

The newsletter for members of The Erythromelalgia Association
FootSteps online: www.erythromelalgia.org or www.burningfeet.org

Special Edition

2008 Member Study Results

This issue of *FootSteps* contains a question-by-question report of the findings of TEA's 2008 Member Study.

A major project for TEA, the survey provides detailed information about the symptoms, onset, diagnosis and treatment of EM, according to Meriwether Jones, TEA board member who coordinated the survey.

Some 66 percent (427 members) returned questionnaires — a high response rate.

As a result, people with EM can share this information — with confidence — with doctors, family and friends. Responses to each question are expressed graphically — one of the advantages of using a survey firm.

TEA hired Survey Design and Analysis of Denver, Colo., to help design the survey, conduct it, compile and report the results.

The firm reported results as bar charts in PowerPoint slides, which are copied inside. Each slide has the number of people who responded to that question. Look for "N=" to find that number.

TEA developed the survey questions and the firm helped word them in language that made them easily counted and reported.

Many of the same questions were included in the 2003 survey. Where possible, the 2003 responses appear on graphs along with 2008.

In the summer and fall of 2008, the firm sent questionnaires to TEA members either by e-mail or the U.S. Postal Service.

The firm also sent additional paper surveys to those whose e-mail addresses were found to be invalid. Two e-mail reminders were sent.

TEA kept the survey open to allow as many members as possible to receive a questionnaire and respond.

Jones and board member Deborah Mosarski worked tirelessly to include late responses and check the accuracy of data.

Doctor Directory on Web

Now on TEA's Web site is a member-recommended Doctor Directory, a new TEA service based on the 2008 Member Study.

The list can be sorted by name or location. It is only a start. TEA encourages any member wanting to add a doctor to the list to send the name to memberservices@erythromelalgia.org.

2008 Member Study respondents were asked if they would recommend their physicians and given the chance to write in their doctors' names.

TEA volunteers helped verify and upload the names to the Web site.

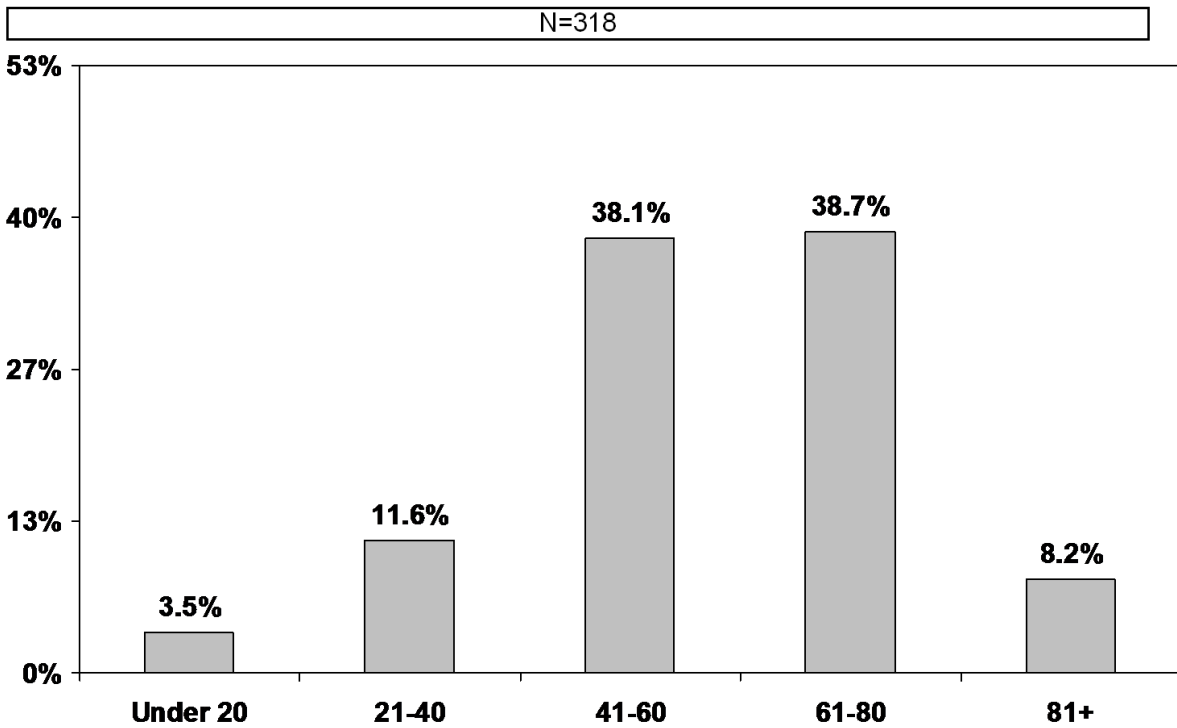
TEA does not endorse the doctors on the list. Physicians were recommended by members based on their individual experiences. If you choose to use one of these doctors, do your own research regarding whether the physician will be a good fit for you.

Summary

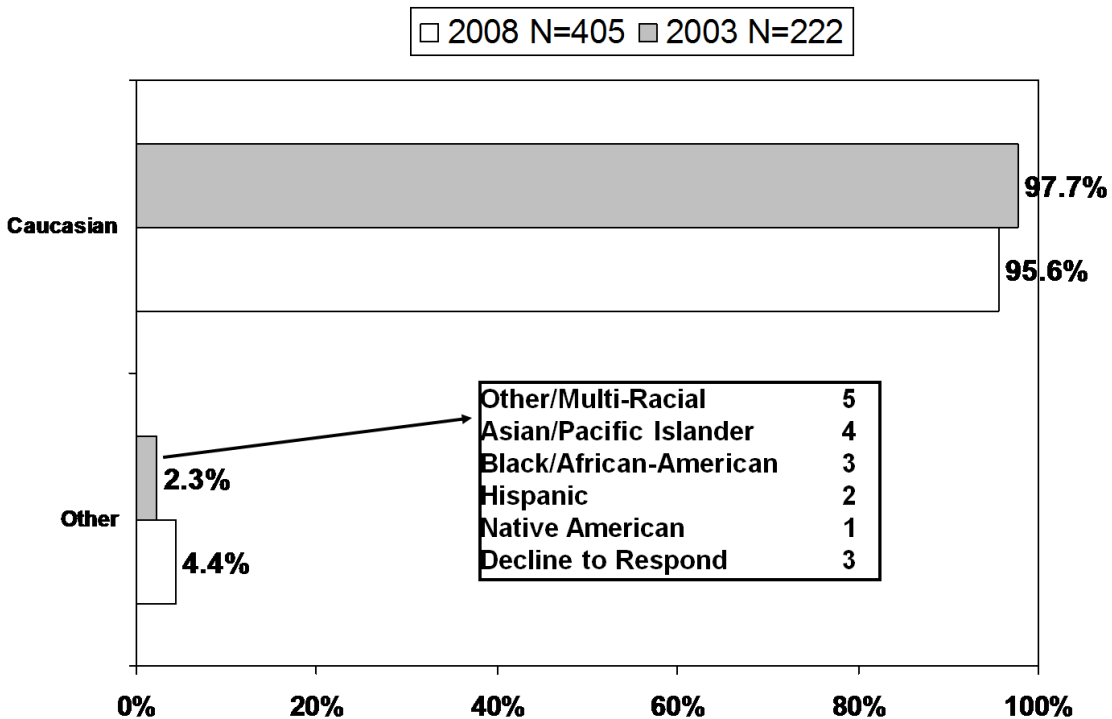
- Respondents to this survey were:
 - 96% Caucasian
 - 80% female
 - 77% within the age range of 41-80
- EM is very distinctive
 - 99% of sufferers experience flares, primarily in their feet (95%), but also in their hands (54%) and/or face (31%)
 - Of the 95% with foot flares:
 - 40% flare only in their feet
 - 29% flare only in feet and hands
 - 25% flare in all three: feet, hands and face
 - 6% flare only in feet and face
 - 93% experience burning and redness in affected areas
 - 96% experience regular flares if their environment is not controlled
 - 85% experience pain at the skin level and 56% also feel pain deep into their body
 - 97% feel their condition is exacerbated by weather conditions, primarily heat
 - 97% have been diagnosed with EM by a doctor; 58% of these credit themselves with helping the doctor determine the diagnosis
 - 87% feel certain things trigger flares [of those answering yes: 82% identified exercise, 49% taking a shower, 45% elevated emotions, 44% alcohol, 36% certain foods]
- Yet the disease appears to follow few patterns
 - Any age person can be affected
 - Symptoms start across all ages about evenly
 - Only 28% report symptoms starting with a defining event
 - 57% report symptoms steadily worsening, but 17% report symptoms improving over time
 - 64% report no period of even a few days in which they have been symptom-free
 - 60% indicate at least some ability to control their symptoms, mostly by altering the temperature or airflow of their environment
 - 53% have a separate condition which accompanies their EM, 34% do not
 - Although no single other condition stands out, Raynaud's is the most frequently reported, appearing in 42% of those who named another condition (or 20% of all survey respondents), followed by peripheral neuropathy at 29% (13% of all respondents) and thyroid disease at 25% (11% of all respondents)
 - Only 46% report their perspiring as normal even when not flaring; another 38% can't sweat at all, and that number swells to 88% during flares
 - No relationship was found between symptoms and age, gender, whether another condition is present and the ability to control flares
- There does seem to be a genetic component to the disease
 - 5% have a relative diagnosed with EM, and another 20% suspect that a relative has EM symptoms
 - These percentages are enormous considering how rare the disease is in the general population
- No treatment works consistently for all diagnosed with EM; although 79% aggressively seek treatment
 - Anticonvulsants¹ have the greatest effect among prescription medicines, helping 43%, followed by SNRI's² at 23% and NSAID's³ at 21.7%
 - Supplements/regimens and invasive therapies were credited as helpful by fewer respondents, but some provided comparable relief among those who did use them, particularly the Mayo Clinic's compounded topical cream (containing 1% Amitriptyline/5% Ketamine in a Plo Gel), magnesium supplements and acupuncture
- Only 26% of respondents feel confident that their doctor knows enough to diagnose and treat EM for others; 49% believe their doctor is not educated enough to do so

