went in to see if I had a toenail with fungus.

I find it hard to explain exactly how I have used the above to be doing as well as I am now. I am so much better but it has taken several years to accomplish this.

While it took less than a year to get a diagnosis, it took a full year before she saw a doctor who was willing to actually prescribe medication for the symptoms. While the pediatric neurologist could prescribe medication, he wanted to wait to see if regulating her thyroid made a difference. She has been taking the thyroid medication about 3 weeks and she has since complained much more about the EM and the arthritis both. The redness in her fingers has increased over this time period. The redness is what gets the school system to believe that she truly has an issue with her hands. One interesting thing we have noticed is when her fingers aren't red they are a very unusual color now. The original few that were affected seem to have a permanent yellow color to them. We are going to give topical medications a try before we try any oral medications.

EM is a horrible condition that is in great need of government research backing. Hopefully soon we will be able to find a cure.

I am depressed and feel that this is a hopeless situation.

I am actually going to see a good homopathic doctor at the moment and during the summer will be going to the Mayo clinic to see if they can help in anyway. I think for the next survey there should be a section on past diseases, because I have had many previous health issues and I wonder if it has anything to do with EM.

The T.E.A site has been the most help to me, God Bless, I have used it to help treat myself and inform my doctor(s).

Have tried most treatments listed in 2004 survey and later issues of Footsteps.

For me EM is a 24/7 thing but some days it is easier to manage.

Having RP as well is tough, it's one or the other no in between, and it hurts either way.

Condition is slowly getting worse year by year.

The medication mentioned is prescribed for treating `small fibre neuropathy` - `depression` & `migraine` as well as `em`.

Please can I ask a question. Since I have been suffering with EM my feet have been getting bigger & much wider.

I am now having to buy shoes 2 sizes larger (difficult to find) and a EEE fitting. My feet are getting so ugly & I feel so ashamed of them. Is it usual for them to be getting bigger like this?

NB Although I feel pain all the time, pain is much worse when I elevate my feet, or whilst in bed.

just happy someone is trying to find out more about this condition. It was a dermatologist that finally figured out what my problem is.

I have been intending for a long time to share with others my experience of erythromelalgia, in the hope that it might help someone. Thank you for giving me the opportunity to do so! My condition was finally diagnosed by a podiatrist. Very few doctors are familiar with erythromelalgia, although its inclusion in the new Merck Manual is encouraging.

A friend of mine has been diagnosed with Raynaud's syndrome. There seem to be some similarities, especially concerning temperature of hands and feet.

Why don't you ask:

What medications do not work?

How has EM affected your life style and activities?

It might be helpful to have a "Comment" option following each question.

Good idea to do this survey.

Thank you.

Thanks.

I find that in my case not one treatment works all the time. When the flares are bad its really a combination of things that work. I also found that sometimes if I have a cold or something else going on, my EM gets better not worse. Also if I take a nap or wake up during the night, I usually have a flare that can last for few minutes to an hour. Living with EM has been very hard and it effects every aspect of your life. Even though I am not symptom free, I haven't had a bad flare in a couple of weeks. I am not doing anything different. When flares come it can last from minutes to hours or days into weeks. At times you feel like your being burned alive, Your skin swells so much, that you can't believe it can stretch that much.

I hope my answers were helpful.

Thank you for this survey and all the hard work of the EM association. I pray it helps all of us.

The longer I deal with the symptoms of EM, the more I am convinced that there is an underlying problem that is not being detected. I have been to 20 doctors and they are all in agreement that something is going on but only my last neurologist has taken the time to research this condition and try to help me stay as comfortable as possible. This is defitely a horrible way to live.

1) Is there a doctor in the Twin Cities area who is familiar with EM?

2) What doctors or types of doctors should I see at the Mayo Clinic in Rochester, MN? (May have to be my next step as my EM of the face has been so debilitating for almost 13 years.)

none

Thank you for the wonderful work you do! I wouldn't have figured out the EM without you.

