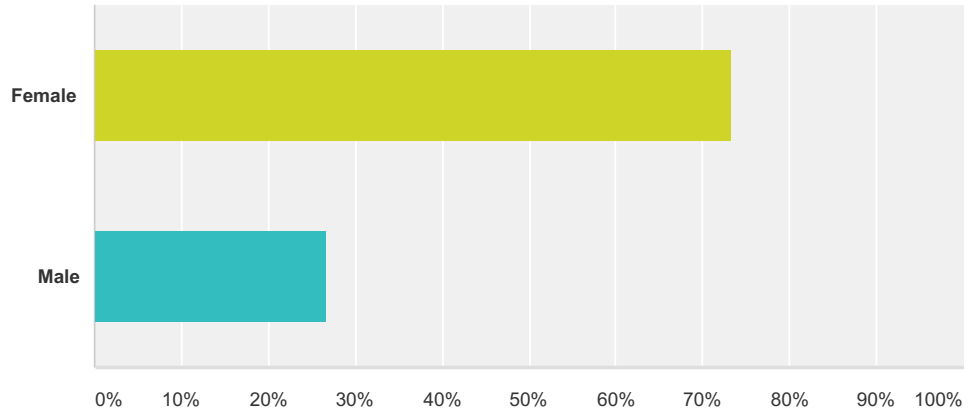


Q1 What gender is the patient?

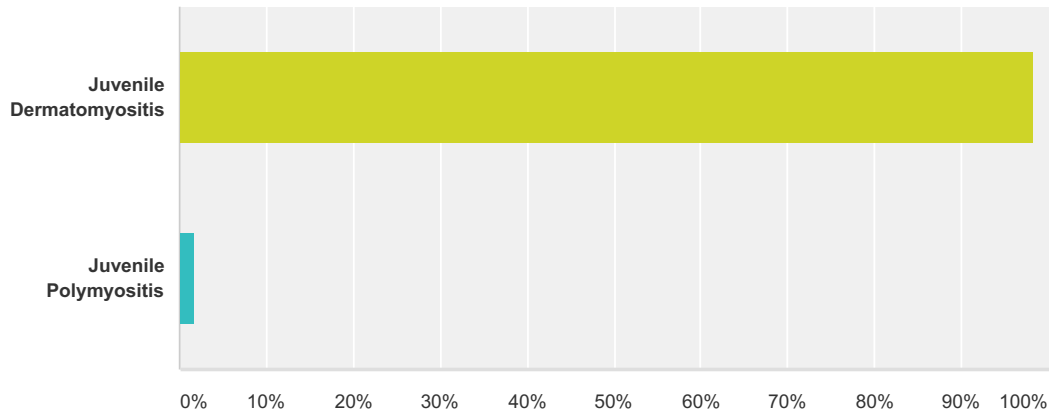
Answered: 401 Skipped: 2



Answer Choices	Responses	
Female	73.32%	294
Male	26.68%	107
Total		401

Q2 What is the patient's diagnosis?

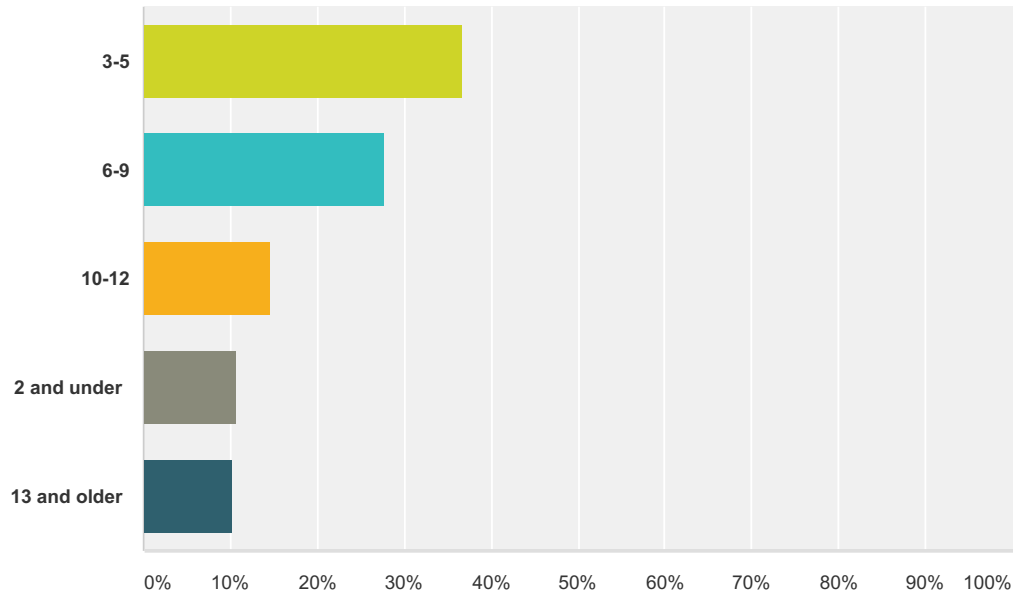
Answered: 401 Skipped: 2



Answer Choices	Responses	
Juvenile Dermatomyositis	98.25%	394
Juvenile Polymyositis	1.75%	7
Total		401

Q3 At what age was the patient diagnosed?

Answered: 401 Skipped: 2



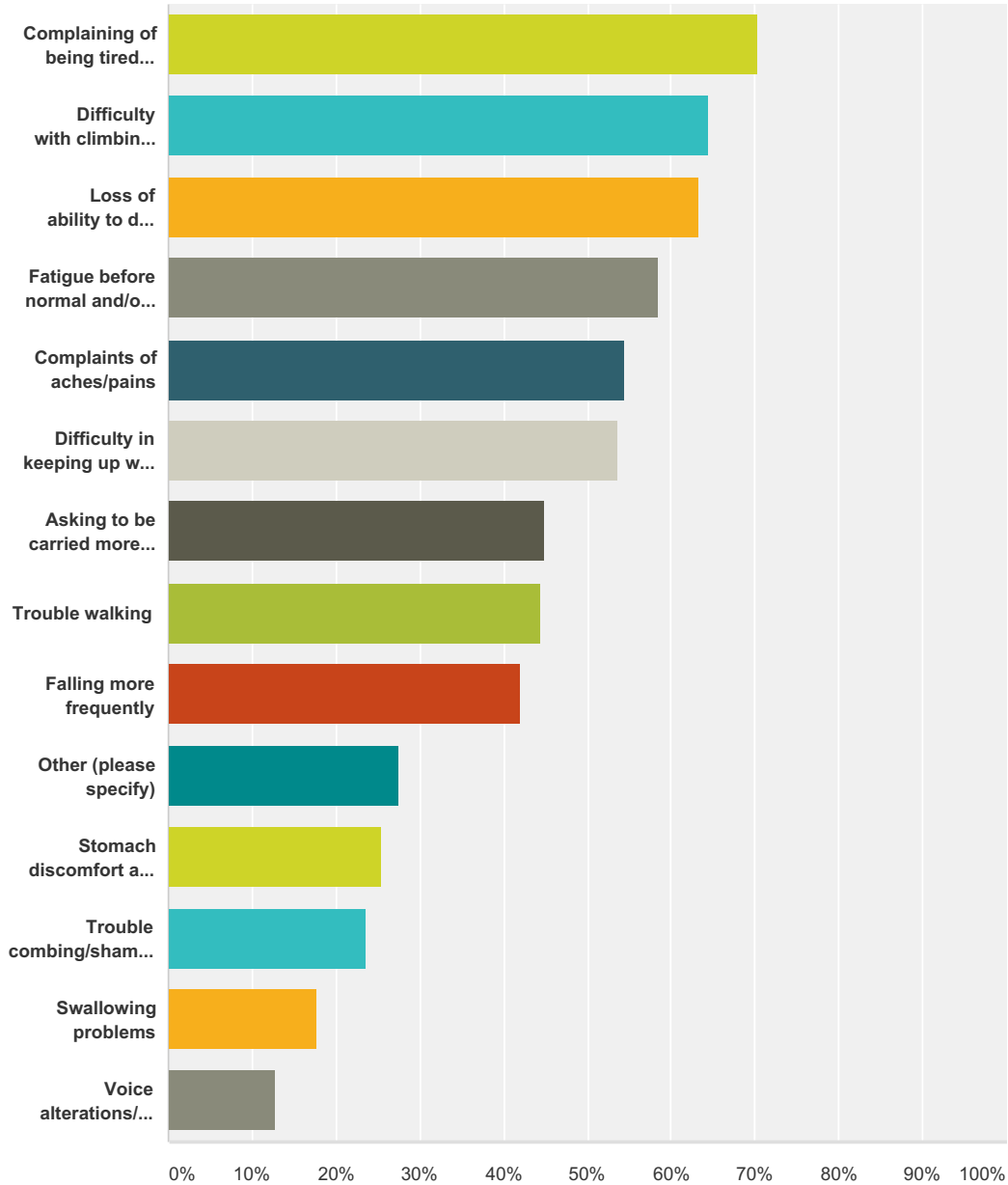
Answer Choices	Responses
3-5	36.66% 147
6-9	27.68% 111
10-12	14.71% 59
2 and under	10.72% 43
13 and older	10.22% 41
Total	401

Q4 In hindsight, how many months prior to diagnosis did the patient start showing symptoms of JM?