NOTE: For all subsequent slides " N= " refers to the number of responses used

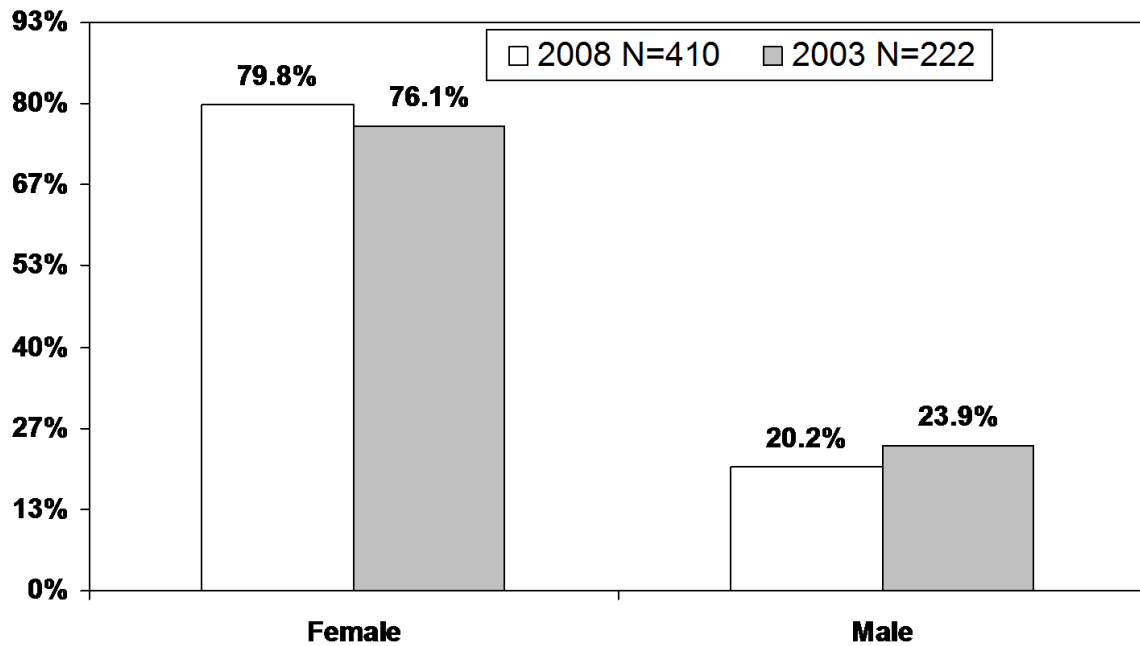
Respondent Age



Ethnic Background

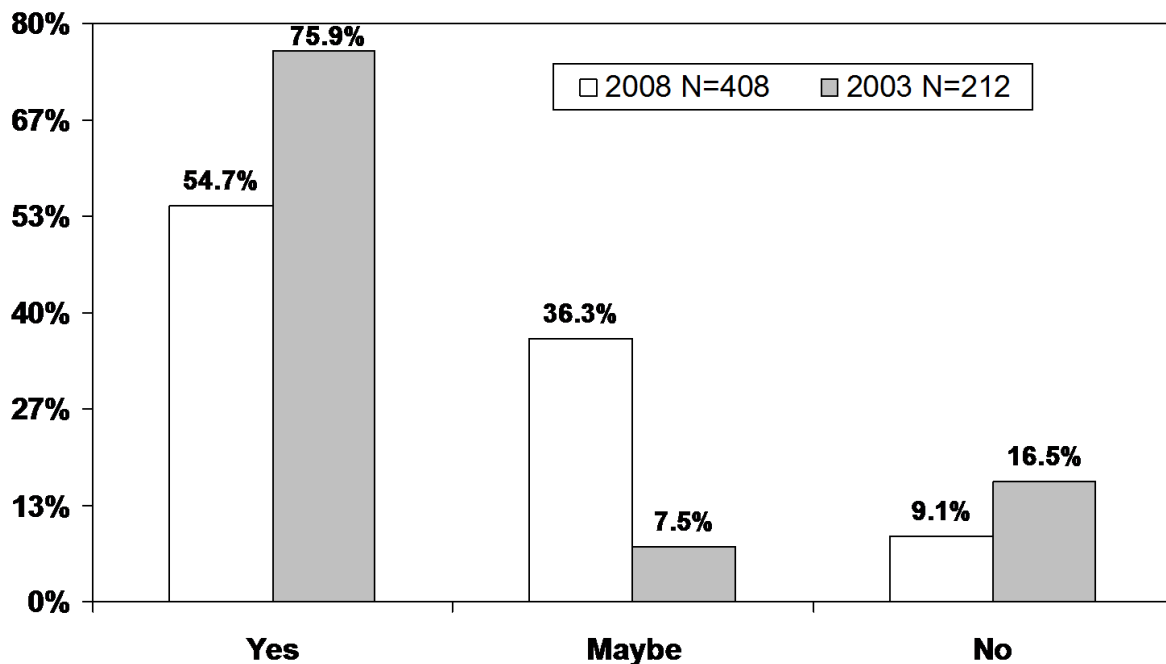


Gender



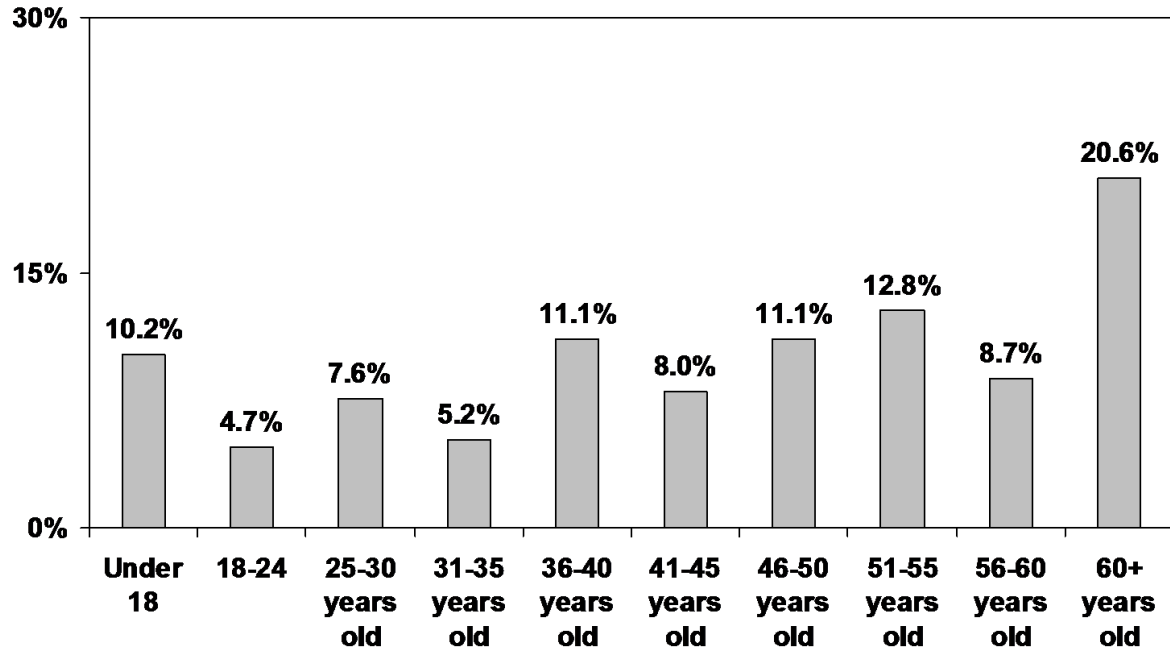
Medical Research Participant

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



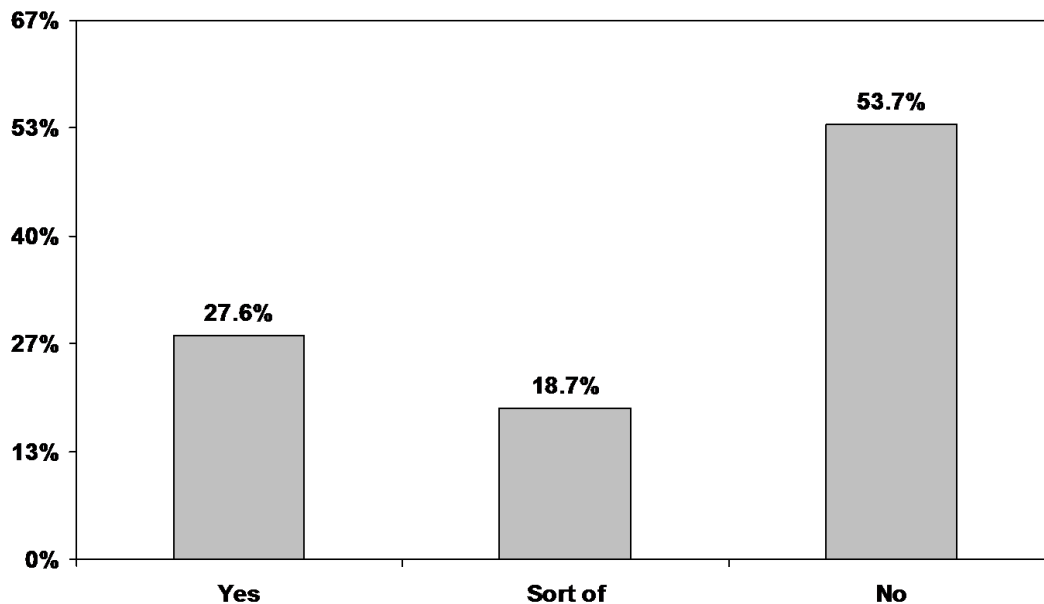
Age When Symptoms Emerged

At what age did you first become aware of your Erythromelalgia (EM) symptoms? N=423



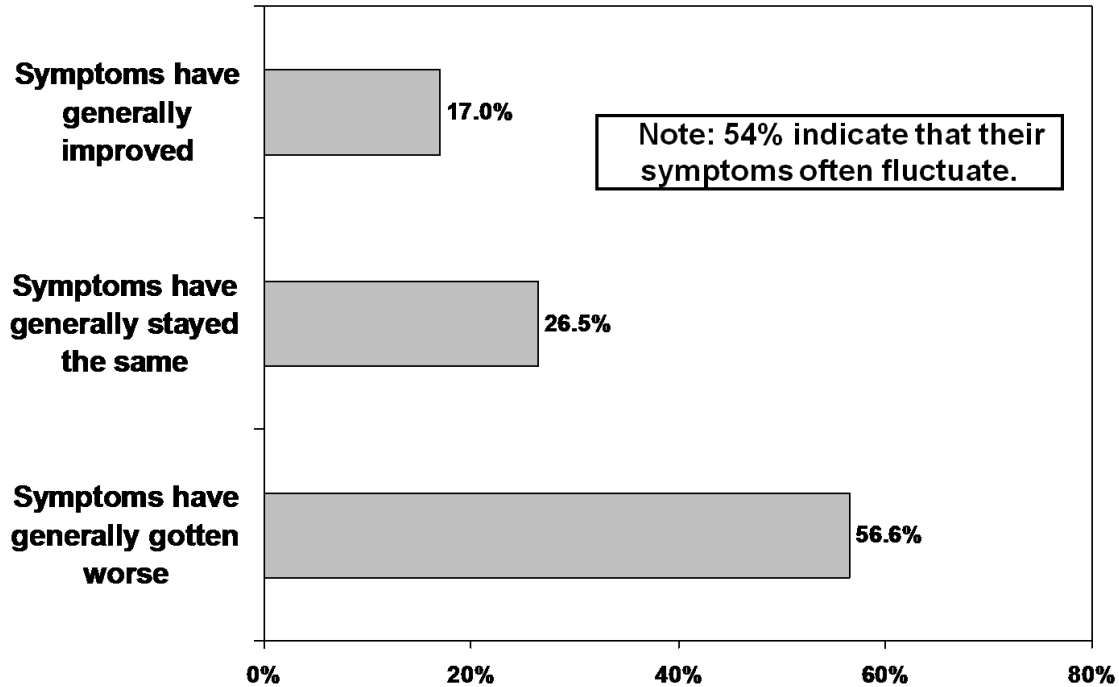
Defining Event Starting Symptoms

Do you feel your symptoms started after some sort of defining event like trauma or change in your life? N=423



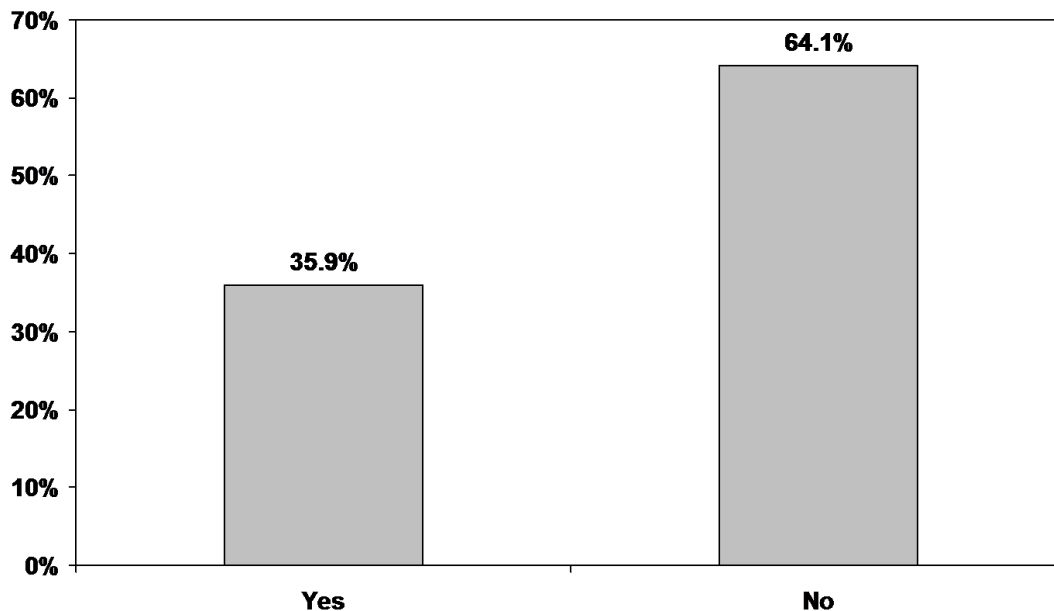
Progression of Symptoms

How have your symptoms changed since you first became aware of them? N=412



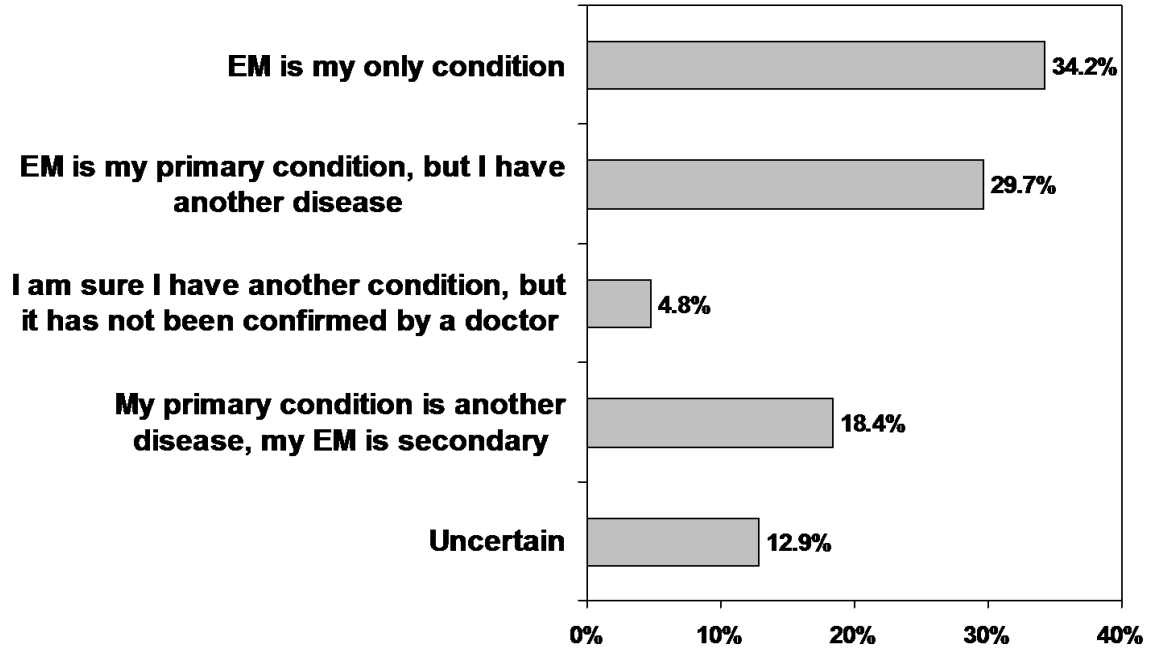
Symptom-free Days

Since your EM symptoms started have you had periods of more than a few days where you were symptom-free? N=401