Of course you know it's hard to talk about the condition in generalities, but the Study seemed to be very well organized and thoughtful. Thank you!

## Open Text Responses:

Due to other health problems my activities are limited which is frustrating but does actually help EM - gentle movement and lots of rest with feet up

I went through early menopause at the age of 44. I thought maybe Hormones played a certain role in this. I was really healthy, playing all kinds of sports....intense walker, swimmer, and dancing. Maybe I did too much. I wish this test would have asked our habits. I use to smoke and drink alcohol before EM.....I wonder if I put my vessels into spasm during my traumatic emotional event.....because I smoked so heavily that week.....the week before EM.

Comment: Thank you for doing this!

Suggestion: Have someone edit this next time, or at least run it through a spell-checker---there are quite a few misspelled words. (I'd be happy to do this for you).

Thanks again.

I feel I did not get to mention the treatments I tried that did not work, or only helped temporarily.

My EM was severest and diagnosed during the latter months of pregnancy. I have it in its milder form--withOUT \*visible\* manifestation--all of the time, which I would never have known had I not become pregnant. Gabapentin, 300 mg./ 3x per day, plus oxycodone, 2.5 mg/ 3x per day, has greatly improved my EM pain--FINALLY!!!

I have primary EM; my middle son shows mild signs as well. Hypothyroidism has recently been diagnosed, with numbers yet in normal range--though I've been saying it for years. [I think the two conditions have been acting against each other, so neither manifests (visibly) fully.]

My dad had Hashimoto's and type 2 diabetes. He died of a brain aneurysm at age 64. His mother died of a brain aneurysm at 54. I think this is significant to note, given the role of vascular dysfunction in EM.

I would like to contribute more fully to research and to the newsletter, if I may, so please feel free to contact me.

Cori

I was just diagnosed a few months ago, so my answers to the treatment section didn't let me tell the whole story. Otherwise, I feel this was a great survey!

I am currently looking for better doctors with an answer or treatments, I have been to neurologists, hematologists, rheumatologists, and just seen a vascular surgeon, they just seem to pass me on to other doctors with no answers for treatments. I would hope to get answers and help soon

I know that walking and heat start my symptoms. If I have an outbreak, it usually starts minor, but if I continue activity the swelling will increase and spread from my feet to my hands and face (tip of my nose, tongue and lips). I have an appointment with my doctor soon for blood work to rule out other problems that may be causing the EM.

I'm still watching this but symptoms get worse around my period (early) and when I'm ovulating.

To help family, friends, and co-workers understand EM and lifestyle ramifications, I compare it to heat stroke. Those who care try to understand.

I have attended leading NEUROLOGIST.He never mentioned ERYTHROMYALGIA while telling me what my complaint was not

My primary case is very mild. My feet and hands do not get red, just flushed in the face after exertion or emotional trauma. I have had to educate my doctors and TEA has been my guide all the way. I first diagnosed myself by putting "hot feet" on a Google search and finding the TEA website. Then I went to a neurologist who confirmed my conclusions. I am so grateful to TEA for education and guidance. I feel fortunate to not be in such a bad a shape as so many other members.

I haven't posted any information concerning the morphine on the EM group. I did take ER 30 mg one in the AM and one at PM. The PM would make me fall asleep or pass out, I don't know which, while I was standing up or using the bathroom or walking. I would wake up all over the house. I cut back to one 30 mg ER, after 1 night I fell 5 times, the last 3 - I hit my temple on the corner of bath vanity, can't remember the 4th, and the 5th time I fell and my head was in the comode down to my nose, and I was trying to get my head out, now it sounds comical but then it was very scary. So there are side effects I did not want to expose anyone to them. The 15 mg IR's are great with no mental side effects that I or my husband can tell, no physical effects, just burning relief.

Is there a listing of doctors who are good at working with this disorder?

I think someone needs to address the emotional side of EM. You can not live w/ a condition like EM w/out it changing all other aspects of your life. Mental health is a big issue.