Answered: 395 Skipped: 8

Q5 What were symptoms relating to muscle involvement, prior to diagnosis, that you recall the patient showing? Please be specific.

Answered: 395 Skipped: 8



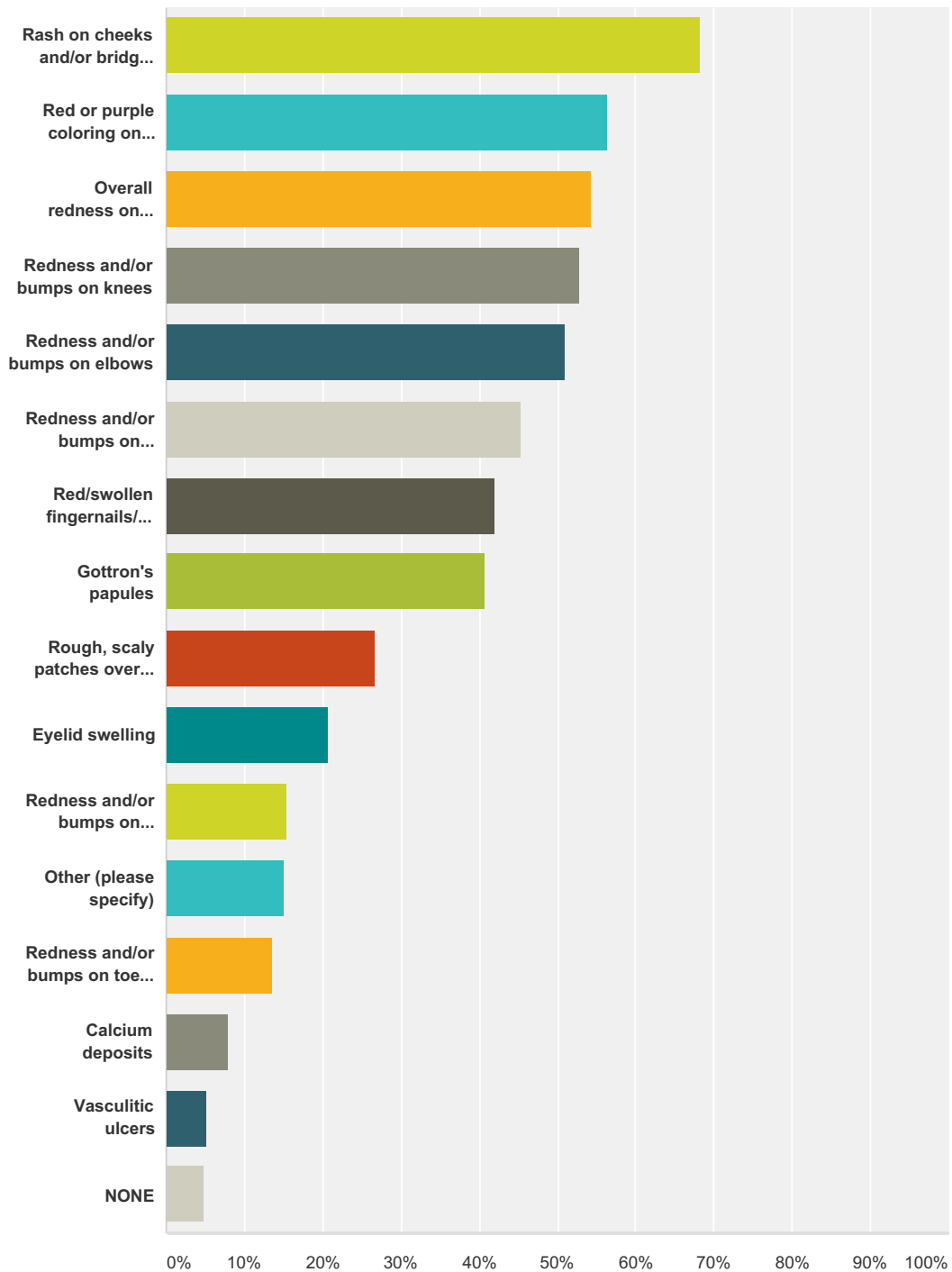
Answer Choices	Responses
Complaining of being tired more often	70.38% 278
Difficulty with climbing stairs	64.56% 255
Loss of ability to do physical activities ie: bike riding, running, soccer	63.29% 250
Fatigue before normal and/or after physical activities	58.48% 231

Cure JM Family Survey

Complaints of aches/pains	54.43%	215
Difficulty in keeping up with friends at school and in sports	53.67%	212
Asking to be carried more often	44.81%	177
Trouble walking	44.56%	176
Falling more frequently	42.03%	166
Other (please specify)	27.59%	109
Stomach discomfort and pain	25.57%	101
Trouble combing/shampooing hair	23.54%	93
Swallowing problems	17.72%	70
Voice alterations/difficulties	12.66%	50
Total Respondents: 395		

Q6 What skin-related symptoms do you recall prior to diagnosis?

Answered: 401 Skipped: 2



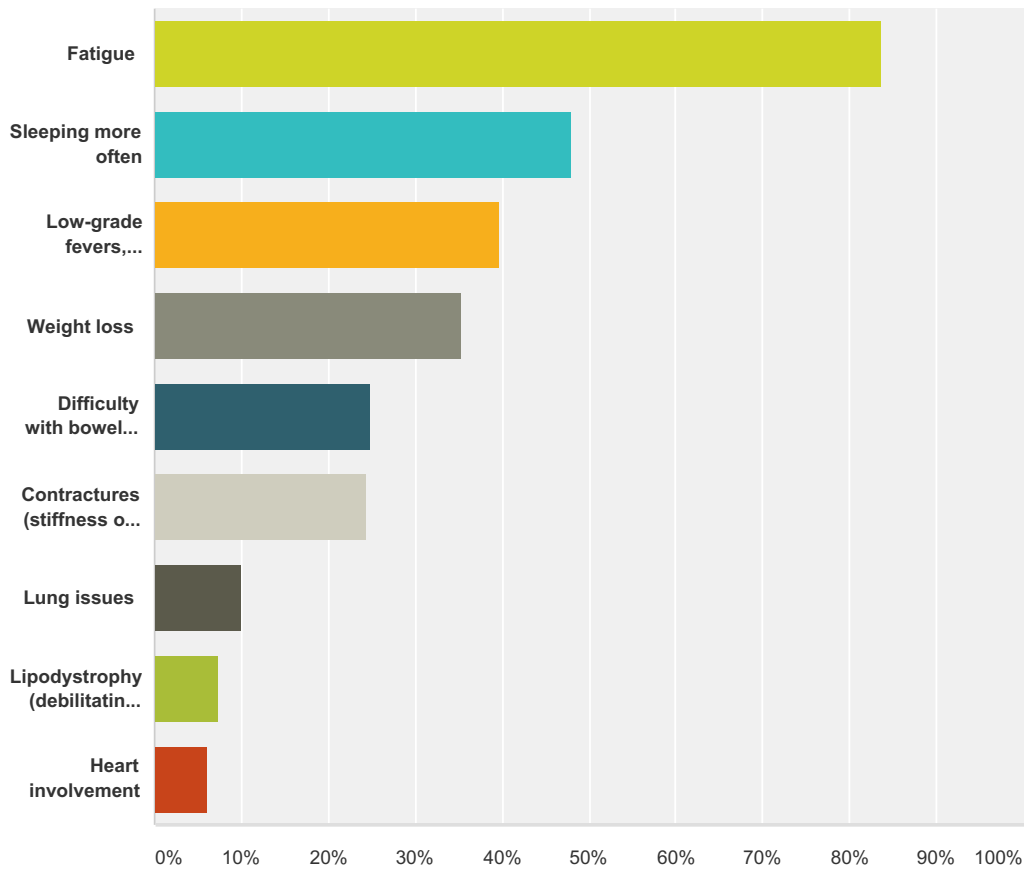
Answer Choices	Responses
Rash on cheeks and/or bridge of nose	68.33% 274
Red or purple coloring on eyelids	56.36% 226

Cure JM Family Survey

Overall redness on hands (joints, knuckles, nail beds)	54.36%	218
Redness and/or bumps on knees	52.87%	212
Redness and/or bumps on elbows	50.87%	204
Redness and/or bumps on knuckles	45.39%	182
Red/swollen fingernails/cuticles	41.90%	168
Gottron's papules	40.65%	163
Rough, scaly patches over joints	26.68%	107
Eyelid swelling	20.70%	83
Redness and/or bumps on ankles	15.46%	62
Other (please specify)	14.96%	60
Redness and/or bumps on toe joints	13.47%	54
Calcium deposits	7.98%	32
Vasculitic ulcers	5.24%	21
NONE	4.74%	19
Total Respondents: 401		

Q7 Prior to diagnosis, did the patient have any of the following symptoms?