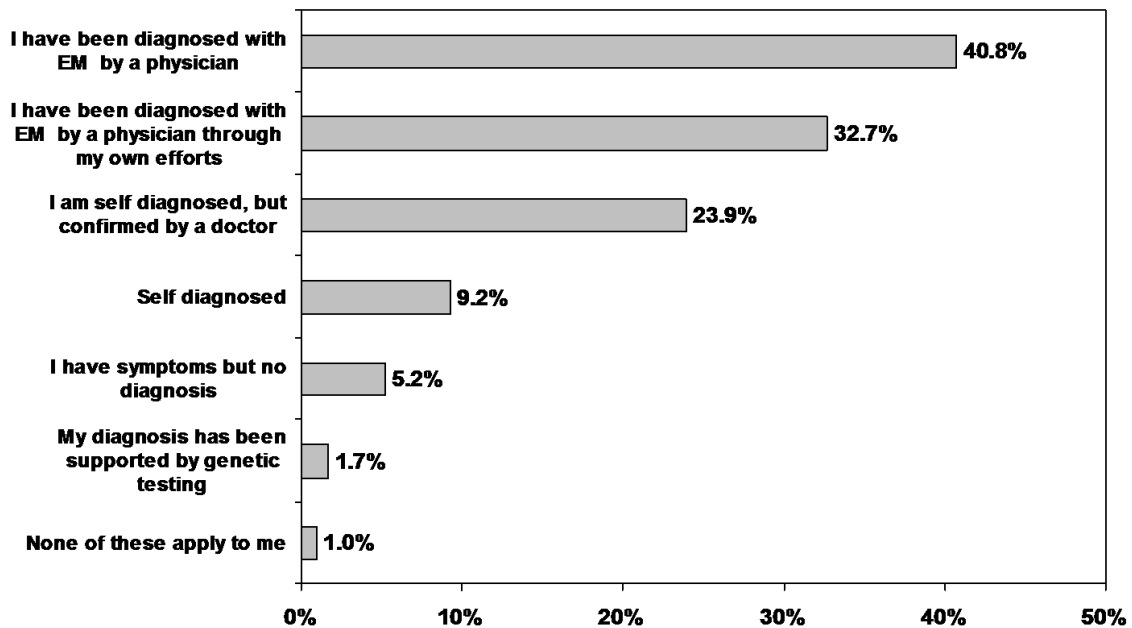
Accompanying Conditions

Other diseases can accompany EM, either in a primary role or a secondary role. Which of the following applies to you? N=418



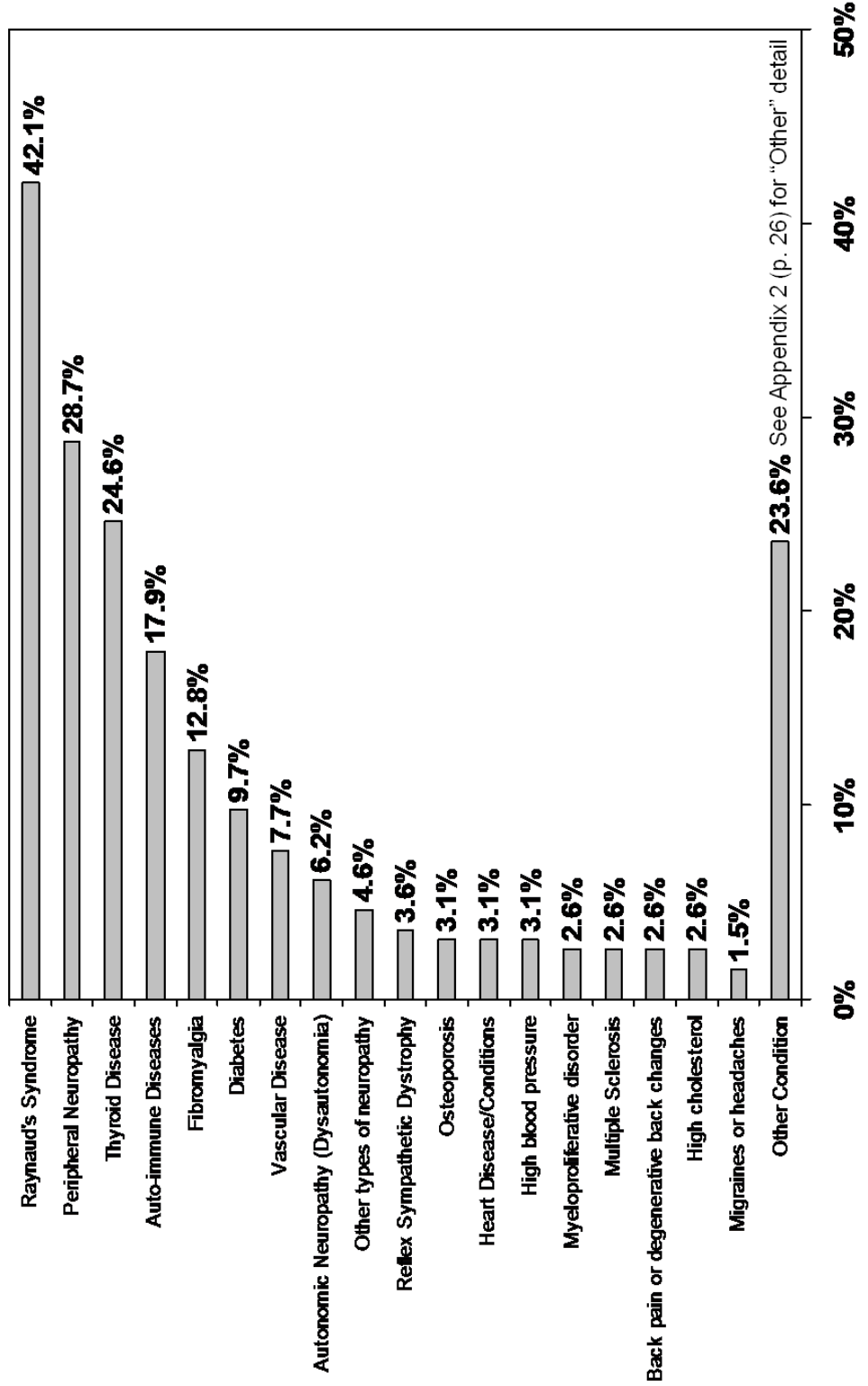
EM Diagnosis

Please indicate which of the following statements applies to your EM diagnosis. (Select all that apply) N=422



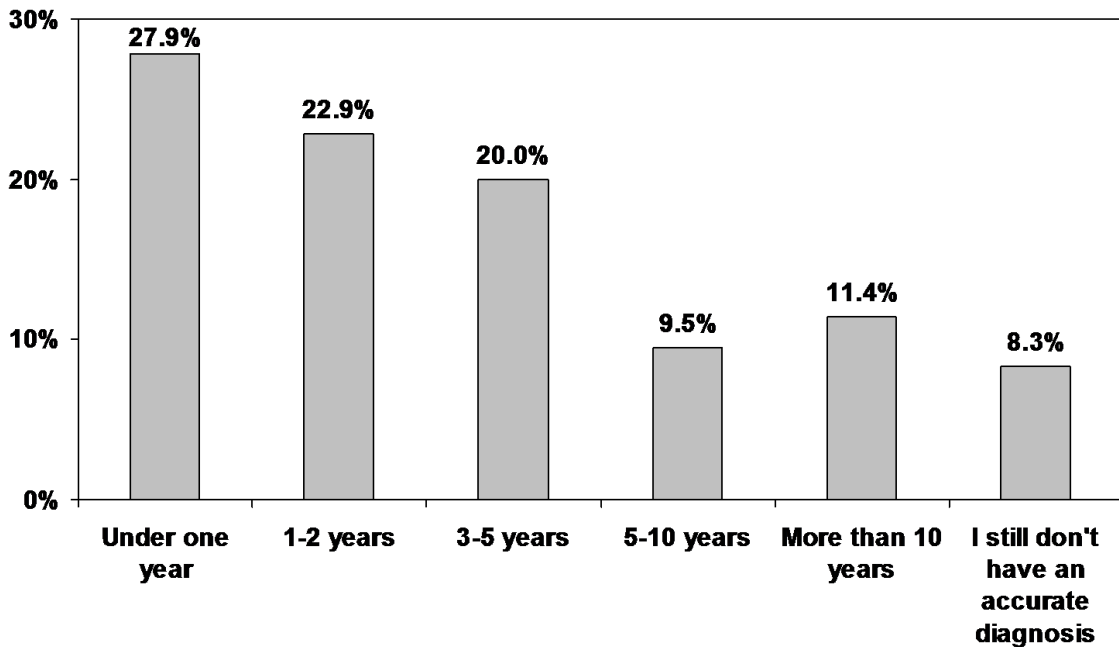
Diseases or Conditions With EM

What other diseases or conditions do you have that accompany your EM?
 (Select all that apply) N=195



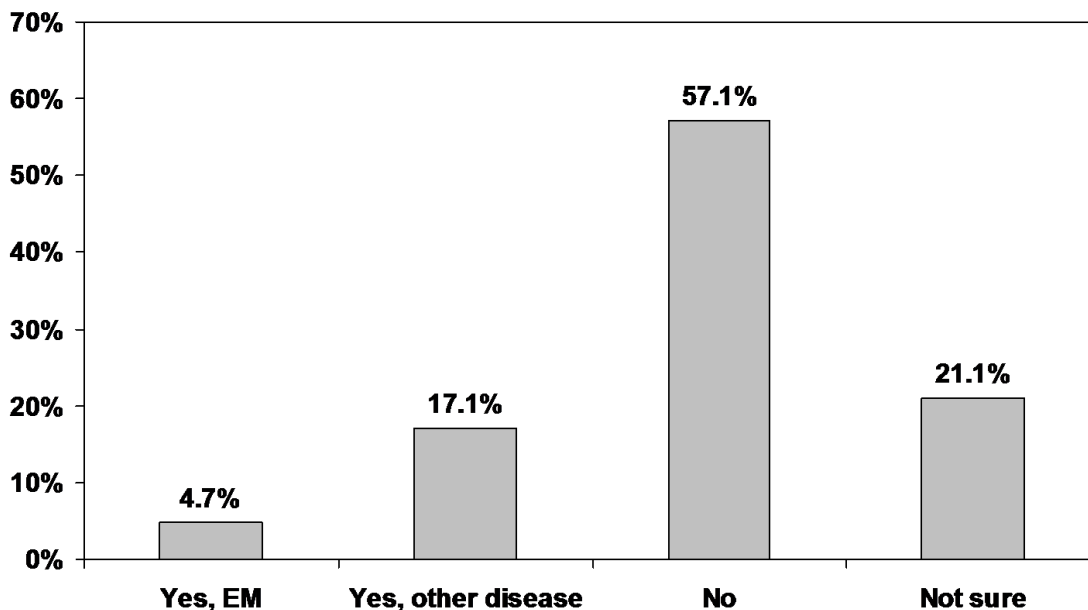
Time From First Symptoms to Diagnosis

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? N=420



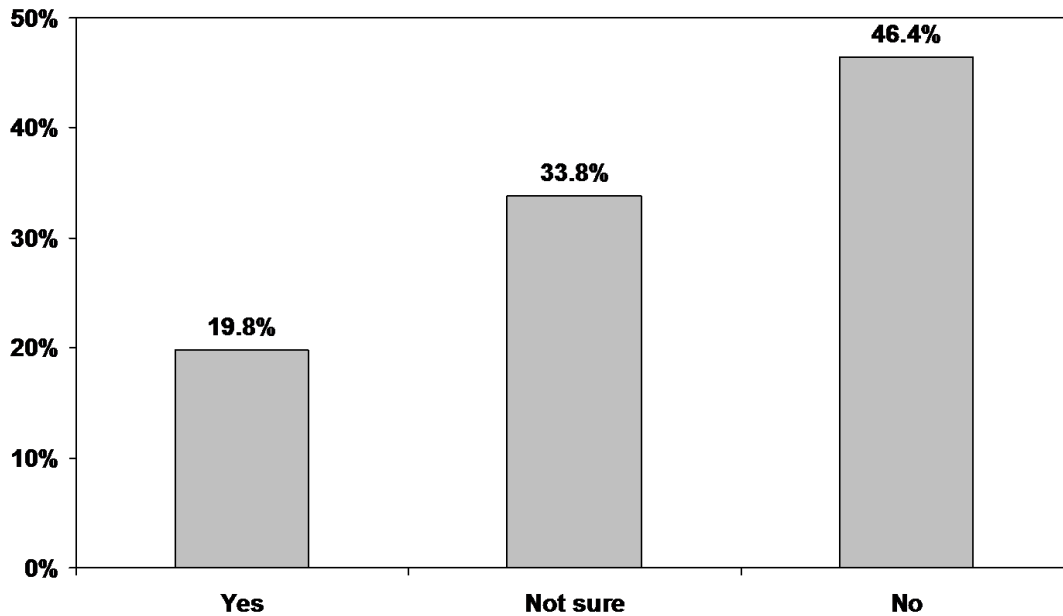
Blood Relatives with EM - Diagnosed

Do you have any blood relatives that have been diagnosed with EM (or any of the other diseases mentioned on page 8)? N=422