EM cannot be treated where Raynauds is a comorbidity as treating one will exacerbate the other. EM also exacerbates Rosacea and associated psychological problems

environmental factors not discussed (yet)

Diagnosed by husband (DPM), and a friend out of state that was a renowned dermatologist. There has been no other confirmation except that symptoms seem to fit the dx well.

I'm not sure what type of medications I take and thus did not fill in the dosages--sorry

Thanks for doing this survey

## Open Text Responses:

Sometimes in the winter, my hands have Raynauds. Also, I experience chilling just prior to significant flaring; core temp. drops to 96 degrees from normal 97.4. Chilling also accompanies major flares; feet & hands burning -- rest of body freezing. I have neuropathic itching deep inside joints of my hands during major flares.

I do not have EM. I joined to learn about it because I have a medical background and a friend of mine who is destitute had a doctor suggest EM as a possible diagnosis for some of her symptoms--her primary diagnosis is colchicine poisoning. At this time no one believes that she has EM, but the education I got from your info was very definitely worth the price of membership, although I don't expect to renew since it has turned out not to apply to her.

My doctor belongs to Kaiser Permanete and screens possible EM patients for their primary care providers. When he first saw me, he had seen 30+ patients with EM. He has had a few others in the last 4+ years. I am the worst case he has ever seen on two counts, sudden onset and severity. In the first 10 mos. I went from minor pain in the ball of my right foot when driving to daily episodes of flaring red, swollen feet. Now flaring always follows even short periods on my feet, severity increases with length of time but can also occur during periods of bedrest. Am on disability, spend most of my time in bed, feet elevated, temp 65-70 degrees.

My symptoms are very light. I keep a rice bag in the freezer during the day and put it in my bed each night for when I need it. There are nights when I end up not needing it.

Keep up the good work. Hopefully more phycians will become aware of this. My major question is should I keep trying to not overtake my Zyrtec and by doing so I have about a week of itching that I try to control with Calamine lotion. If Zyrtec is not going to loose effectiness I would simply take one about ever 5 to 7 days and have no itching.

I wanted to let you know I only had the magnesium IV because I had pre-eclampsia during pregnancy and needed it after my C-Section. It completely relieved my EM symptoms for 2 weeks, which has never happened. But, I did try an oral magnesium which did nothing.

Being undiagnosed, I found one option for selection extremely interesting. You offered as a selection for the onset of symptoms, temperatures above, I think you stated 66 degrees. My threshold is 66 - 68 degrees. Even at those temperatures I use a small fan by my desk, recliner and bed. Even in my tolerable temperature range, if I am active, say with ordinary housework for 10 - 15 minutes, I can have an attack of a hot face which can lead to a hot feeling head ache which can lead to nausea and feeling ill all over and sometimes shortness of breath. (I am on disability for MS with the primary symptom being severe fatigue. I am a house husband.)

There is a possibility that my symptoms could be caused by medicine interactions.

Thank you so much for your work creating this survey. :o) It is exceptionally well done.

Richard :o)

Thanks! I appreciate the work being done regarding this condition! As I am weaned down on my dose (200mg/day), my doctor said that we would tweak other drugs to use along with the Lyrica which seems to be causing me some problems. I have tried so many meds and treatments over 7+ years!!!

Keep on doing what you are doing

Feet are cracked and bleed upon walking. Feet and ankles turn purple during flare-up. Standing causes flare ups. Hands swell and do not respond to any type of medication. Both my children have EM. The 6 year old was diagnosed and the 2 year old started having flareups. We were all born with this.