Answered: 318 Skipped: 85



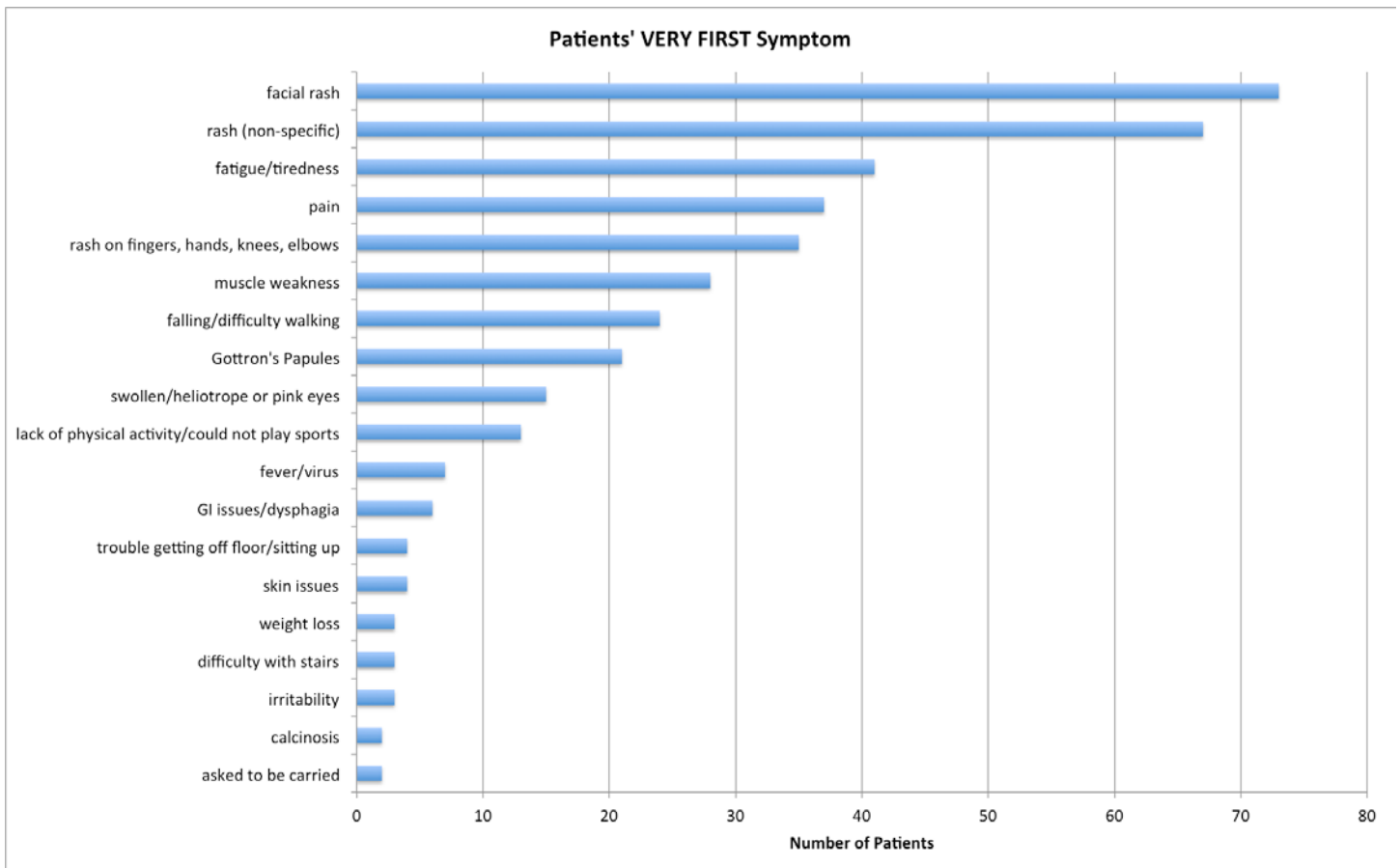
Answer Choices	Responses
Fatigue	83.65% 266
Sleeping more often	48.11% 153
Low-grade fevers, particularly at night	39.62% 126
Weight loss	35.22% 112
Difficulty with bowel movements	24.84% 79
Contractures (stiffness or constriction of a joint)	24.53% 78
Lung issues	10.06% 32
Lipodystrophy (debilitating loss of body fat)	7.23% 23
Heart involvement	5.97% 19
Total Respondents: 318	

Q8 What was the VERY FIRST symptom that the patient displayed?

Answered: 401 Skipped: 2

The very FIRST symptom for the majority of patients was:

- 1) Facial rash
- 2) Non-specific rash
- 3) Pain
- 4) Fatigue/tiredness
- 5) Rash on fingers, hands, knees, and/or elbows

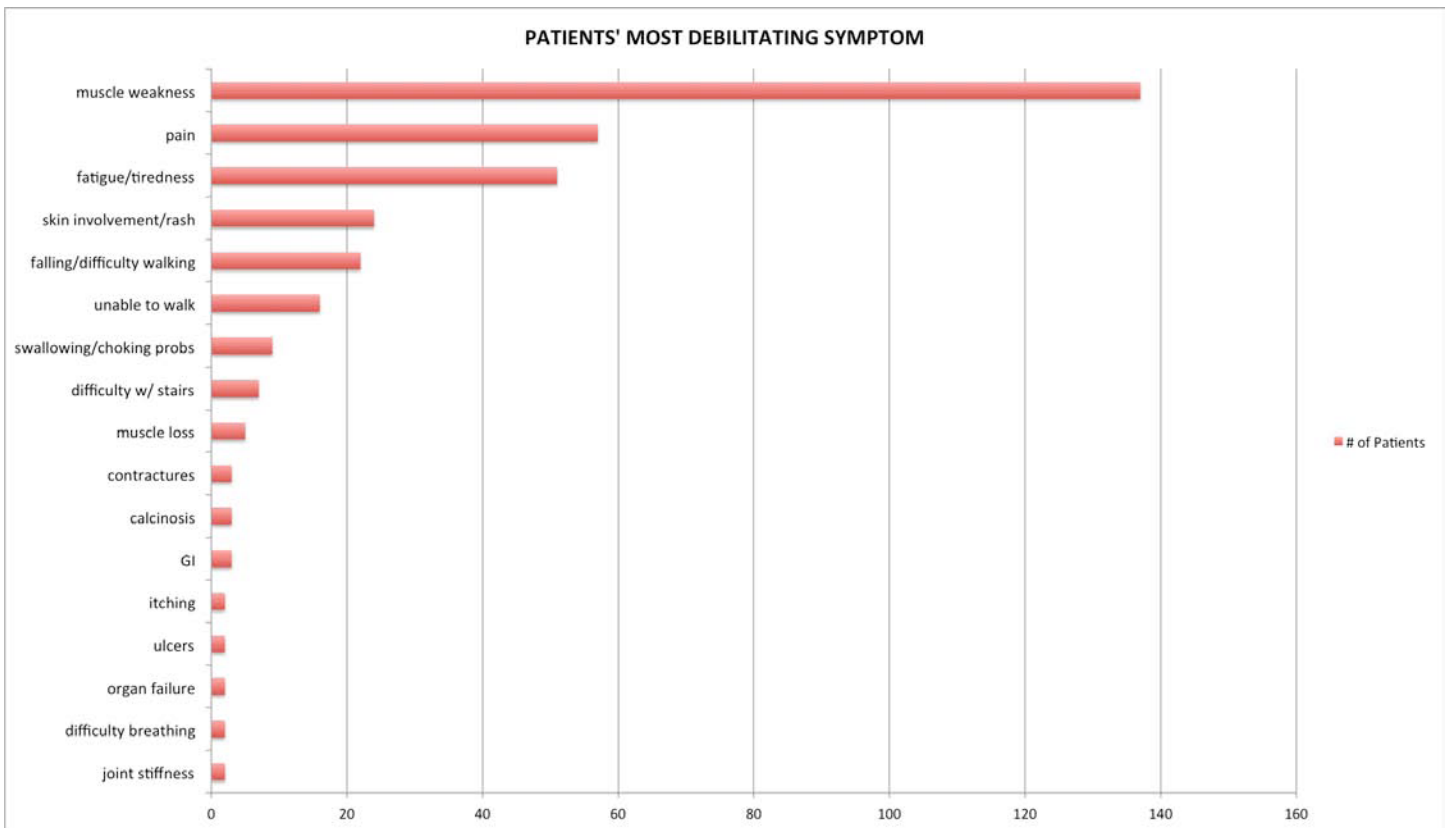


Q9 What was the patient's most debilitating symptom?