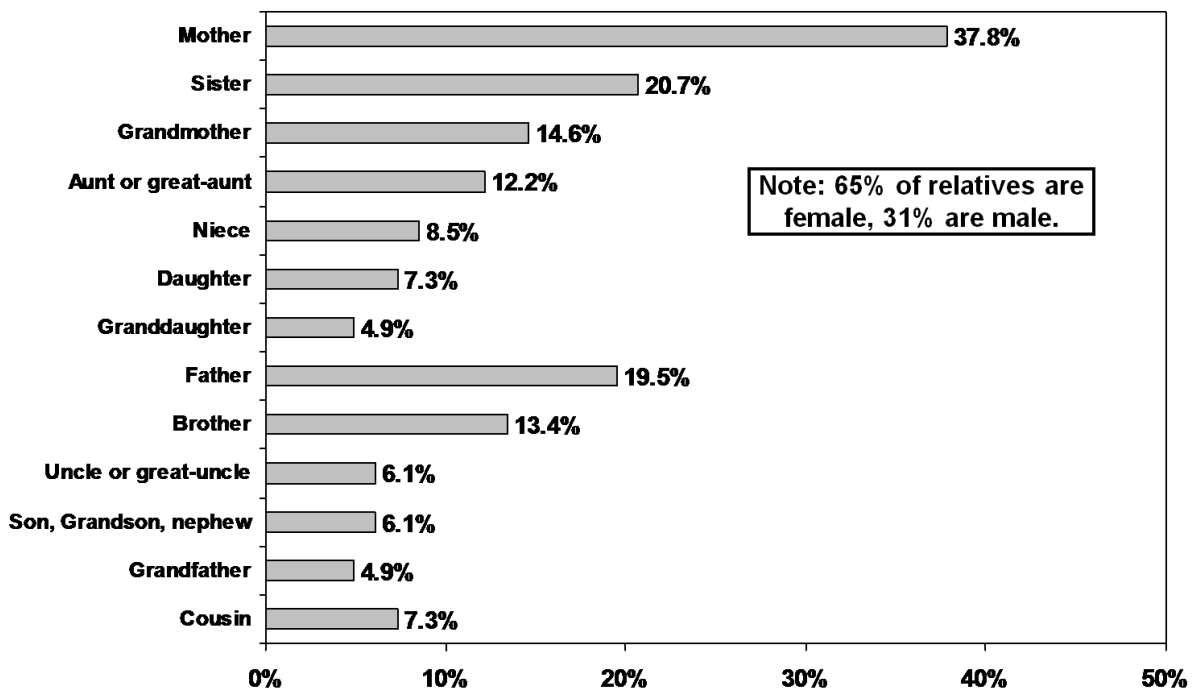
Blood Relatives with EM - Undiagnosed

Do you think any of your blood relatives have EM symptoms but have not actually been diagnosed with EM? N=422



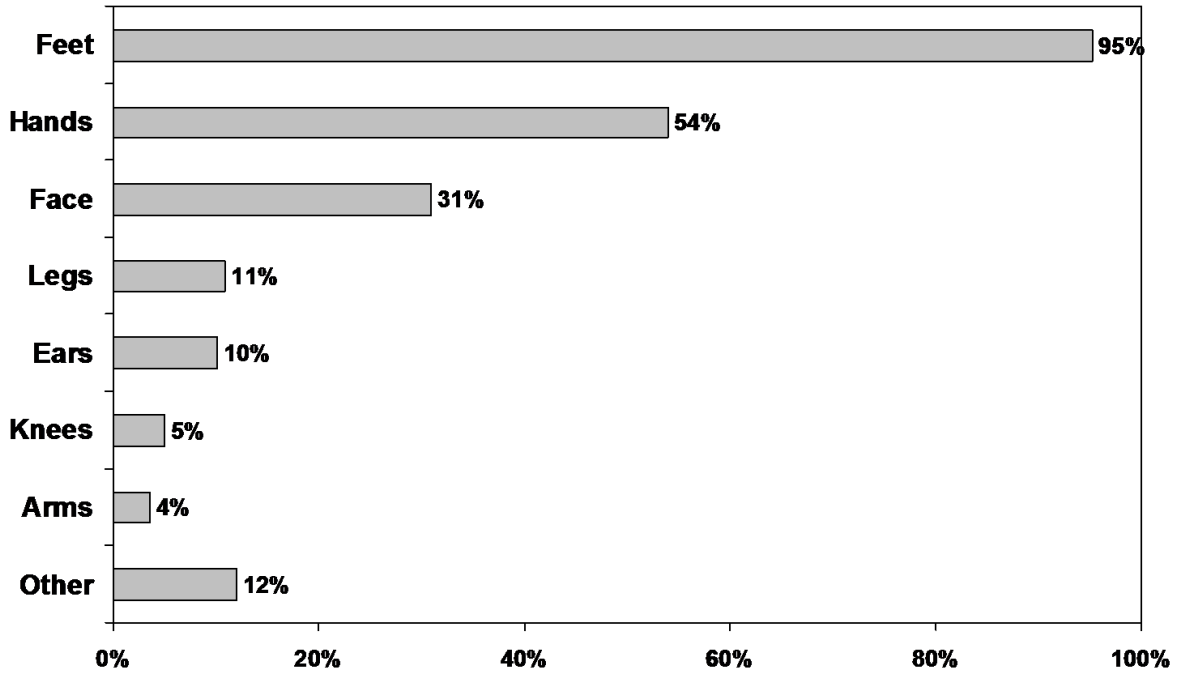
Blood Relatives with EM

List your relations that have been diagnosed with EM or who you think might have EM symptoms. N=82



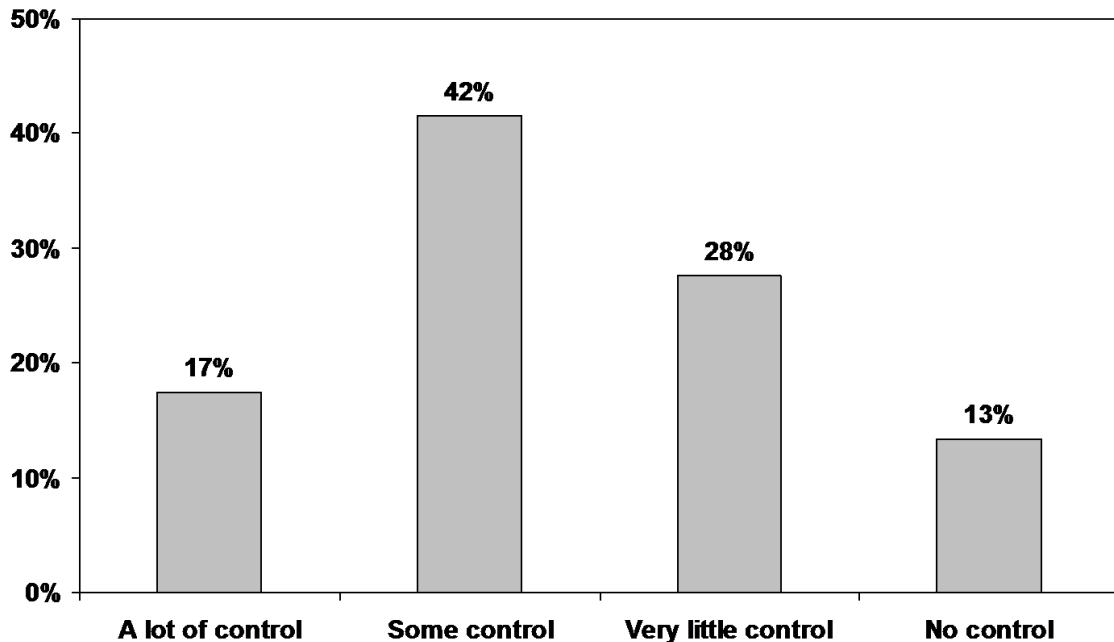
Location of Flares

Please indicate in which of the following locations you experience painful flares which you attribute to your EM. (Select all that apply) N=423



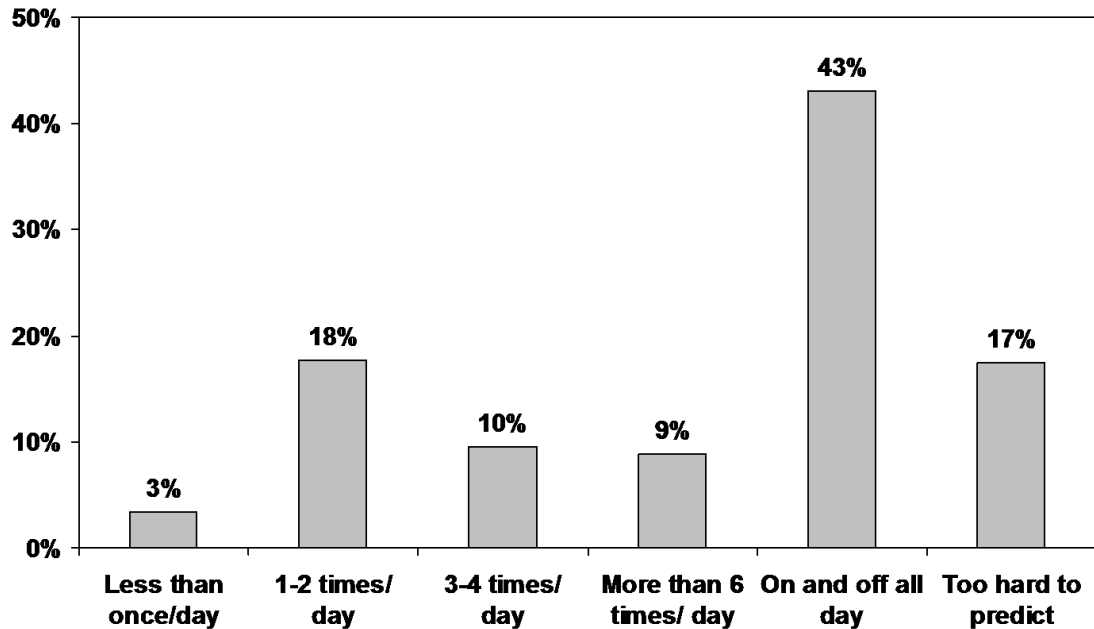
Control Over the Frequency of Flares

Based on actions you take to control your environment, how much control do you have over the frequency of your EM flares? N=412



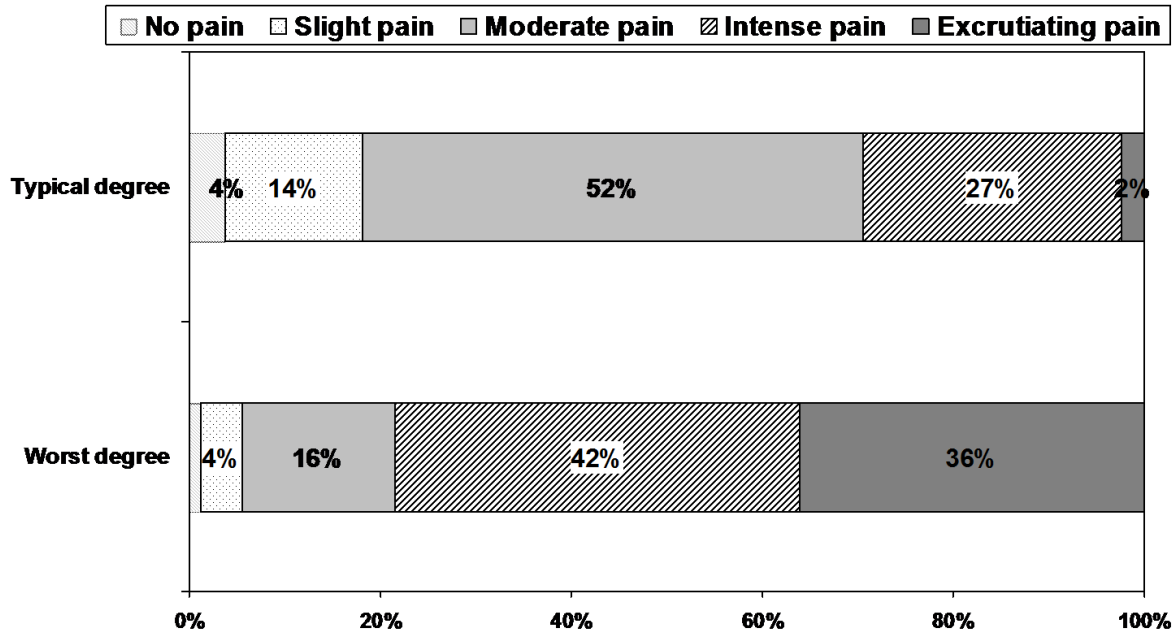
Frequency of Flares w/No Intervention

If you did NOTHING to control your EM flares, how often would you experience a flare-up?
N=418