Sorry about responding so late, I've been out of town for the last two weeks and had some catching up to do. I've noticed my symptoms have gotten progressively worse over the last 5 years. I can't really stand up for more than 20 minutes at a time, so doing any significant walking around outdoors is difficult. I also have been getting attacks after 30 minutes of exercising (indoors, with an AC on) when I used to be able to go 2 hours at a time (I fence, so it's always indoors with AC). I was wondering if you or the association had any tips? I've been on magnesium for a while now, I recently (in the last week) started taking vitamin B supplements, and I took neurontin but it only treated the pain, not the symptoms themselves so I stopped it. Should I simply up the dosage of the magnesium? Any help / tips would be appreciated. It's nice to finally find a group of people with such specialized knowledge. Thanks.

Sometimes I feel I'm dying, over the last 11 years, from the feet up.

The only way the pain is bearable is knowing that it will stop in about 40 minutes.

Tom Fyfe (son-in-law) responding on behalf of Nancy.

thanks alot for the work you do! I think I would have lost my mind if I had not discovered your group and heard other people stories. I wish there was a local support group to go to. Most people think it's funny, ha ha ! your feet are too hot, wish I had that problem.! Being burned alive is most peoples worst fear, and that what it feels like alot, other people simply cannot understand. It is horrible.

I would like to know if other people have any other strange symptions, the last news letter had a blurg about separating fingernails, which I did not know about but very much affects me, hardly a problem compared to other things, but collecting related symptoms might eventually lead to more ideas about what is going on, I also wonder about the hormone piece for women, most women get the sweats, are there those of us who go the other way? If I am sweating I get some relief but many days no matter what i do, I seem to produce no cooling sweat, these are bad days.

Keep trying to find some docters/clinic who will step up to the plate, and where enough of us can go the same place, that we will actually get some attention, it is so exhausting when you have to be your own researcher and provide all your confused ideas on what to do next to your doctor. We need to find a few places where we can all go.

Again, thanks for asking and doing this.

## Open Text Responses:

I originally thought I might have MS and went through numerous tests for MS as well as other AI diseases. I find that the depression and the unknown with this is extremely difficult and the fact that the med. comm. knows next to nil and really does not seem to care makes it difficult to be positive.

I am/was extremely active, marathons etc, and am struggling majorily with this awful condition.

I feel that this condition should be made public - esp. since I believe that there could be a psychological trigger - stress, depression etc - there MUST be more (info and affected people) out there with this - if someone would have told me that this could happen to me/if I was aware that such a thing could have happened to me, assuming that stress/depress may have caused this, I would have seen a dr a long time ago and taken some anti-dep meds. Ofcourse I do not know the true cause but I think stress played a part and now I am more stressed than before.

None. There is just not enough known about this disease. It seems that some treatments work for some and not for others. It's a hit or miss situation, with little help from any of them. What seems to work well at first, doesn't last for long. I have about given up.

Yoga and strictly limiting my level of activity are crucial to living with EM. Air-conditioning and a lot of support are crucial.

After having tried the Mayo-prescribed creams, lidocaine patches, Lyrica, Effexor, etc., I realized the "common sense" actions were still necessary -- cooling, elevating, eliminating humidity, exercising regularly, wearing open sandals or shoes. I could not tolerate the effects of Lyrica or Effexor, even in small dosages. I am now able to control all of my symptoms very well.

I would like someone to tell me if EM can CAUSE neuropathy. I have asked on the chat site and CANNOT get an answer.

Thank you, glad to take this test....

does hormonal imbalance play a part in em? my worst times were premense and now menapausal times and during pregnancy of three children

Over the years it has been extremely frustrating trying to find a doctor who is familiar with EM. When I first saw Dr. Dreher in a Kaiser pain clinic she had never heard of EM. Over the 7 years I've been seeing her for acupuncture, she has educated herself about EM and has given me hope that someday I might be able to go into remission.

It would be great to have a visiting medical specialist come to different centers to confirm EM diagnosis and help with recommendations as current health providers (e.g. Indep. Health) have set up impossible roadblocks for this.