Answered: 379 Skipped: 24

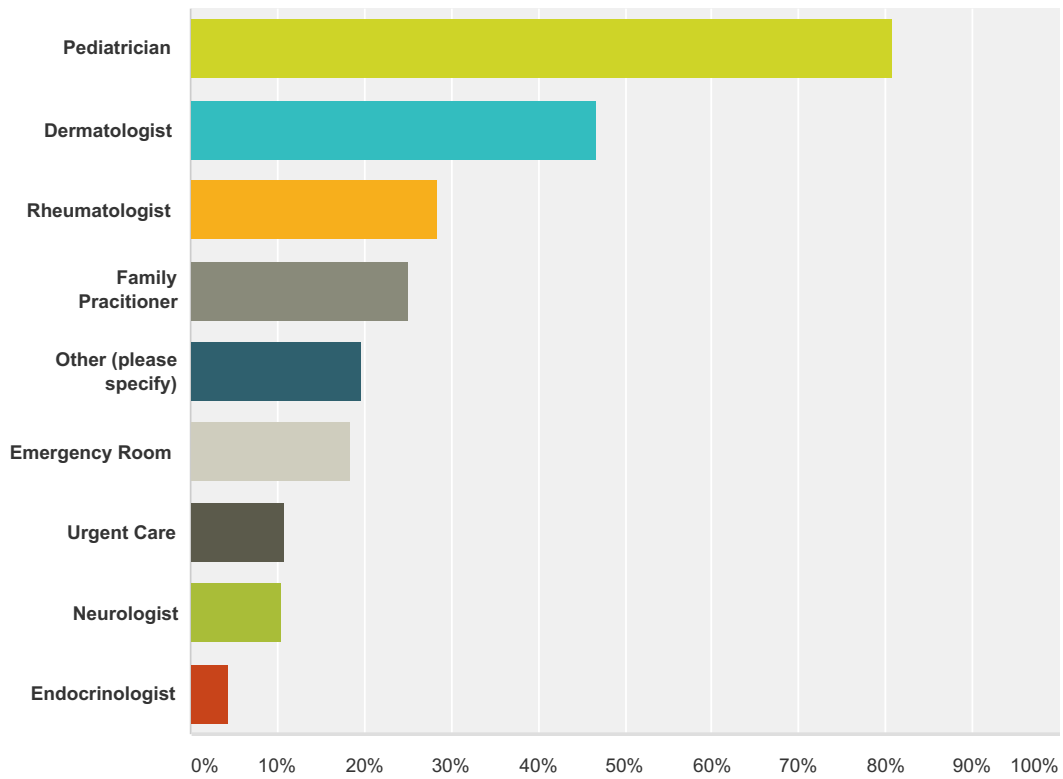
The most DEBILITATING symptom for the majority of patients was:

- 1) Muscle weakness
- 2) Pain
- 3) Fatigue/tiredness
- 4) Skin involvement/rash
- 5) Falling/difficulty walking



Q10 What type of doctor(s) was consulted BEFORE diagnosis of JM was made?

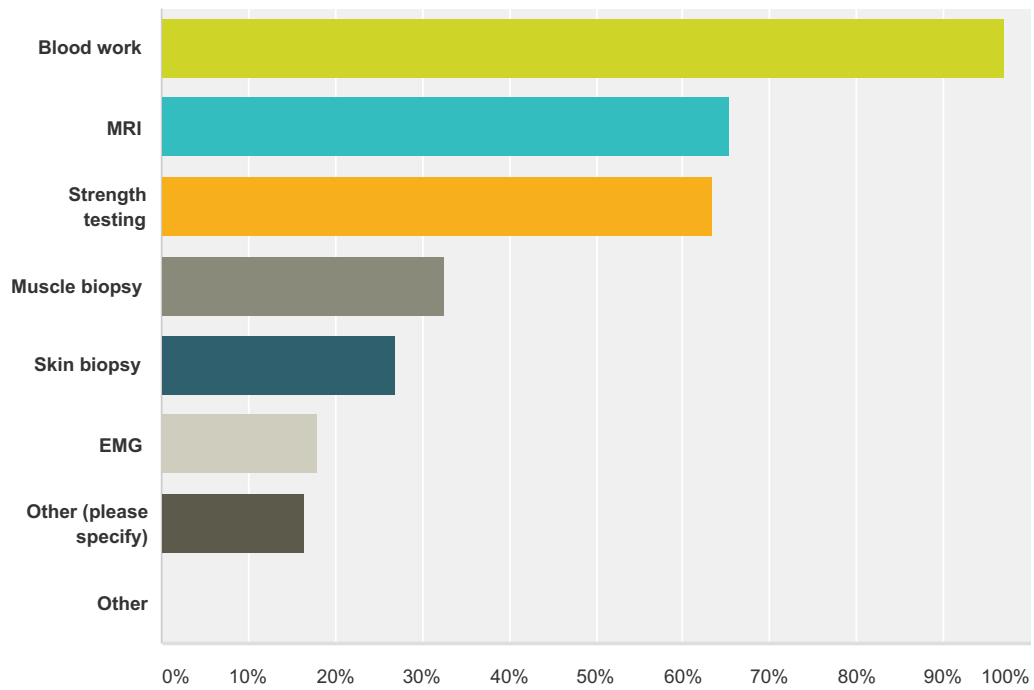
Answered: 402 Skipped: 1



Answer Choices	Responses	Count
Pediatrician	80.85%	325
Dermatologist	46.77%	188
Rheumatologist	28.36%	114
Family Practitioner	25.12%	101
Other (please specify)	19.65%	79
Emergency Room	18.41%	74
Urgent Care	10.95%	44
Neurologist	10.45%	42
Endocrinologist	4.48%	18
Total Respondents: 402		

Q11 Which of the following tests did the patient undergo prior to/during diagnosis?

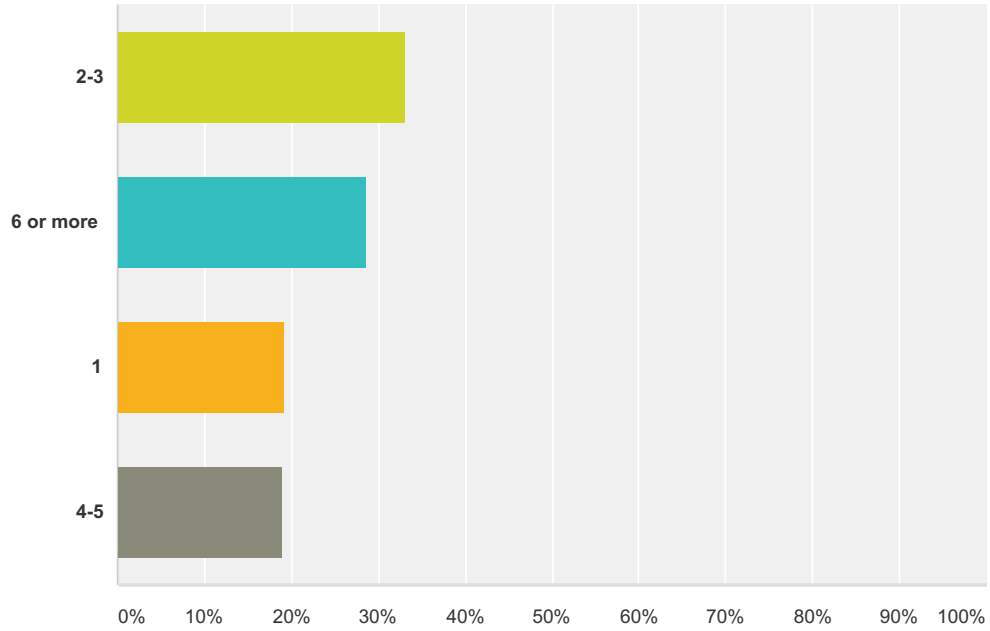
Answered: 402 Skipped: 1



Answer Choices	Responses	Count
Blood work	97.01%	390
MRI	65.42%	263
Strength testing	63.43%	255
Muscle biopsy	32.59%	131
Skin biopsy	26.87%	108
EMG	17.91%	72
Other (please specify)	16.42%	66
Other	0.00%	0
Total Respondents: 402		

Q12 How many times did the patient go to a doctor before a referral to a specialist and/or a diagnosis?

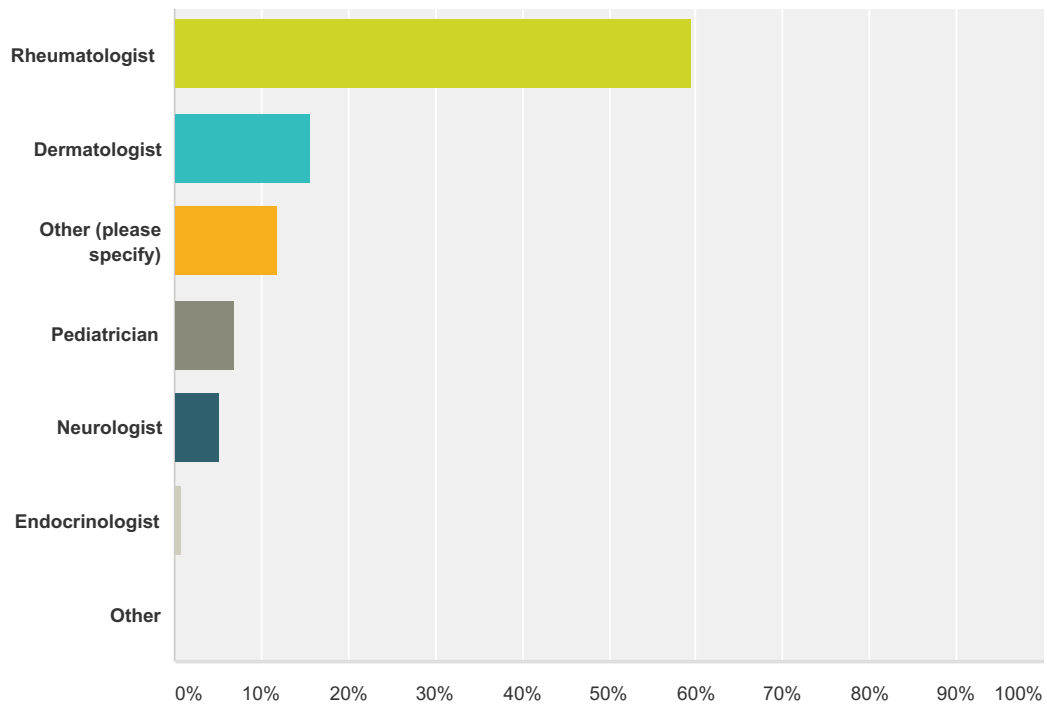
Answered: 401 Skipped: 2



Answer Choices	Responses
2-3	33.17% 133
6 or more	28.68% 115
1	19.20% 77
4-5	18.95% 76
Total	401

Q13 What type of doctor ultimately made the diagnosis for the patient?