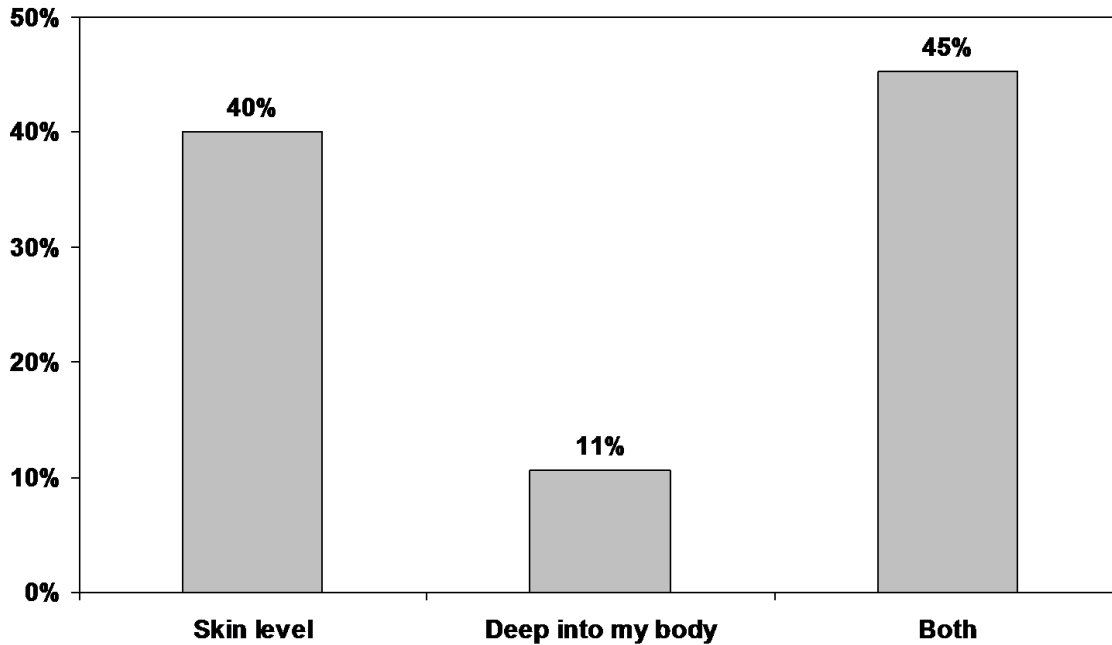
Degree of Pain During Flare Up

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. N=423



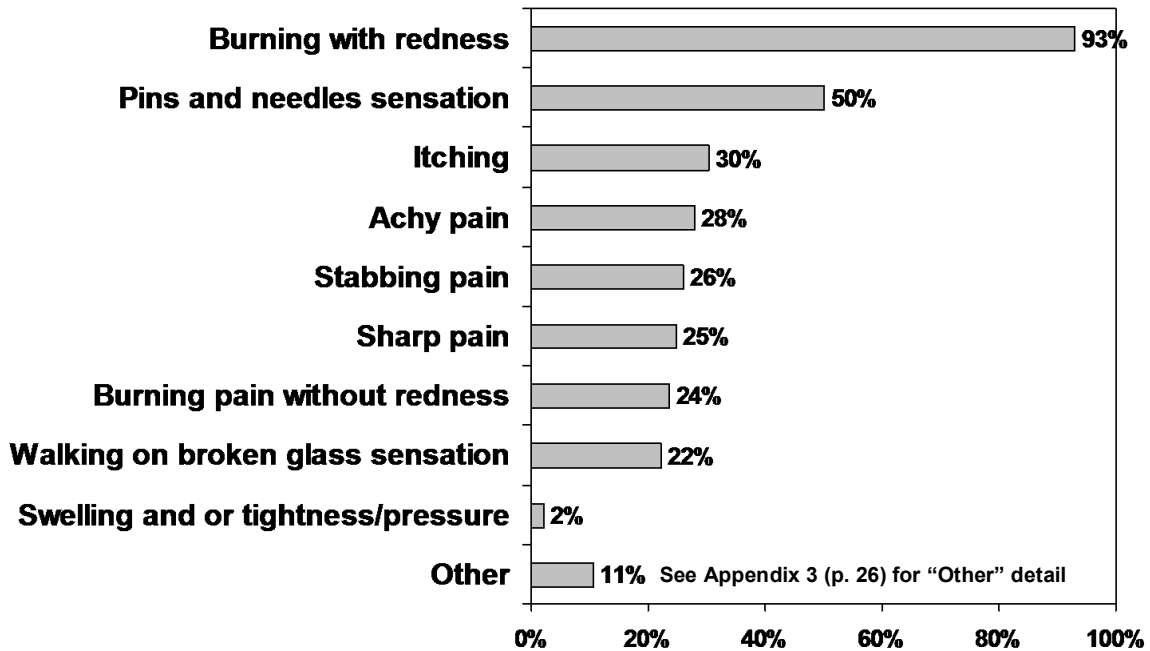
Level of EM Pain

At what level would you say you experience your EM pain? N=400



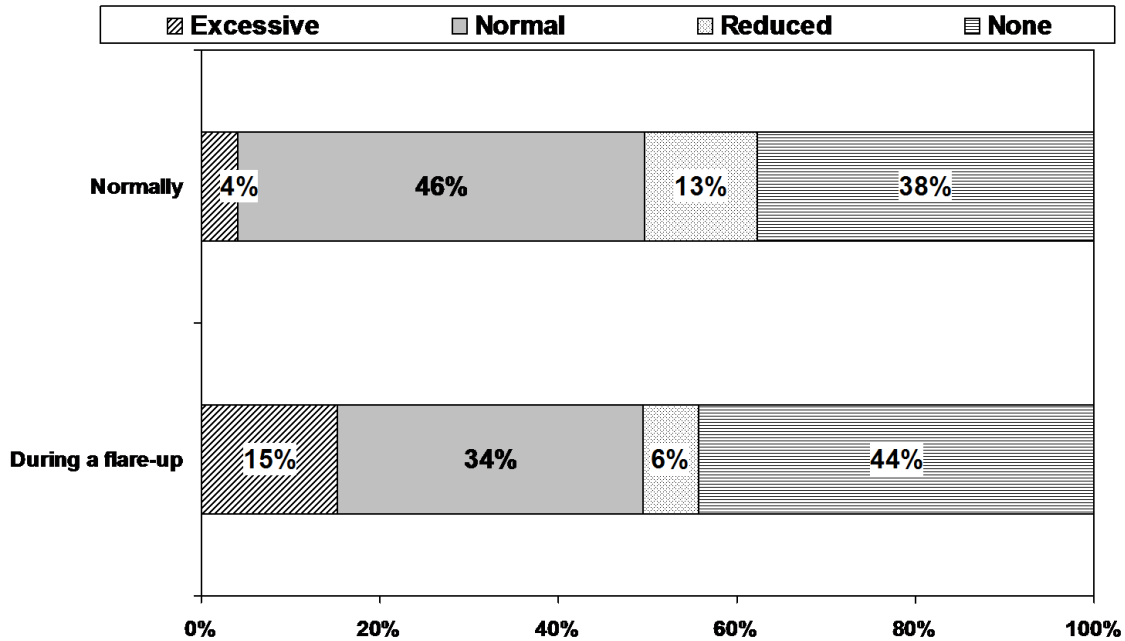
Type of Pain with Flares

Please indicate the type of pain you experience with your EM flares.
(Select all that apply) N=420



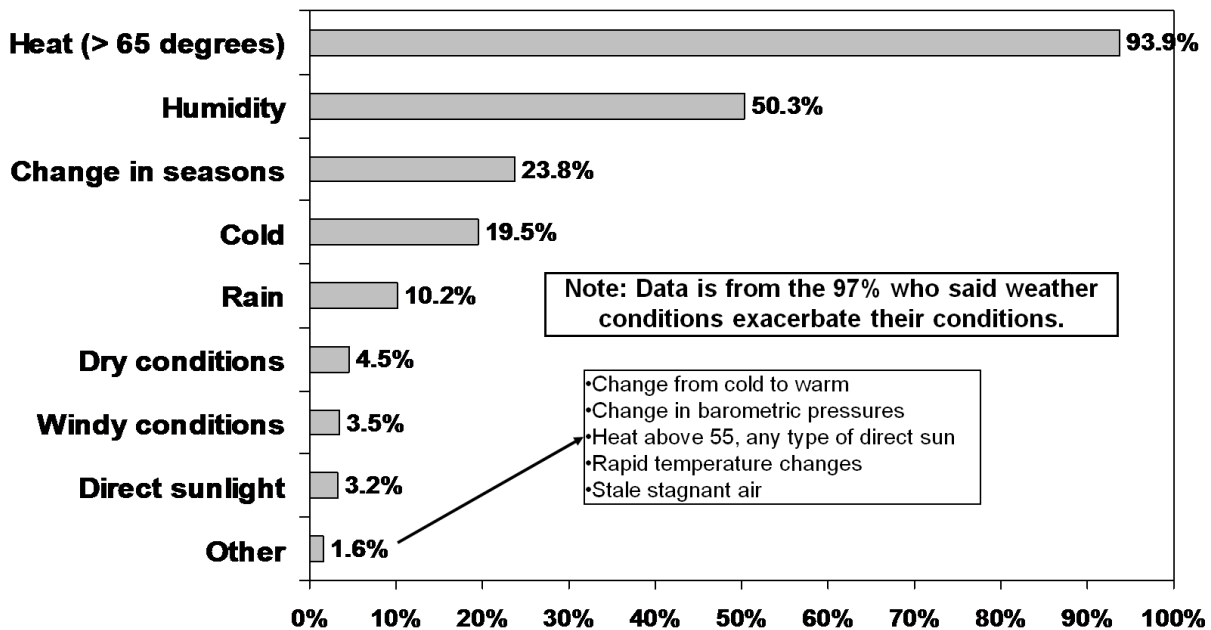
Perspiration

Which of these choices most closely describes your perspiration (sweating)? N=419



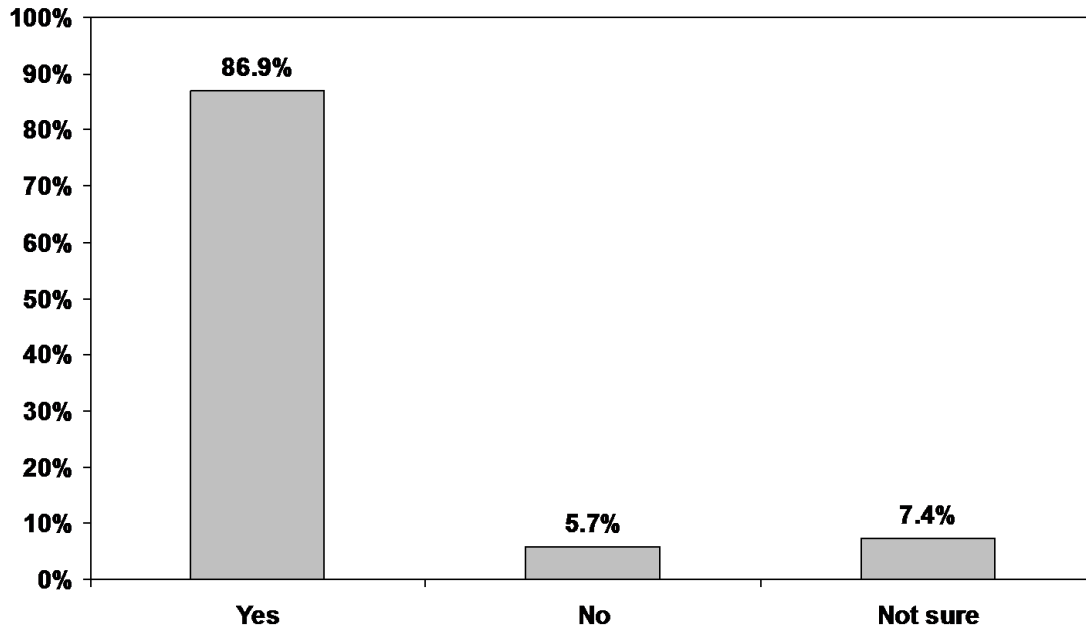
Weather Conditions and EM

Which of the following weather conditions, if any, cause or exacerbate your EM flares?
(Select all that apply) N=376



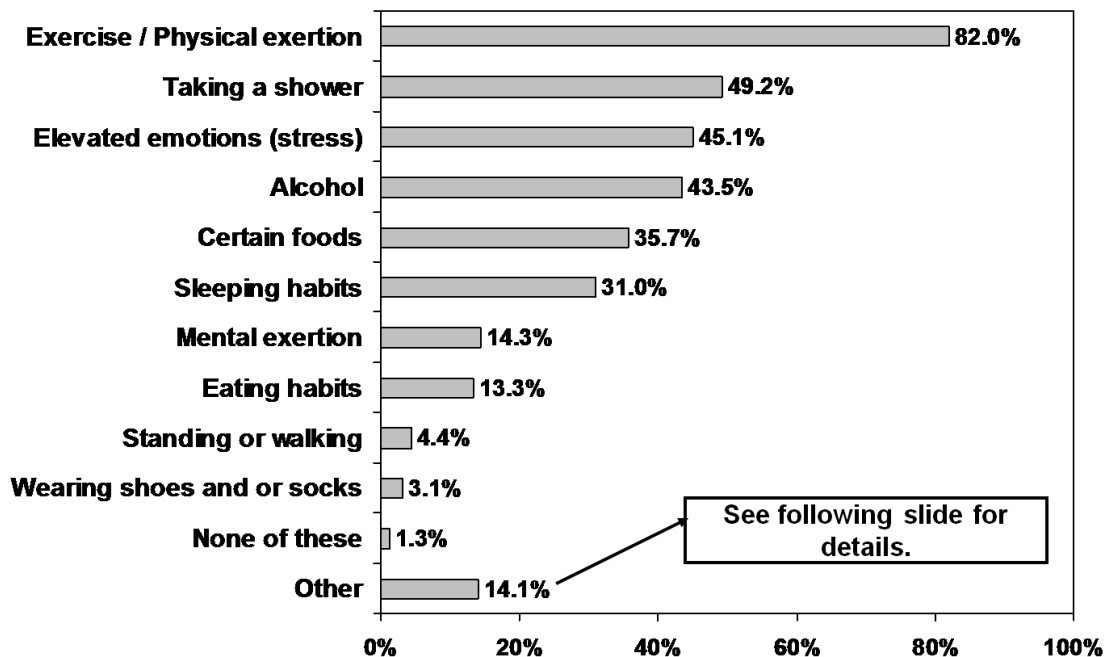
EM Triggers

Have you established that certain things you do can trigger your EM symptoms or make them worse? N=420