When I was diagnosed, I had been refered to a vascular surgeon in Titusville(Dr. Zambos) who know what I had but couldn't think of the name of it. He called Dr. Salach(a Rhumatologist here in Titusville) who knew what the name was... Erythromelalgia. Dr. Salach had never had a patient with EM but knew about it and he has been my treating Dr. for my EM for about the past 6 or seven years since being diagnosed. I can at least sleep at night now without being kept awake with the pain of burning and neuropathy. I still have to deal with it during the daytime but it's bearable where as the night pain was so much harder to deal with.

thank you for the opportunity to help in a small way.

I've been to every medical specialty that exists, I think, and giving up on all except to get sleeping medication. Even tried twice with injections to spinal nerve to see if sympathectomy would help. I'm now having hopes on accupuncture. It at least helps general health.

I was diagnosed less than a year ago by my dermatologist. She recommended some cream twice a day. Don't know if it helps or not.

I have tried many of the other drugs listed in this survey but they have not helped me or my body will not tolerate them. I have found I am very sensitive to drugs. My doctor does not know much about EM specifically but is willing to work with me to control the pain and is unafraid to try new approaches.

Please that you sent this questionnaire. Very thankful for what you do to try and help and find a cure.

My feet are in a constant state of low burn but ramp up quickly with heat or exercise.

Because I take a variety of prescriptions there is not much opportunity to add more of them such as mentioned in question 25. Therefore I only use 10 mg amitriptyline and cold water.

Keep trying to find relief. Try anything. When all else fails, pray.

I have been seen by many doctors, including the Mayo Clinic dermatology dept., Duke Univerisity Hosp., Univ. of North Carolina, and several other doctors in Fayetteville. Only the doctors in the Mayo Clinic were aware of the name, which I had named prior to my visit.

I'm hoping that someday a treatment/intervention/surgical procedure/gene therapy will be discovered that can shut off the trigger that starts the flares. I'm fortunate that I can (so far) minimize flares by controlling my environment and activity level. But since I'm not a hermit (yet) I frequently get into situations when my feet flare (especially during the summer). I get so mad at my body when that happens. I just want to tell my legs and feet to chill. But the blood surges to the feet as though my life depended on it. One question I have: What should I expect as I age into my 60's - 80's? Does every flare destroy a bit more of my good tissues? What's the overall damage to the body with all this surging blood? Thank you so much.

Thank you for allowing my input.

I found the results of the last survey very helpful. Two out of three of the medications I take have been prescribed on the basis of the survey results plus the accompanying article by Dr. Cohen.

## Open Text Responses:

I realize after reading your newsletters that I have been totally blessed. The Nortriptyline has kept the EM totally under control with no flareups since I started the medication. I am now undergoing extensive tests for "roaring" in my head and triple amount of tinnitus. I have had no results from the tests (the most extensive ones) as they I had them yesterday. I am now wondering if nerves/nerve endings is involved.

Thank you!!

I have lost about 3.5 stone in weight and I am going swimming every week. I find this is the only exercise I can tolerate. But I do feel a lot better in myself. My feet only flare up now if I go shopping or do a lot of walking and my hands if I do housework, etc. Unfortunately, these things have to be done.

Please find help for us. And thank you for caring. Someone out there does care.

Please forgive my many comments throughout. I now it is not time to give up Oxycotin but i don't know where to turn. I am thankful for the 7 years of relief I have had from this disabling disorder by using Oxycotin.

My feet feel like they are in a cast all the time. I use ice packs almost every night.

I have not been treated for my EM by a doctor for several years. They were very helpful and wanted to try more medications but I did not like the side effects from the drugs. If my EM becomes worse I will try more treatment. I feel that i am maintaining fairly well with my cold packs.

I "illegible" for the cure. Need help with cook and clean. How do we get a life back? Always should live on flat level floor plan. My most imp decision is to move alone, where how need help most of the time. How to survive this. Find me someone to communicate with. Help. Thank you.

I have had a brain MRI and they have found while matter changes similar to an MS diagnosis. Could you find out how many other EM patients have had an MRI? What was their diagnosis. Thanks. I have no MS symptoms.