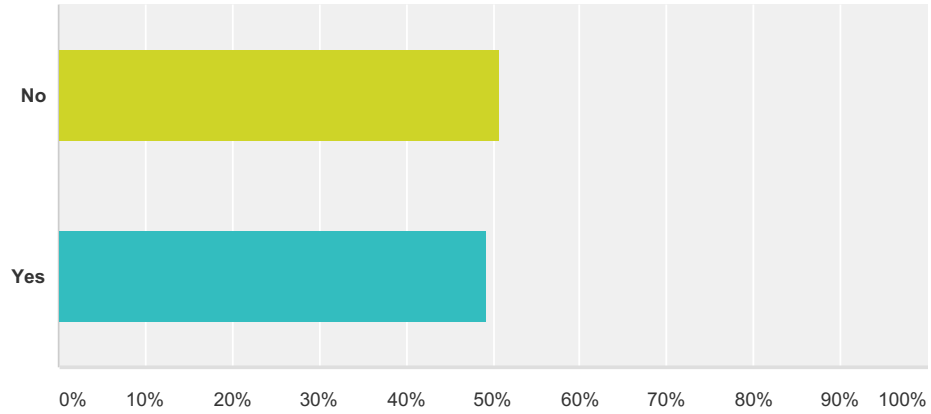
Answered: 403 Skipped: 0



Answer Choices	Responses
Rheumatologist	59.55% 240
Dermatologist	15.63% 63
Other (please specify)	11.91% 48
Pediatrician	6.95% 28
Neurologist	5.21% 21
Endocrinologist	0.74% 3
Other	0.00% 0
Total	403

Q14 Did the patient have signs of an infection, or virus, within three months of the onset of skin rash or muscle weakness?

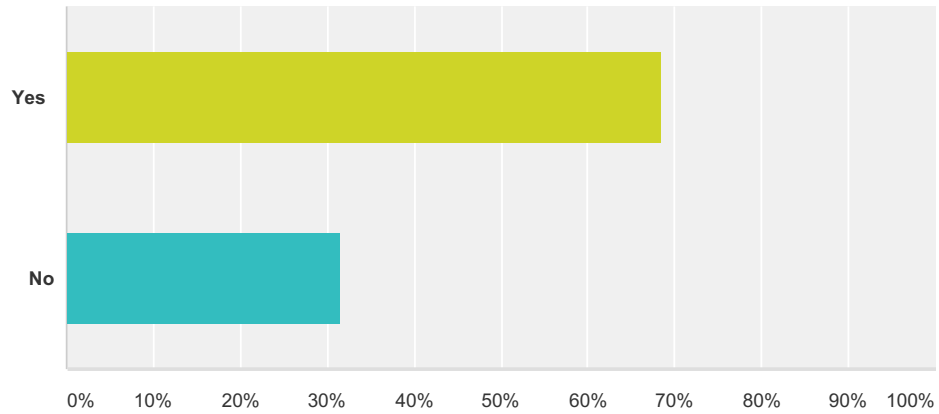
Answered: 370 Skipped: 33



Answer Choices	Responses
No	50.81% 188
Yes	49.19% 182
Total	370

Q15 Would you be willing to provide photos of your child prior to diagnosis? These photos would be used to educate the medical community on the symptoms of Juvenile Myositis.

Answered: 369 Skipped: 34



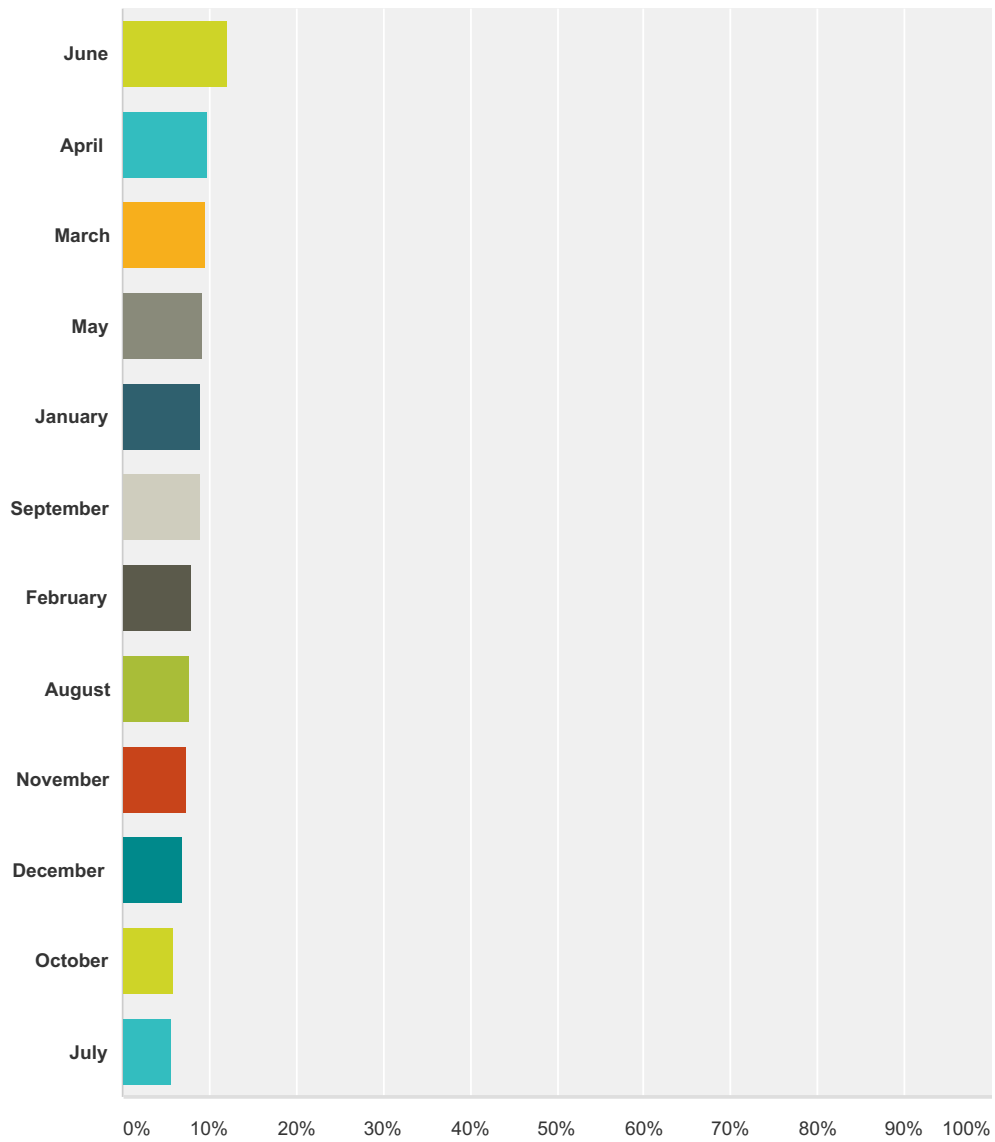
Answer Choices	Responses
Yes	68.56% 253
No	31.44% 116
Total	369

Q16 What City & State were you living in when the patient first showed symptoms of the disease?

Answered: 400 Skipped: 3

Q17 What month did the patient first show symptoms of the disease?