EM Triggers (cont'd)

Which of the following do you feel might trigger your EM symptoms to occur? (Select all that apply) N=391



Triggers: “Other” Responses

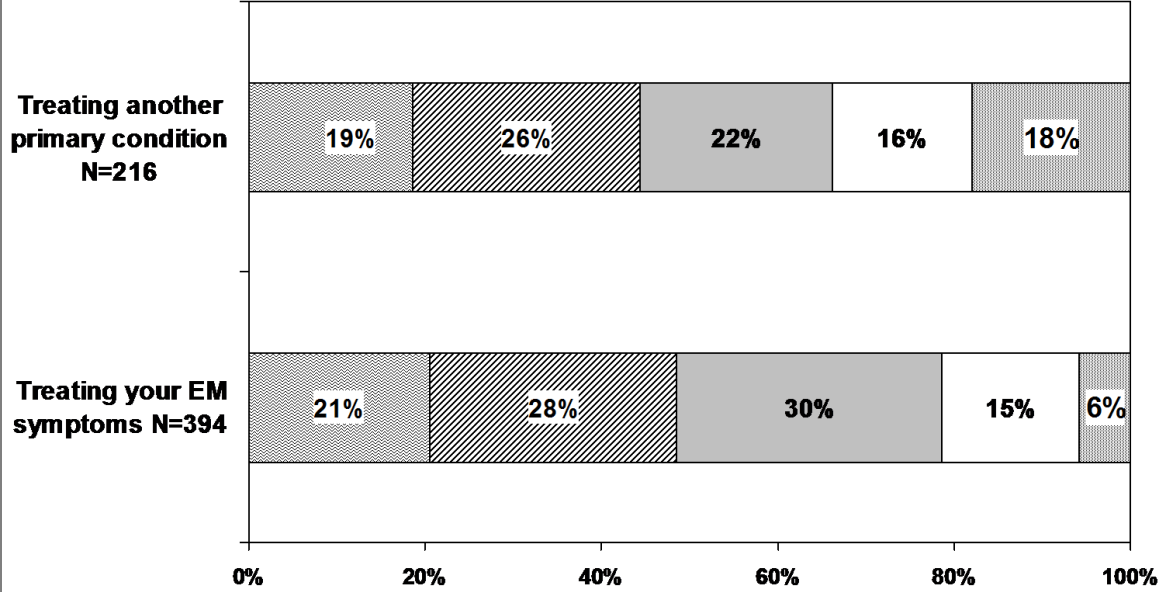
Which of the following do you feel might trigger your EM symptoms to occur?

- | | | | |
|--------------------------|--|--------------------------|---|
| <input type="checkbox"/> | Legs down/not elevated (7) | <input type="checkbox"/> | Elevated body heat |
| <input type="checkbox"/> | Exposure to direct sunlight (6) | <input type="checkbox"/> | Feet on warm surface or covered |
| <input type="checkbox"/> | Hot tub/spa/hot bath (6) | <input type="checkbox"/> | Feet up with toes point up |
| <input type="checkbox"/> | Being in a warm place (5) | <input type="checkbox"/> | Holding a warm object like a laptop or plate, when stressed like when giving a presentation |
| <input type="checkbox"/> | Type of footwear (4) | <input type="checkbox"/> | Hot flashes |
| <input type="checkbox"/> | Elevation of limbs (2) | <input type="checkbox"/> | Infection |
| <input type="checkbox"/> | Allowing my hands or feet to get really cold - EM flares as they warm | <input type="checkbox"/> | My 12 days of progesterone |
| <input type="checkbox"/> | Also toes get warm/hot in the evening time | <input type="checkbox"/> | Positional (e.g.: legs dependent, or lying on my side will always trigger EM flare) |
| <input type="checkbox"/> | Ambient temperature | <input type="checkbox"/> | Raynaud's in my toes causes blanching, then I get EM if I warm up too quickly |
| <input type="checkbox"/> | Being warmly dressed or under bed covers in cold weather | <input type="checkbox"/> | Resting; any change in heart rate |
| <input type="checkbox"/> | Bending over, standing for more than a few minutes | <input type="checkbox"/> | Room temperature above 69 degrees, sitting with feet down, lying in bed |
| <input type="checkbox"/> | Cold/ice compresses | <input type="checkbox"/> | Smoking |
| <input type="checkbox"/> | Contact with running water (hand washing); when sitting on softer surfaces | <input type="checkbox"/> | Too many blankets in bed |
| <input type="checkbox"/> | Covering feet (including use of rich creams) | <input type="checkbox"/> | Vasodilator drug or body cream |
| <input type="checkbox"/> | Drinking hot beverages, sitting for long periods of time | | |

EM Treatment

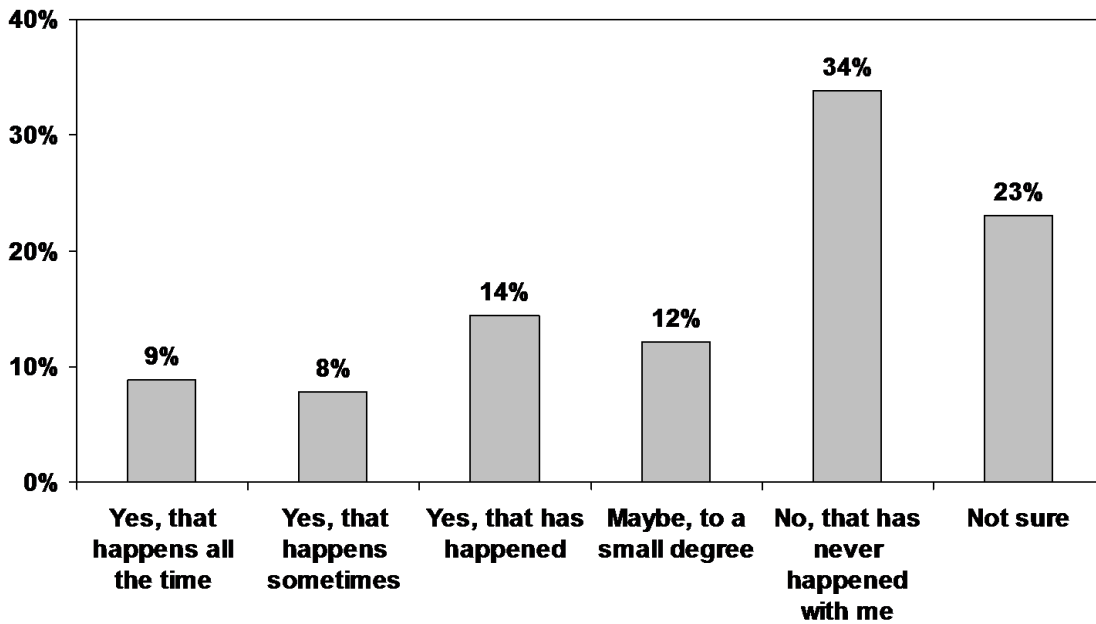
Please rate how aggressively you treat your EM condition or another primary condition that affects your EM.

5= Very aggressively
 4=Aggressively
 3=Somewhat aggressively
 2=Passively
 1=Not at all



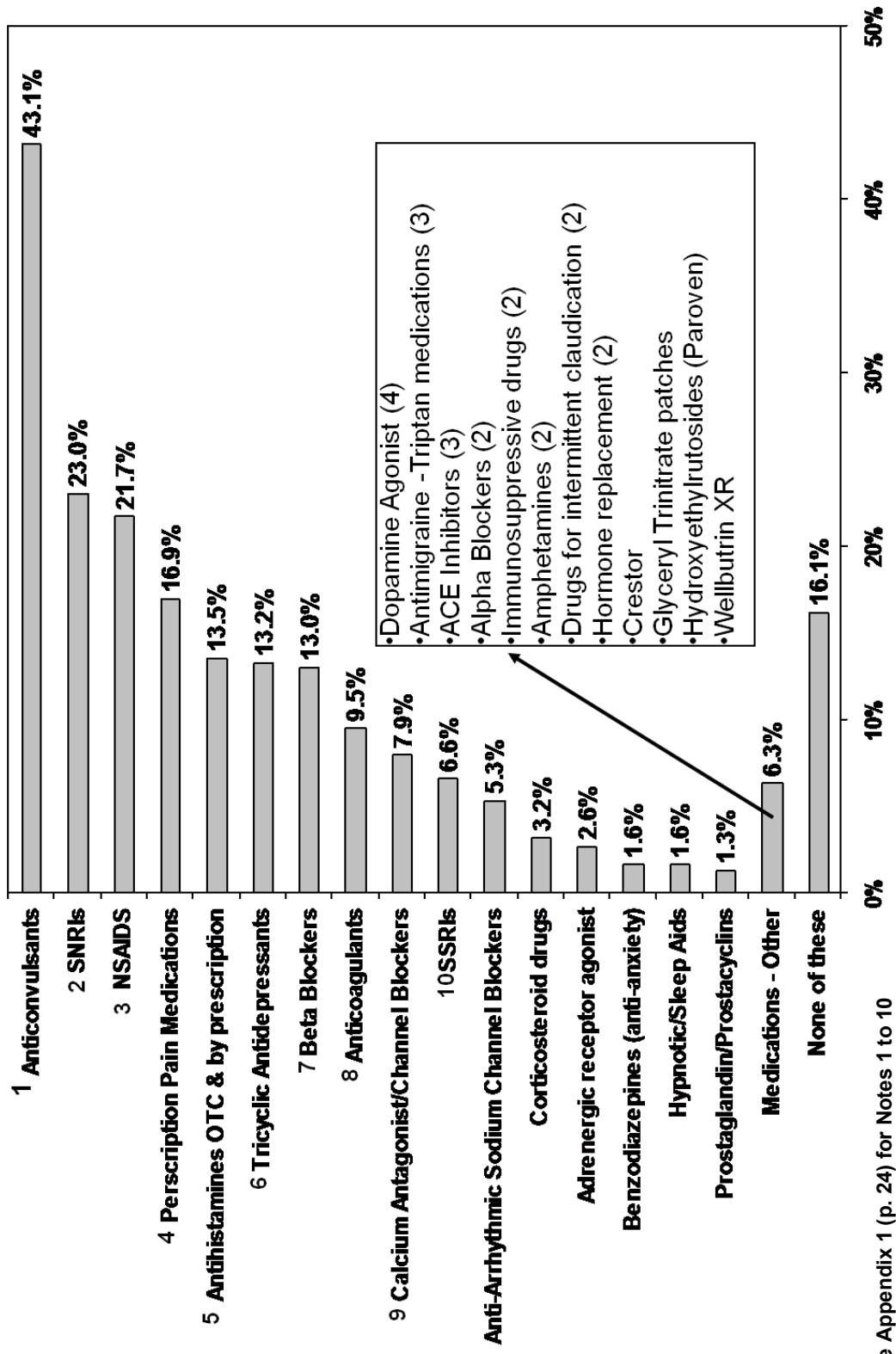
Treatments Over Time

Have you found that some treatments are effective at reducing symptoms for a period of time, only to lose their effectiveness over time? N=396



Most Successful Medications

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) N=378 ~ ~ ~ Percent selecting each item.

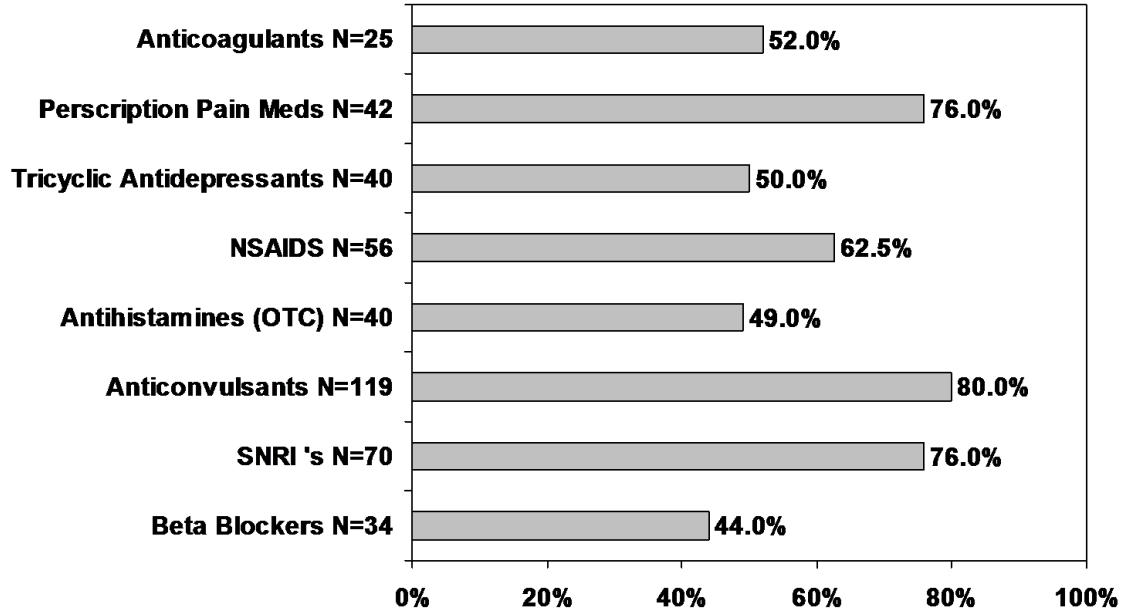


See Appendix 1 (p. 24) for Notes 1 to 10

Medication Relief

Please RATE each medication or treatment's effectiveness for treating your EM symptoms.