Dr. Cohen's article about temperature control seems to apply to me. I've said all the time that my thermostat doesn't work.

I have many unanswered questions about EM. My doc is ignorant. Who can I ask questions? I live in SF area of California. Is there any doctor in my area who is knowledgeable about EM. Or treating EM patients?

I have used the cold water and ice and vaseline for a couple of years now and it seems the only way to enjoy my life.

I am more grateful to the TEA for all the support and valuable information, especially the articles of Dr. J Cohen which have proved enormously helpful. In Britain I feel we are still so far behind in diagnosis and treatment.

I value information from TEA doctors in UK say I seem to know more about EM than they do. I have accumulated a file 3 inches thick. The only profs over here who seem to know about EM in depth are Professor Jean Belch at Dundee Univ Hosp and Professor Black at the Royal Hosp in London. Not possible to complete properly in 15 minutes but no problem. I'm pleased to complete the document and what a great job you people do in USA. UK medics are the least interested if all the occasional ones and I have yet to meet a medic who has ever heard of EM.

THANK YOU!!!!!!

See earlier comments. I know this is a difficult topic to tackle due to the variability (primary, secondary, etc, etc.). Thanks for your efforts!

I take the Clonidine 0.1 to lower my blood pressure, though it helps with the EM. Having people take it for just that purpose could be dangerous.

I have answered this to the best of my ability on behalf of my granddaughter Jade who suffers this terrible disease in spite of also having recovered from a benign brain tumour that meant she had to have her pituitary gland removed and also lost her sight due to optical nerve damage,

None at this time. Thanks.

if there was any research on em it would have to very close to home in order to participate..

zlt would be great to just once find a doctor that would even be interested in learning about the problem instead of taking any information you have & tossing it into the waste basket & telling you this is something you just made up

Thanks for doing this.

Thank you for your efforts.

Its great that you do this exercise. THANK YOU

Is there a master list of doctors known to be "experts" at evaluating and treating EM? I consider myself pretty lucky that a very smart military doctor finally diagnosed my condition but I have had zero luck finding a doctor qualified to evaluate and chart a treatment course.

Thanks!

The anti-inflammatory all natural supplement, has turned my life around for me, now just over 1 yr. I accidentally ran into it in the natural store. The email for the product is [www.newchapter.com](http://www.newchapter.com). I take the 2 softgels, twice a day with water and food. I started them in July 07., nothing else worked more than 2 wks. for me. The redness remains but no swelling and no pain!! Others on the EM site have tried it and it has worked for some I think..but it doesn't sound like it's worked as well for them as it has for me. I really am not sure ..one guy Dave, whose son was 14ish was having good results and Gregg Wadley..off the top of my head.

Thankyou for your survey. Sincerely, Nancy Gaseau

## Open Text Responses:

Your survey is missing the list of diseases you wanted to know about in relatives.

Also my trajectory with EM was mild to mod/severe (then started effexor which made it mild) and very mild now with my dietary changes and no effexor.

Your questions about drugs and topicals didn't allow me a good way to say which ones I tried that didn't work. Here's what I tried that didn't work (nortriptyline, gabapentin, mirapex, OTC capcasin, lidocaine patches, topical lidocaine, accupuncture 4 sessions with herbs, massage).

I have received treatment at the mayo clinic, but it is geographically and economically not pheasable for my family on a regular basis. I can only afford to go once or twice a year. I have had no luck finding someone regionally with knowledge or experience of email, which has resulted in spiratic treatment over the past 7 years.

Thank you for all of the effort you have comitted to in doing this survey.

Dr. Heidi Rendall did not know what I had when I first showed her my feet. She found out within 2 weeks, and within 3 months I had been to a dermatologist, a top notch Rheumatologist at the University of WA, a Psychiatrist to prescribe the best medications for EM and a pain Dr. (Dr. Stacey) in Oregon. They ALL knew about EM and medications for treating it. I feel I was VERY lucky to have Dr. Rendall as my Primary Physician. She treats others who have EM and I take her articles from the EM publication so she can learn and share information.