Answered: 378 Skipped: 25



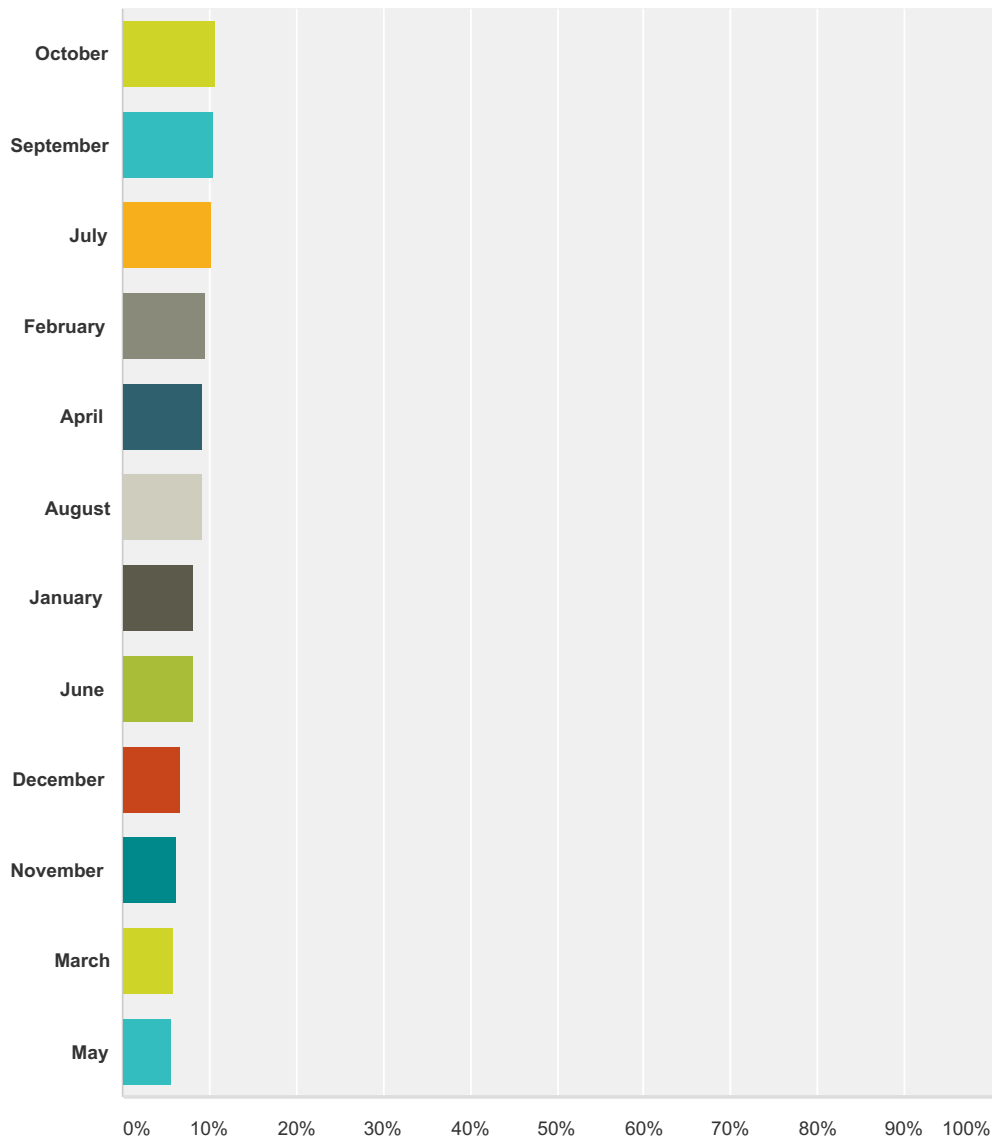
Answer Choices	Responses	Count
June	12.17%	46
April	9.79%	37
March	9.52%	36
May	9.26%	35
January	8.99%	34
September	8.99%	34
February	7.94%	30

Cure JM Family Survey

August	7.67%	29
November	7.41%	28
December	6.88%	26
October	5.82%	22
July	5.56%	21
Total		378

Q18 What month was the patient diagnosed?

Answered: 393 Skipped: 10



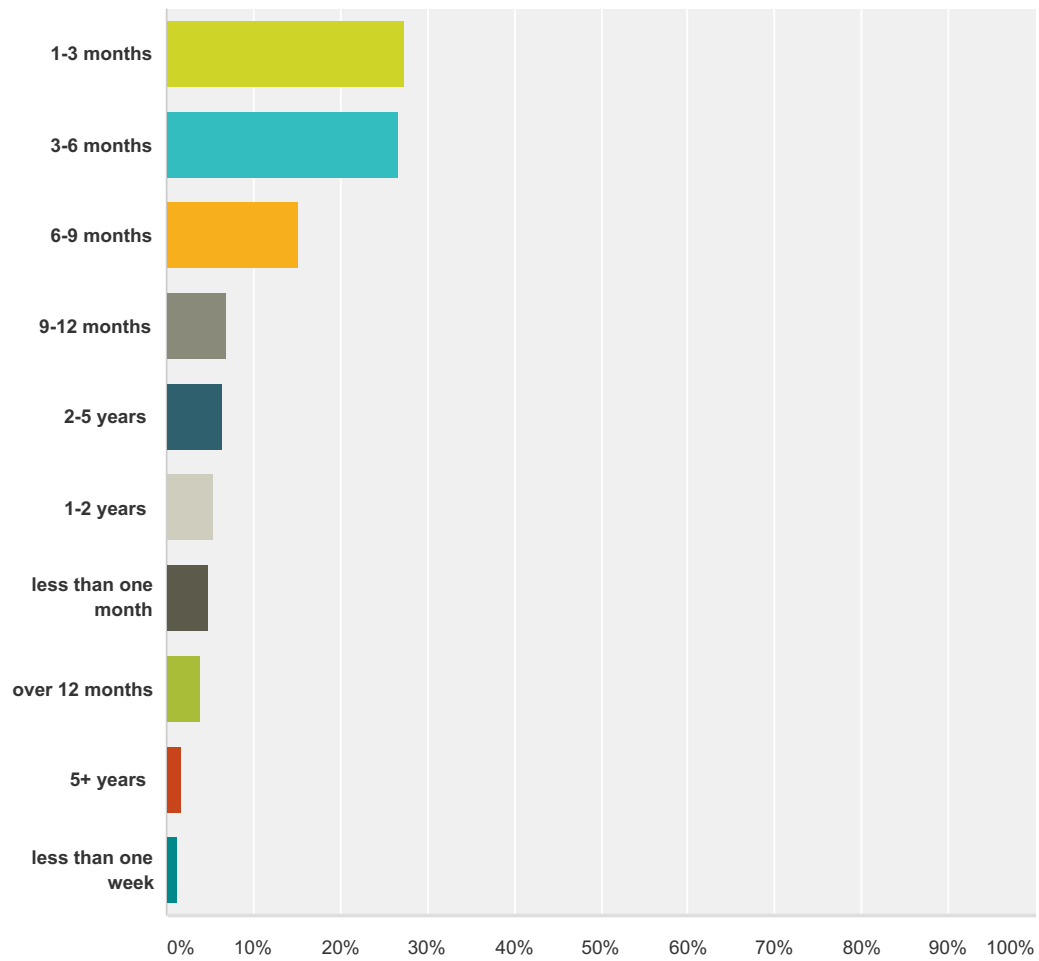
Answer Choices	Responses
October	10.69% 42
September	10.43% 41
July	10.18% 40
February	9.67% 38
April	9.16% 36
August	9.16% 36
January	8.14% 32

Cure JM Family Survey

June	8.14%	32
December	6.62%	26
November	6.36%	25
March	5.85%	23
May	5.60%	22
Total		393

Q19 What was the length of time between the patient's first symptoms and diagnosis?

Answered: 401 Skipped: 2



Answer Choices	Responses	Count
1-3 months	27.43%	110
3-6 months	26.68%	107
6-9 months	15.21%	61
9-12 months	6.98%	28
2-5 years	6.48%	26
1-2 years	5.49%	22
less than one month	4.74%	19
over 12 months	3.99%	16
5+ years	1.75%	7
less than one week	1.25%	5

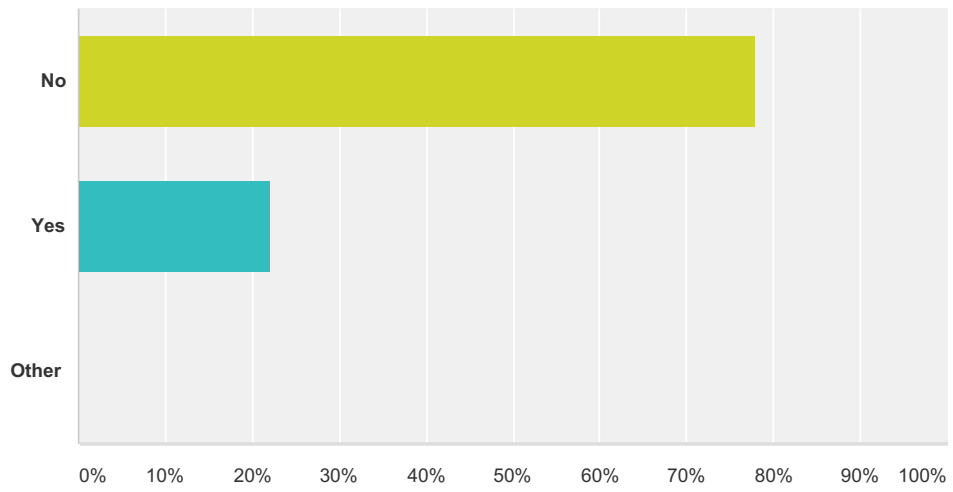
Cure JM Family Survey

Total

401

Q20 Is the patient in remission (two years no symptoms/no medications)?