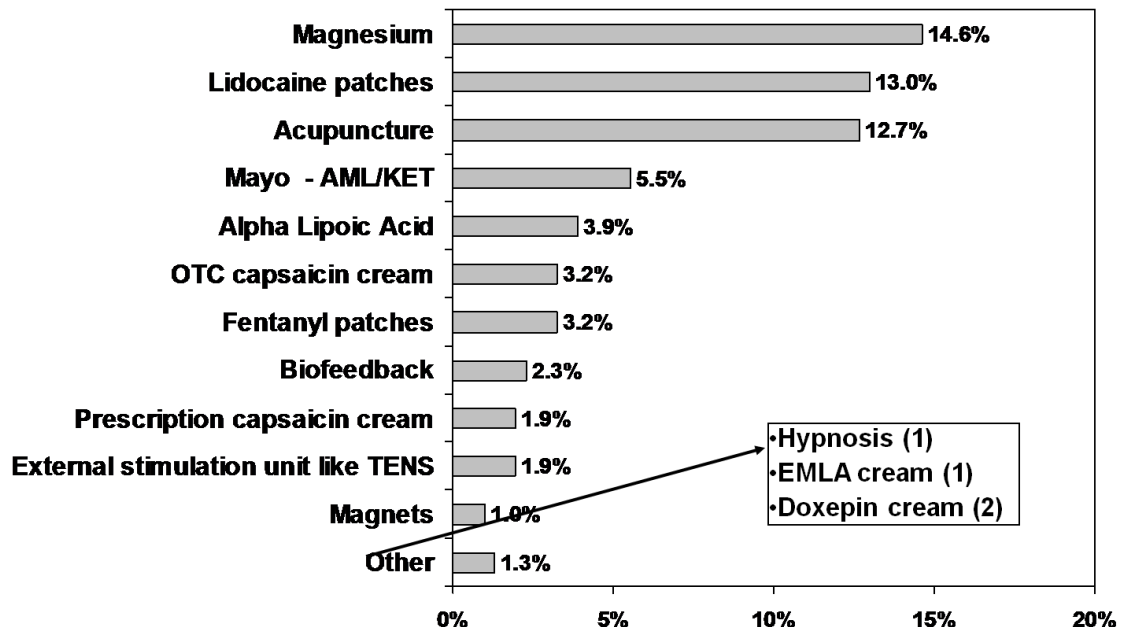
Percent expressing "Good" or "Moderate" relief shown in this chart



Most Successful Supplement/Regimen

With which of the following topical creams, supplements and/or regimens have you had the MOST success in treating your EM symptoms or your primary condition? (Select NO MORE THAN 4) N=308

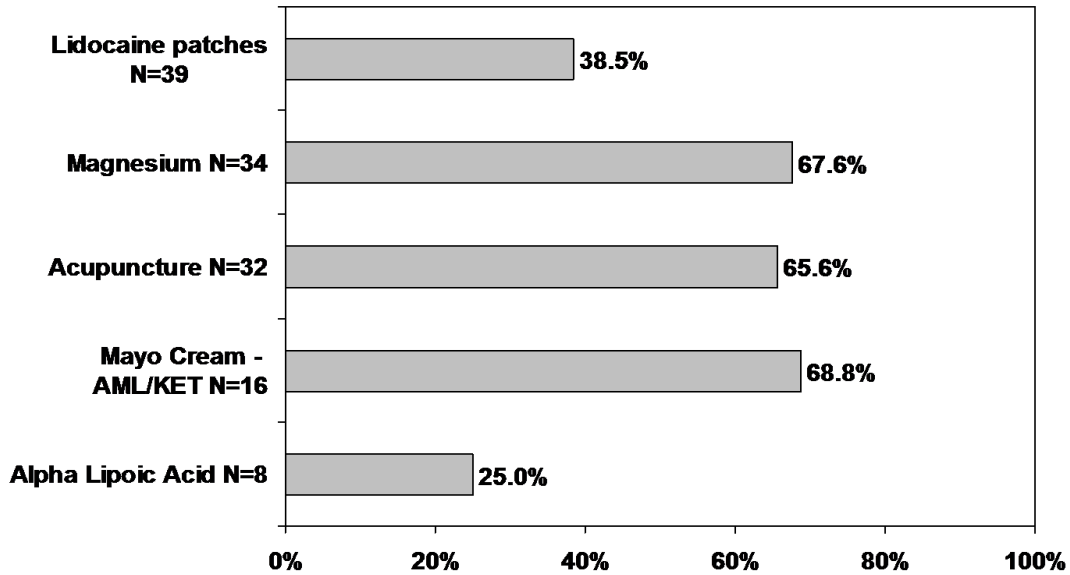
This graph shows the percentage of respondents selecting the listed item.



Supplement/Regimen Relief

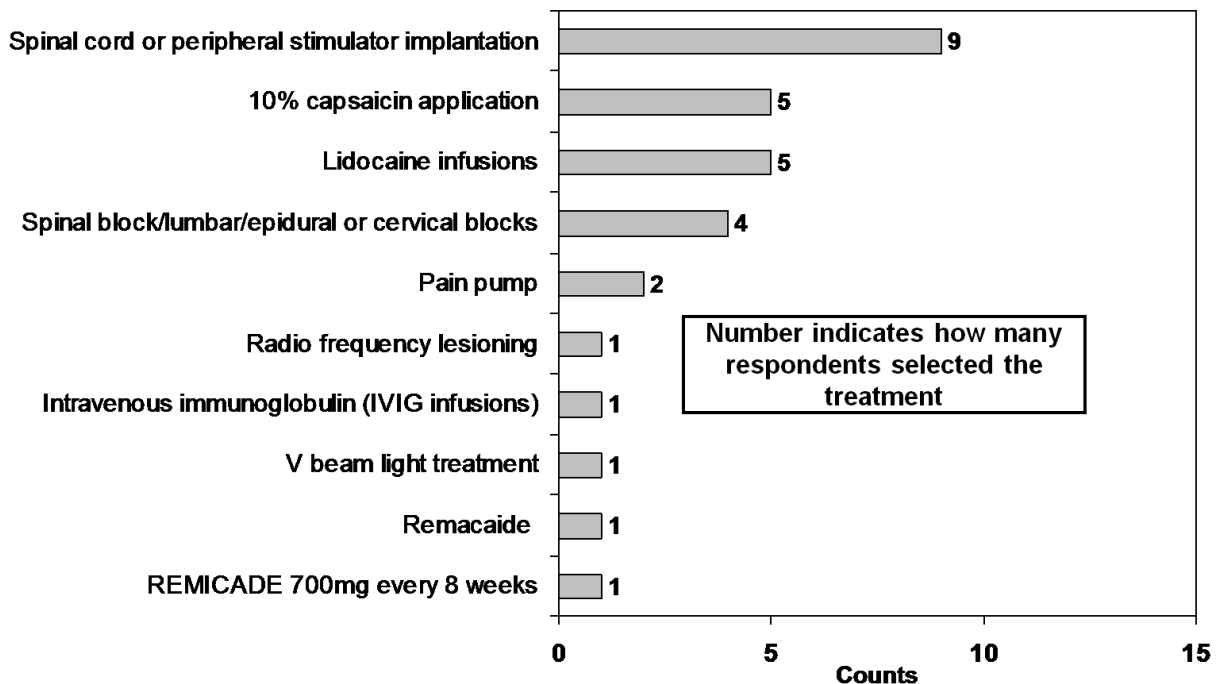
Please RATE each topical cream, dietary supplement or regimen's effectiveness for treating your EM symptoms.

Percent expressing "Good" or "Moderate" relief shown in this graph



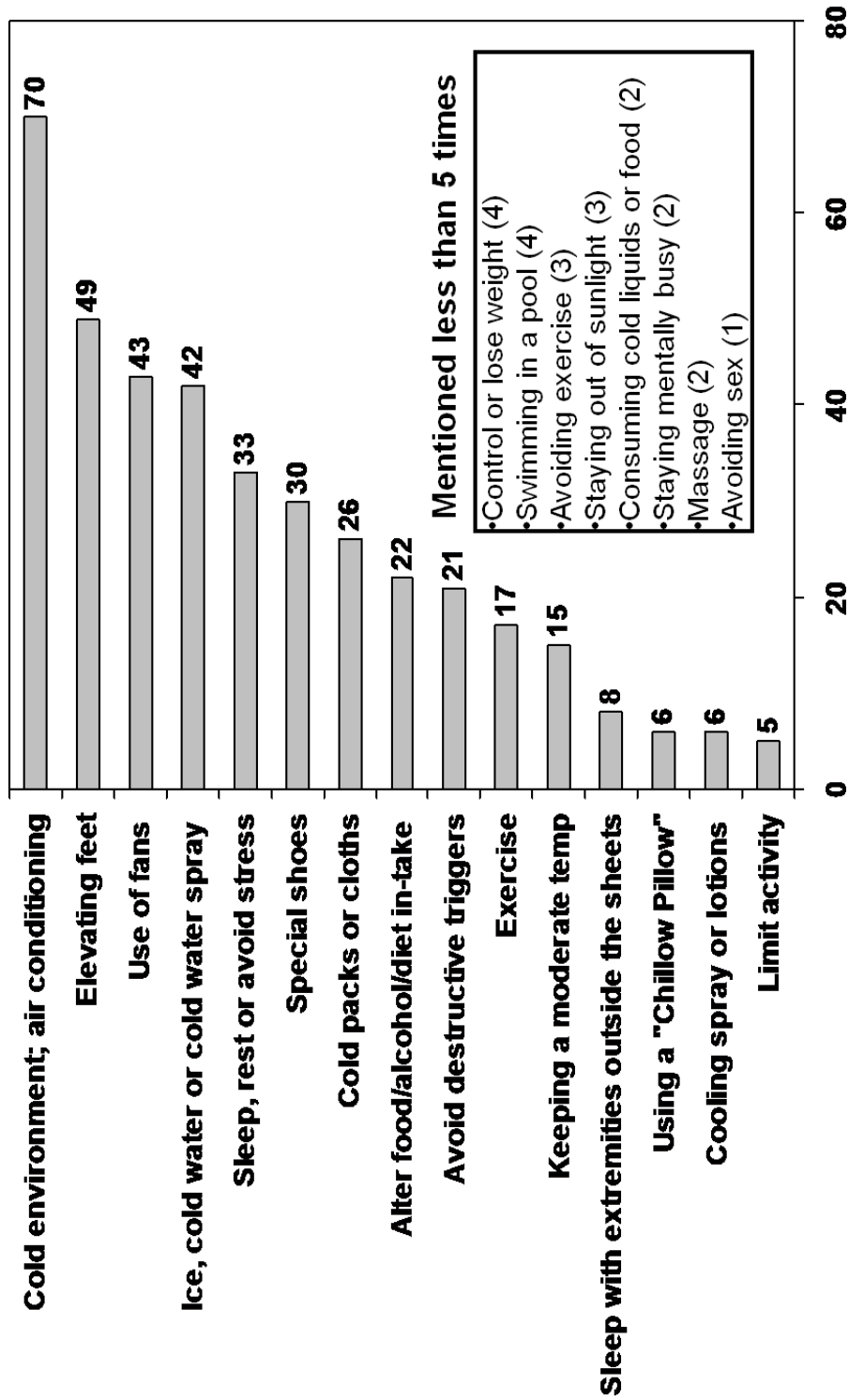
Most Successful Invasive Treatments

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) N=257



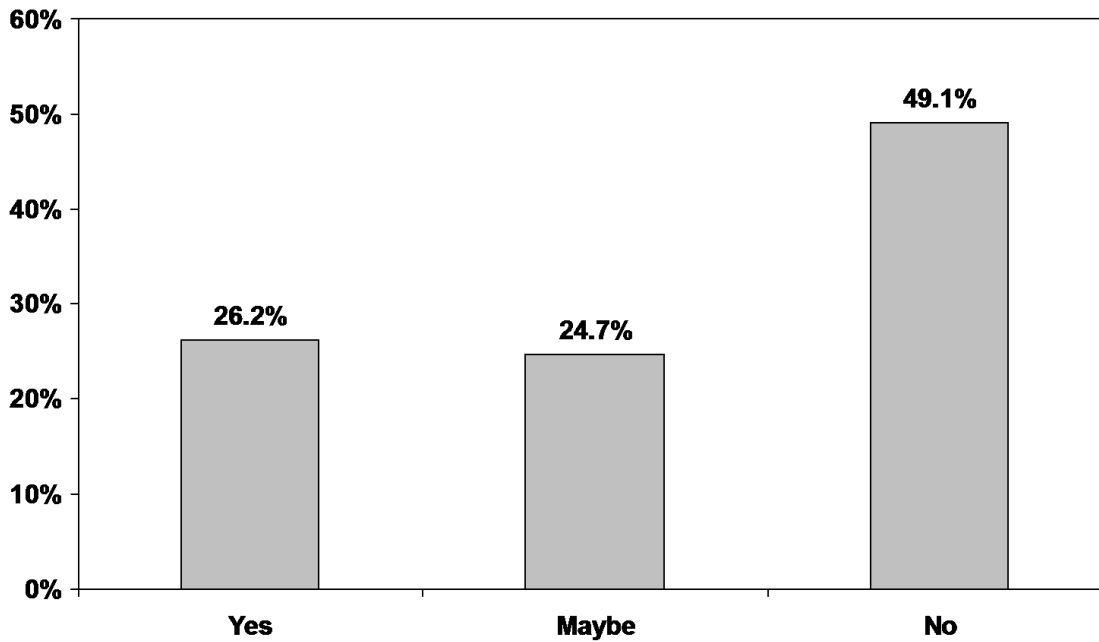
Other Treatments Used

Is there ANYTHING else other than things already covered that you have found that seems to reduce the frequency or severity of your EM symptoms? N=269