In our replies to medicines, we have no way to report what the dosages were when we first started them and how much we were taking when we stopped, or if we stopped them. Also, sometimes we were taking some of them concurrently, such as morphine/methadone.

There was not an opportunity to report that I was answering on behalf of someone. My husband was the one with the symptoms that I (through research) am sure had EM. He committed suicide on May 10, 2008; he had lost all hope of ever getting relief. I wasn't sure of his medicine dosages and a couple of things (such as spinal thing) he had just had the opportunity to try once. I answered that he would be willing to be included in medical research because I would both be glad to share his medical story and/or I would like our daughter included because of my fear that she will manifest this condition.

I would also be very interested in writing my husband's story/journey for your newsletter if you'd like.

We saw 25 medical professionals. None of them were too appreciative of my bringing to them a diagnosis that I had found. His only diagnosis ever was in the neuropathy family: diabetic, peripheral, small fiber.

Jackie Eye

My comments re. the time and place of my discomfort, (in feet and ankles) is described above.

P.S. I don't think my advanced age has anything to do with this condition. I am active -- still drive, travel, and entertain. My younger friends refer to me as being 90, going on 70.

The diagnosys given by physitiains for my condition is CRPS. I have been interested in EM, however, because I feel my condition is more smilar to what are described for EM in someways.

This survey makes little sense to someone not suffering from erythromelalgia

I have also found that Aloe Vera Gel is very good for cooling the soles of feet at bedtime, making sleep easier.

THANK YOU! I am looking forward to receiving these results.

I completed this survey on behalf of my son, Andrew, who is age 10.

@I listed no d octors name as I have been to at least three or four but n ,t much help. internest. neurologist

In retro, minimal symptoms appeared at around age 35-40 then exacerbated 3 years ago (onset gradual). Questionnaire did not allow for that senario.

None of the treatments help prevent a flare, only help control the other foot pain/symptoms. The lower my B/P, the better my feet feel.

Questionnaire does not address the residual symptoms after a flare has resolved; should provide opportunity to share positive approaches/solutions.

My EM is a mild case.

I would welcome questions that covered the medications, topicals that I have tried with no relief. I am curious how many have used the doctors at the Mayo Clinic and what level of relief was experienced.

## Open Text Responses:

TEA has helped tremendously. Specifically a couple years ago Dr. Cohen had a phone conference and when people asked questions i learned a lot form his answers...

This disorder is too rare and complex for the doctors. They have many more common things to treat. If we leave it to them, progress is slow. Everything i am taking or doing now is by my suggestion to the Doctorss after reading TEA stuff or talking to other people...or reading other things, or just trying things! I feel like an EM expert (for my case). I am an Engineer by trade. :) Doctors are like engineers, they use knowledge, logic, and experience to solve problems... i have increased my knowledge and experience over these few years and applied geeky-style logic. I kept a log of everything i did and looked for trends after trying things. I have improved my symptoms a bunch from that.... I say all this because i think there is hope for living better WITH EM by making the contacts and trying things with a patient Doctor, and just learning and documenting what works for you....

I am also not normally this wordy. :)

All the Best  
George

Thank you for giving those of us who may not have seen the first e-mail about this survey a chance to complete it by contacting us again.

The only thing I found difficult to answer was whether my EM is secondary to another condition...I have had symptoms of Renaud's Disease for many years but have never been definitively told that it is linked to my EM, although I understand that Renauds is often associated with vasoconstrictive EM. I also experienced neuropathic pain for almost five years before the EM symptoms (ie. flushing, etc.) developed, and still have problems with it at times. Anyway, please correct my answer to the 'primary or secondary' question if necessary. I have never treated my Renauds or neuropathy with any medication.