Answered: 396 Skipped: 7



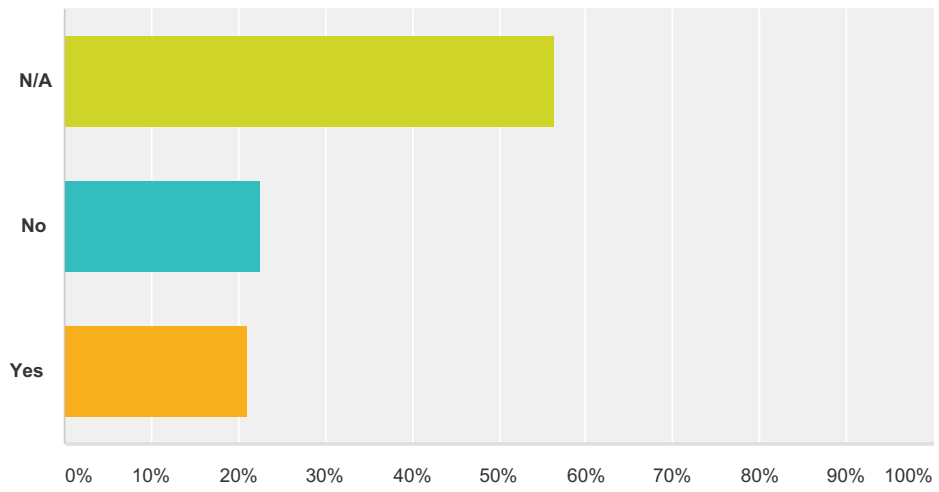
Answer Choices	Responses
No	77.78% 308
Yes	22.22% 88
Other	0.00% 0
Total	396

Q21 If the patient is in remission, how long after diagnosis did remission occur? (If the patient has never been in remission, please answer n/a)

Answered: 219 Skipped: 184

Q22 Did the patient have any relapse after initial remission?

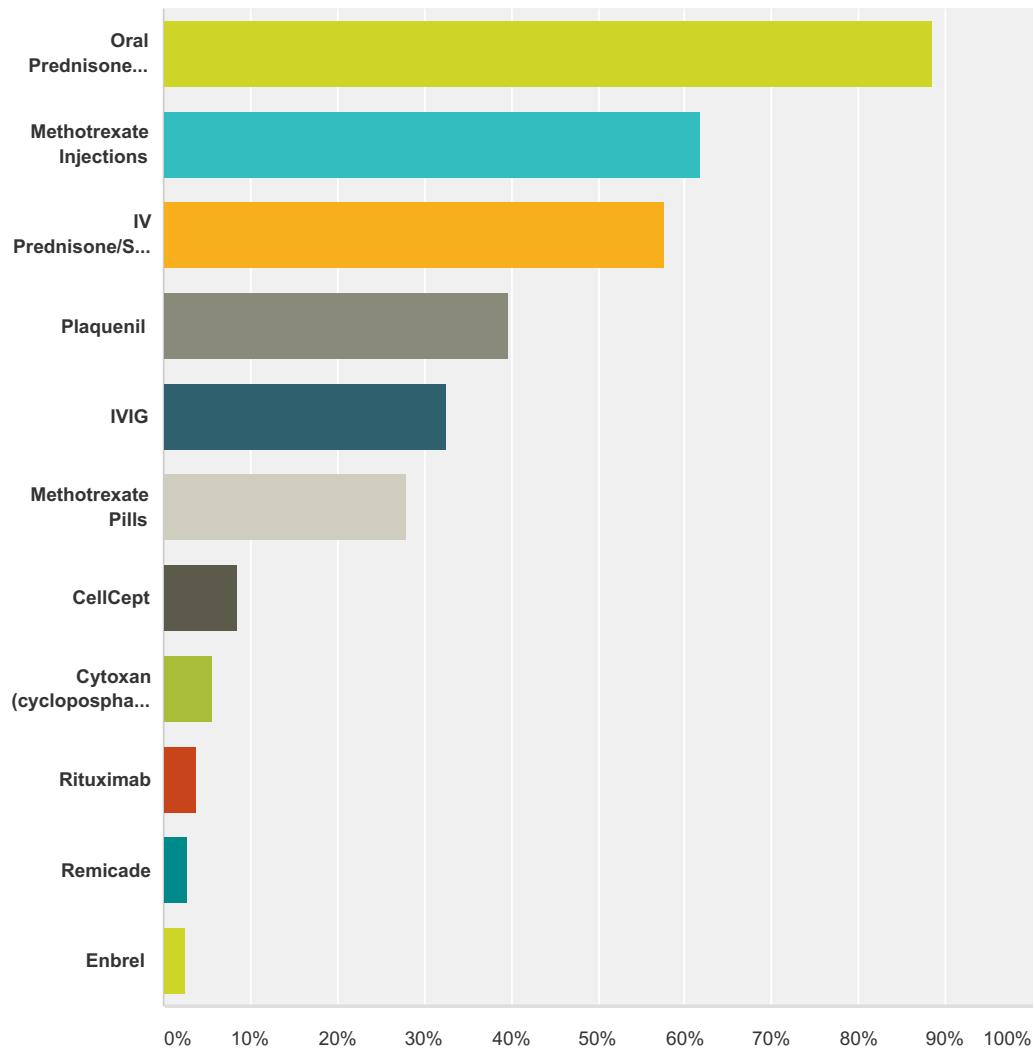
Answered: 364 Skipped: 39



Answer Choices	Responses
N/A	56.32% 205
No	22.53% 82
Yes	21.15% 77
Total	364

Q23 Which of the following medications were prescribed at the time of diagnosis?

Answered: 401 Skipped: 2



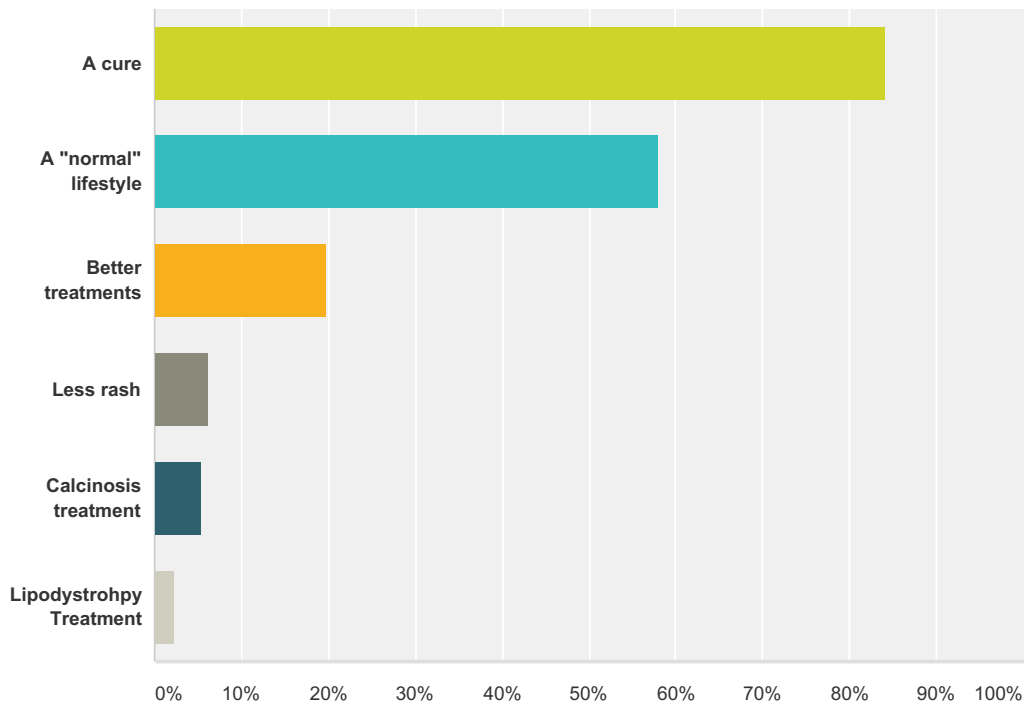
Answer Choices	Responses	Count
Oral Prednisone (pills, tablets)	88.53%	355
Methotrexate Injections	61.85%	248
IV Prednisone/Solmedrol	57.61%	231
Plaquenil	39.65%	159
IVIG	32.67%	131
Methotrexate Pills	27.93%	112
CellCept	8.48%	34
Cytoxan (cyclophosphamide)	5.74%	23
Rituximab	3.74%	15

Cure JM Family Survey

Remicade	2.74%	11
Enbrel	2.49%	10
Total Respondents: 401		

Q24 What is the most important outcome that you want for the patient?