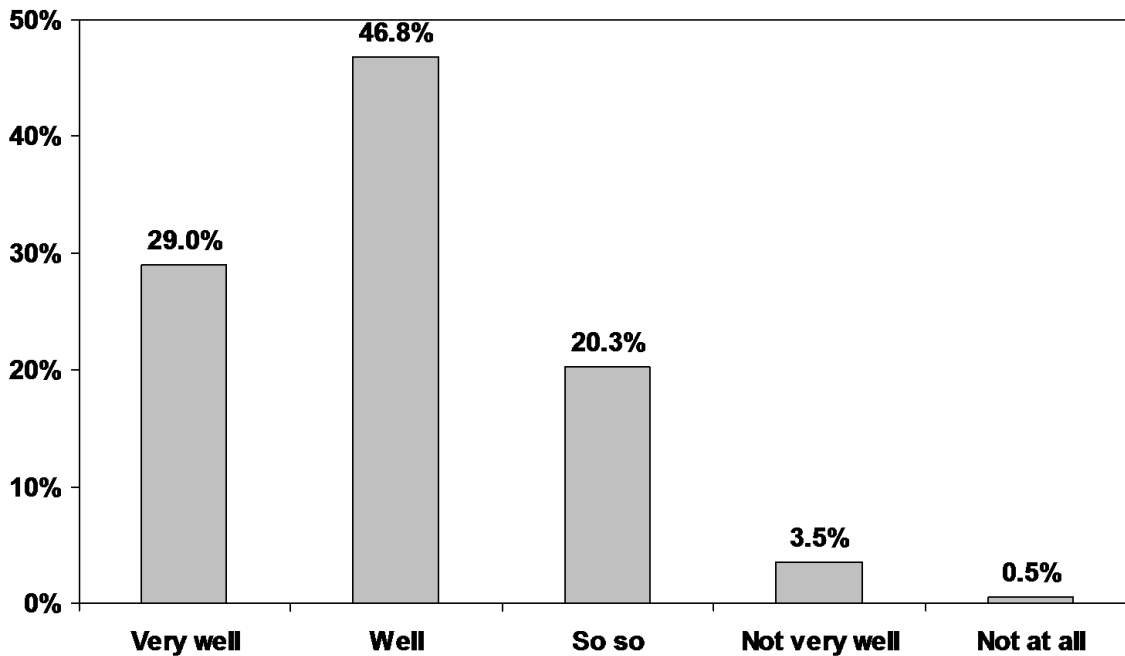
Doctor Able to Diagnose and Treat EM

Do you think your doctor is educated enough to diagnose and treat others that may have EM? N=409



Survey Relevance for Respondent

Please rate how well you feel this questionnaire provided you the opportunity to characterize your EM experience? N=400



To view the raw survey results, visit the web link below.

Of particular interest, all the write-in responses can be viewed at this site.

Note, however, that some of the bar charts will not match those in this summary. Some respondents relied on the fill-in boxes to respond to questions or otherwise elaborate on their conditions or treatments. As a result, the “Other” categories for those questions were artificially inflated, and some of the response options were undercounted.

This summary reflects adjustments based on what people wrote when given the opportunity to complete open-ended “Other” lines; the web link shows only the data as originally entered.

<http://app.sgizmo.com/reports/2747/40761/YS1IX69R3LJ3IB6AYC8HHRB7H090YB/>

***Please see following pages for Appendices
noted on earlier slides***

Appendix 1 Drug types – notes from p. 18

¹**Anticonvulsants** – drugs that aid in preventing seizures often prescribed for epilepsy as well as nerve pain. How some of these drugs work is not fully understood. They are thought to bind to certain areas in the brain that reduce seizures, nerve pain and anxiety. Drug names include **Klonopin (clonazepam)**, **Lyrica (pregablin)**, **Neurontin (gabapentin)**, **Tegretol (carbamazepine)**.

²**SNRIs (serotonin-norepinephrine reuptake inhibitors)** – class of antidepressant drugs that enhances use of both norepinephrine and serotonin in the central nervous system. Drug names are **Effexor (venlafaxine)**, **Cymbalta (duloxetine)**.

³**NSAIDs** – (Non-steroidal anti-inflammatory drugs) – drugs that relieve aches and pains and reduce fever such as **aspirin**; **Advil and Motrin (ibuprofen)**; **Aleve (naproxen sodium)**.

⁴**Prescription pain medications** – drugs with sedative or narcotic effects similar to those containing opium or its derivatives. Drugs include **Duragesic (fentanyl)**, **Utram (tramadol)**.

⁵**Tricyclic antidepressants** – older class of antidepressant medications that is less targeted in its impact on brain substances than are newer antidepressants like the SNRIs. Drugs include **Elavil (amitriptyline)**, **Pamelor (nortriptyline)**, **Tofranil (imipramine)**.

⁶**Antihistamines** – drugs used to counteract allergic reactions such as gastric secretions, bronchial smooth tissue constriction and vasodilation. Drugs include **Benadryl (acrivastine, diphenhydramine)**, **Periactin (cyproheptadine)**, **Claritin (loratadine)**.

⁷**Beta-blockers** – drugs often used for management of hypertension and cardiac arrhythmias that block the action of substances within the autonomic nervous system. Drugs include **Inderal (propranolol)**, **Tenormin (atenolol)**.

⁸**Anticoagulants** – substances that delay or prevent the clotting of blood. Drugs include **aspirin**, **Coumadin (warfarin)**, **Liquaemin (heparin)**, **Plavix (clopidogrel)**.

⁹**Calcium channel blockers/calcium antagonists** – drugs often given to lower blood pressure. They interfere with calcium's role in maintaining vasoconstriction in blood vessels thereby causing vasodilation. Magnesium is sometimes called "nature's natural calcium channel blocker" because it is believed to produce a similar result. Drugs include **Cardizem, Tiazac (diltiazem)**; **Norvasc (amlodipine)**.

¹⁰**SSRIs (Selective serotonin reuptake inhibitors)** – class of antidepressants that enables serotonin to be used more efficiently. **Drugs include Prozac (fluoxetine)**, **Zoloft (sertraline)**, **Paxil (paroxetine)**, **Celexa (citalopram)**.

Note: These drugs do not suit all people with EM. Some drugs will improve EM, others will give no benefit, and some may seriously worsen EM symptoms. Many people with EM are highly sensitive to these drugs, so low initial dosage is advised. Please work closely with your doctor to get more complete information about these medications.

Appendix 2

Diseases or Conditions with EM: “Other” Responses

What other diseases or conditions do you have that accompany your EM?

- | | |
|---------------------------------------|--|
| ■ Antiphospholipid Syndrome (2) | ■ Multiple vasculitis |
| ■ Anxiety, ADHD | ■ Muscle spasms of feet & calves |
| ■ Asthma | ■ Non-malignant tumor on my pituitary gland |
| ■ Benign brain tumor | ■ Obstructive Sleep Apnea |
| ■ Bowen's Disease | ■ Panic Disorder |
| ■ Breast Cancer | ■ Parkinson's (MSA) - Multisystem Atrophy |
| ■ Bronchiectasis Disease | ■ Periodic paralysis |
| ■ Burning mouth | ■ Perniosis - also known as chilblains |
| ■ Chronic Fatigue Syndrome | ■ Polymyalgia rheumatica |
| ■ Chronic renal failure / on dialysis | ■ Postural Orthostatic Tachycardia Syndrome (POTS) |
| ■ Colitis | ■ Premature ovarian failure (early menopause) |
| ■ Depression | ■ Problems with blood clots |
| ■ Eczema | ■ Prostate surgery |
| ■ Ehlers Danlos – (hyper mobility) | ■ Pseudohypoparathyroidism |
| ■ Fibrosing Alveolitis | ■ Psychiatric disorder |
| ■ Food allergies | ■ Reactive hypoglycemia |
| ■ Hepatitis C | ■ Restless Leg Syndrome |
| ■ Interstitial Cystitis (2) | ■ Rosacea |
| ■ Irritable Bowel Syndrome (2) | ■ Scoliosis |
| ■ Lichen planus | ■ Sleep disorder |
| ■ Macrocytic anemia | ■ Temporal arthritis |
| ■ Menieres Disease | ■ Thalassemia |
| ■ Metatarsalgia | ■ von Willebrand Disease |
| ■ Monoclonal gammopathy | ■ Waldenstrom's Macroglobulinemia |
| ■ MTFHR - blood clot disorder | |

Appendix 3

Type of Pain: 'Other' Responses

Please indicate the type of pain you experience with your EM flares.

- | | | | |
|--------------------------|--|--------------------------|--|
| <input type="checkbox"/> | Throbbing (5) | <input type="checkbox"/> | Feeling of raw flesh, burnt, stinging nettle rash, itching, burning |
| <input type="checkbox"/> | Electrical Sensation in Feet (4) | <input type="checkbox"/> | Feels like I'm walking on metal nuts/bolts, skin feels like it's 3/4 sizes too small |
| <input type="checkbox"/> | Crushing Pain (3) | <input type="checkbox"/> | Feet and ankles feel like they will burst |
| <input type="checkbox"/> | Feels like a layer of skin has been ripped off (3) | <input type="checkbox"/> | Heaviness and aching in arms and/or legs |
| <input type="checkbox"/> | Feels like a layer of skin has been ripped off & then salt rubbed into the open wounds | <input type="checkbox"/> | It's like a bad toothache in my limbs sometimes |
| <input type="checkbox"/> | Carpet feels like sharp stones | <input type="checkbox"/> | Like an asphalt burn on the bottoms of my feet |
| <input type="checkbox"/> | After blow torch is touched to gasoline drenched feet | <input type="checkbox"/> | Sinus pain from EM on face |
| <input type="checkbox"/> | Bee-stings | <input type="checkbox"/> | Pain in ball of my right foot where it all started. |
| <input type="checkbox"/> | Boiling acid poured over feet | <input type="checkbox"/> | Pulsing |
| <input type="checkbox"/> | Bottom of feet incredibly sore | <input type="checkbox"/> | Writhing and crying |
| <input type="checkbox"/> | Buzzing pain in toes and bottom of feet | <input type="checkbox"/> | Skin feels ready to split |
| <input type="checkbox"/> | Cramping | <input type="checkbox"/> | Twitches |
| <input type="checkbox"/> | Crawling sensations | <input type="checkbox"/> | Uncomfortable hot skin |
| <input type="checkbox"/> | Deep bone pain | <input type="checkbox"/> | Walking ankle-deep in burning hot sand |
| <input type="checkbox"/> | Extreme skin sensitivity | <input type="checkbox"/> | Walking on blisters |
| <input type="checkbox"/> | Facial bone, teeth, and jaw pain | <input type="checkbox"/> | Walking on fire with burned off skin |
| <input type="checkbox"/> | Feeling of being on fire | <input type="checkbox"/> | Walking on rocks sensation |
| <input type="checkbox"/> | Feeling of large painful blisters on bottom of feet | | |

'Thank You' to Our Generous Donors

TEA thanks the members, family, friends and organizations who made donations from February 1 through May 31, 2009.

* includes gifts to the second annual appeal

^ includes gifts made in honor or memory of someone

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Your stories — everyone has one

Most of us have tales to tell. TEA encourages you to write your story. Then, send it to Gayla Kanaster, gaylakanaster@aol.com or 2532 N. Fremont Street, Tacoma, WA, USA 98406.

Gillian Birrell writes:

Hello. I'm happy to be volunteering with TEA and hope to help and support others by networking with other EMers in Canada. I work as much as my severe EM will let me. (*Editor's Note: Gillian is the TEA Networking Program Coordina-*

tor for Canada.) I am 33 years old and live in Barrie, Ontario, Canada. I suffer daily from EM as well as fibromyalgia, Raynaud's, endometriosis, interstitial cystitis and irritable bowel syndrome, among others.

Before EM, I traveled internationally as a fashion model. I later married and had a son, now 14. I then worked as a medical office administrator for a "Pain and Stress Clinic" — ironic, I know. I was forced to quit due to increasing health problems. Doctors told me I had optic neuritis and a lupus-like connective tissue disease, but had no explanation for the burning, redness and pain — only suggesting counselling. I did research



Gillian Birrell

on the Internet and discovered a disorder called erythromelalgia. My neurologist finally confirmed it. Depression hit me hard at first. I then found TEA and immediately knew I was not alone. ... I am trying to spread the word that EM **DOES EXIST** by contacting local newspapers and news channels.

FootSteps is published by **The Erythromelalgia Association**

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Q & A Q & A Q & A by Gayla Kanaster

Q Marcy Lilley, Thousand Oaks, Calif., U.S.: *Do others have more flares when under stress, such as when rushing around or feeling anxious about something?*

Also, does the EM cause extremely dry skin on your hands and feet?

Q Rae Ann Anderson, Templeton, Calif., U.S.: *Has anyone tried taking Benadryl and Aleve at night? It's really helped my EM.*

The Benadryl seems to constrict blood vessels and keep them from flaring and the Aleve decreases the discomfort.

I also wonder if others have found that flares happen less often when fighting another illness. Mine went away when I had pneumonia.

Send your answers (and questions) to Gayla Kanaster, 2532 Fremont St., Tacoma, WA, USA, 98406 or GaylaKanaster@aol.com.