It is very difficult to cope with 24/7. Not many people can symathize with this. It is difficult at work and around family members who do not understand not only the constant discomfort but the mental stress it causes. Plus the medical community is not much help.

Summers are easier than winters. While in the summer when the A/C is on I can tolerate 68 degrees, I cannot tolerate any central air heat period. My house could be 50 degrees but I cannot tolerate heat so it is not all just about the temperature. Some questions were not worded in a way that I could answer. For example, my symptoms did not change for 15 years, then recently I started to sweat again (no known reason why) which has had a hugh impact on my symtoms. Some treatments, like magnesium/alpha lopeic seemed to help but caused potentially fatal side effects from elevated blood pressure. So was that a helpful medication? Heat is the main driver of my EM, so I control my environment to the point of alienating my family and co-workers.

I have recently heard of a hematologist here who is familiar with EM and I have an appointment set up for October 20th. This will be my first doctor who knows about the disease so I am very anxious for this meeting.

I experience varying degrees of pain and burnig 23/7. Also I have numbness only on the left side of my face and body which can last for 2 weeks.

I was interested to note on pages 5 and 6 the possibilities available for the treatment and relief of EM. Obviously I haven't begun to explore even the "Tip of the Iceberg"! I really have not met with any Doctor who understands the EM condition at all. Usually a blank stare or a somewhat mocking attitude to the name "Erythromelalgia" followed by an offer of pain medication.

I am so sorry it took me so long to respond. I hope it was in time for you. The cymbalta I took helped my PN I was having at the time but did not reduce my flaring as a reaction to certain foods. I am considering stopping it because of having a lack of libido as a side effect.

I also take the medications for back pain and they helped with the EM  
thank you for giving us a voice! Best wishes,

Russell Jarrett and Family

Please share my thoughts on Niacin with others as I have been wanting to get the word out since I discovered this help years ago. Thanks for giving me the opportunity with this questionnaire!

I pray that this survey is an answer for those of us who suffer with EM.

My left foot was first affected. Symptoms started with the right foot a year ago, come and goes but is getting more flare-ups of late.

I could not fill in the questionnaire online. The site asked for ID and password which I did not have.

I truly believe my symptoms were stress related. I was able to remove myself from a stressful situation and my symptoms improved drastically.

When I first had the signs of EM my face, ears, back, legs and feet were affected. Now I only suffer with my feet and sometimes my knees.

Since I had my spinal cord stimulator placed last Han I have been able to completely stop cooling my feet. My feet no longer burn or flare. I still use my knee scotter and try to limit my time on my feet but my life has improved to a vast degree. My circulation in my feet has improved, they are no longer red or purple but look like normal feet. I still have neck and shoulder pain if I over use my arm or shoulder but it is quite tolerable compared to my previous pain.

Thank you for doing this.

## Open Text Responses:

I have not found doctors very sympathetic or helpful. A rheumatologist said "I only see this about once a year".

I appreciate hearing more about other who suffer with EM. My address is 528 Hill Cir., Wanamingo, MN 55983

Very comprehensive questionnaire. Needs more writing space in certain areas.

I have used 600 mg of gabapentin but stopped. With the other 2 things I am taking I didn't like the way I felt (light-headed, dizzy at times, my memory).

Does any one know a Dr. in Honolulu, HI who is versed in EM treatments?

My apologies for the delay in responding. Hope the survey gets to you in time to be included.

willing to try anything. I carry ice packs with me when i go out. Wear sandals all the time. Place feet on ice packs when out - theatre dinner, etc. Sleep on electric bed with raised legs and take cold packs with me.

Use heat packs for my hands and other upper regions. try to raise legs for 2 hours during the day when I can . Sleep in summer with electric fan playing on my feet.

Willing to give further information.

The Propanolol or inderal helps keep my extremities cool and cymbalta reduces the pain. My prayers go out to everyone who deals with this disorder. Try to keep positive thoughts and help other

Thank you.

Suggestion: Maybe address impact of Em on ability to work.