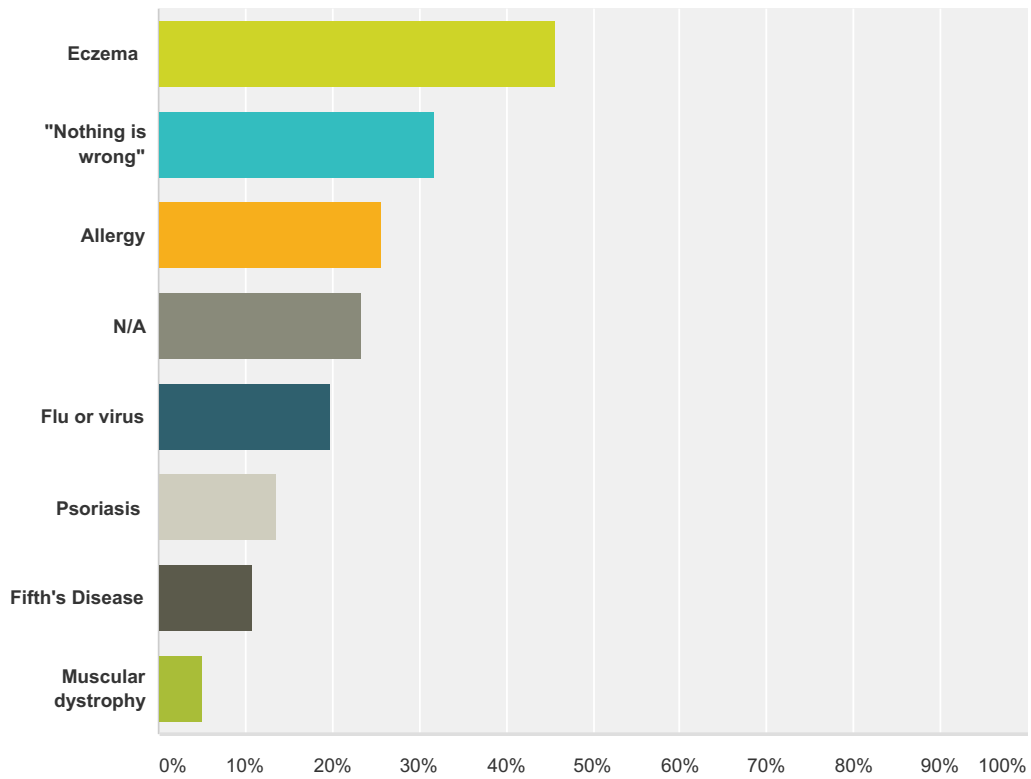
Answered: 402 Skipped: 1



Answer Choices	Responses	
A cure	84.08%	338
A "normal" lifestyle	57.96%	233
Better treatments	19.90%	80
Less rash	6.22%	25
Calcinosis treatment	5.47%	22
Lipodystrophy Treatment	2.24%	9
Total Respondents: 402		

Q25 What (if any) misdiagnosis did the patient receive prior to the JM diagnosis?

Answered: 334 Skipped: 69



Answer Choices	Responses	Count
Eczema	45.81%	153
"Nothing is wrong"	31.74%	106
Allergy	25.75%	86
N/A	23.35%	78
Flu or virus	19.76%	66
Psoriasis	13.47%	45
Fifth's Disease	10.78%	36
Muscular dystrophy	5.09%	17
Total Respondents: 334		

**Q26 What is your preferred brand of
sunscreen?**

Answered: 342 Skipped: 61

Q27 Please use this space to give us any further detailed information about the patient's diagnosis, that you feel would be helpful for purposes of physician education, research, early diagnosis, etc.

Answered: 174 Skipped: 229

Q28 If you would like to provide your name and contact information, in the event that we have additional questions that might help our research, please fill out the below form. Name, phone and email address would be appreciated. We will not use this information to solicit you in any way. The survey will only be used for purposes of developing a better education initiative to help physicians recognize the signs of JM and diagnose patients more quickly.

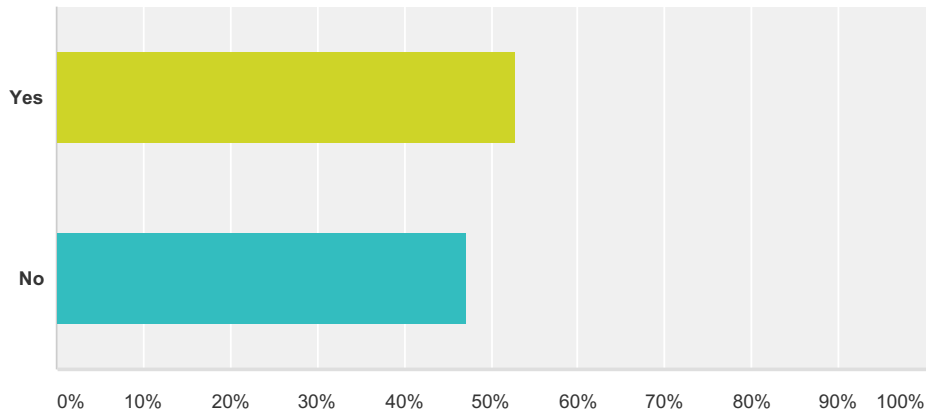
Address

Answered: 319 Skipped: 84

Answer Choices	Responses	
Name	99.37%	317
Email Address	97.18%	310
City/Town	92.48%	295
ZIP/Postal Code	92.48%	295
Address	91.22%	291
State/Province	89.03%	284
Phone Number	84.01%	268
Country	81.50%	260
Address 2	5.02%	16
Company	0.00%	0

Q29 Would you like to be contacted to discuss this survey further?

Answered: 350 Skipped: 53

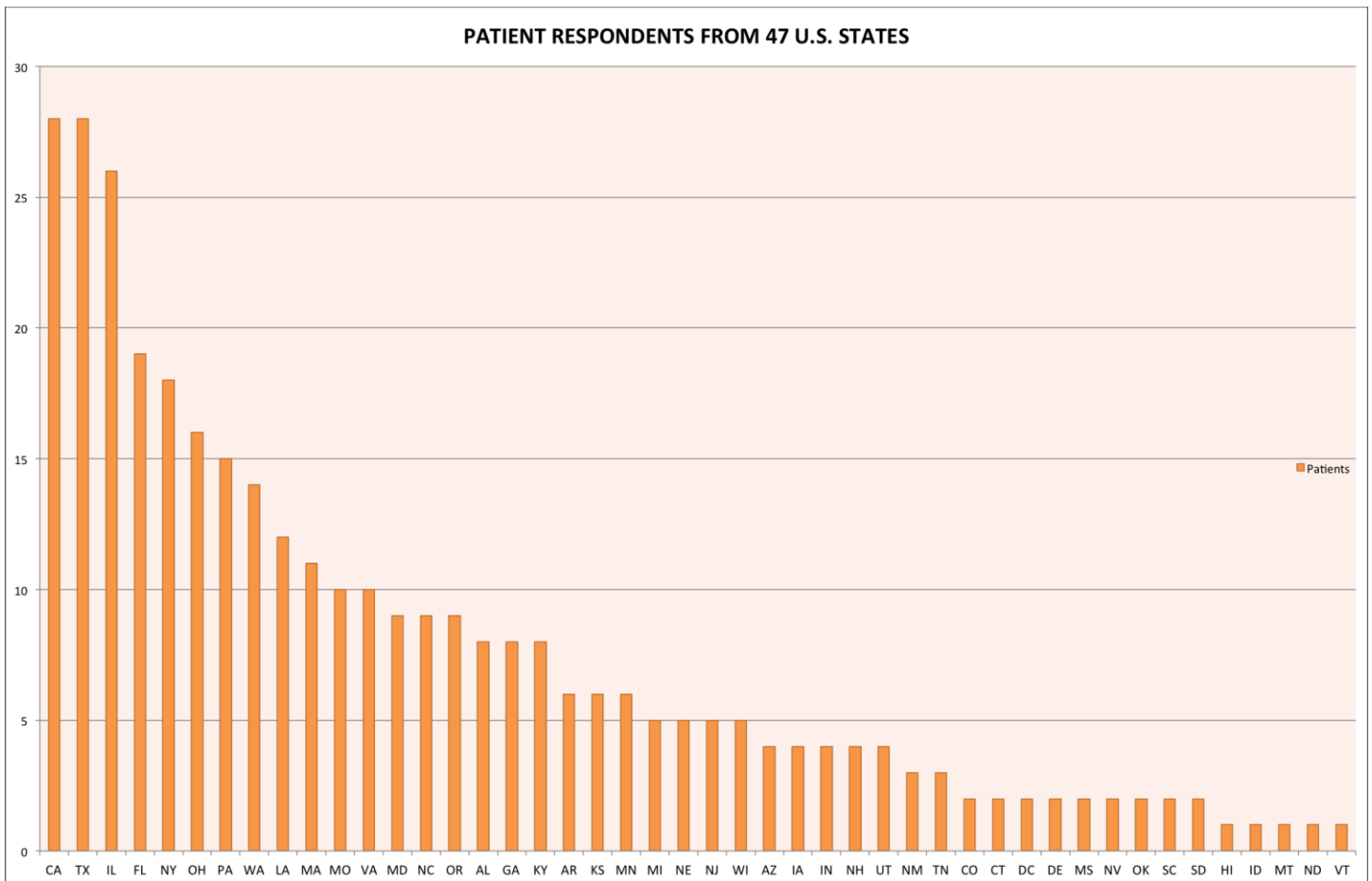


Answer Choices	Responses	
Yes	52.86%	185
No	47.14%	165
Total		350

Where did your child first develop symptoms of Juvenile Myositis?

The top 5 states in the U.S. were:

- 1) California
- 2) Texas
- 3) Illinois
- 4) Florida
- 5) New York



Where did your child first develop symptoms of Juvenile Myositis?

Outside of the U.S., the top 5 countries were:

- 1) Canada
- 2) United Kingdom
- 3) Australia
- 4) New Zealand
- 5) South Africa

