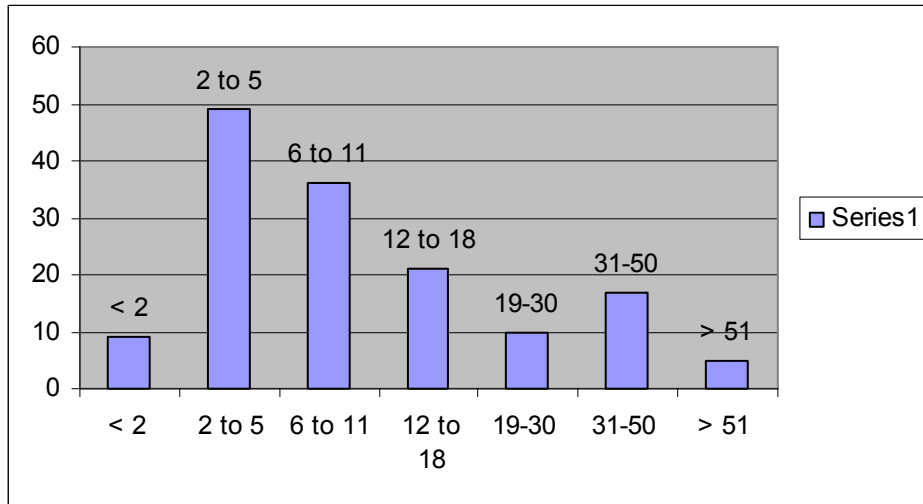


Survey Results!! Thank you to everyone who responded to APFED's 2005Q4 survey! We received 153 responses to help guide our organization.

Who are you?

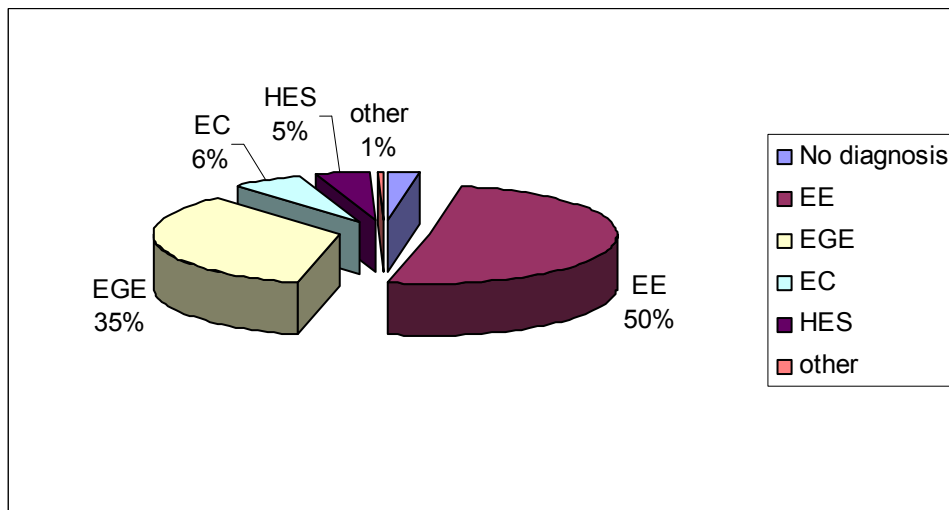
The majority of respondents were **parents** of children with eosinophilic disorders. 40% of children were age 5 years and younger. **Adults** were also well represented, accounting for nearly a quarter of respondents.



Age of Individual with Eosinophilic Disorder (years)

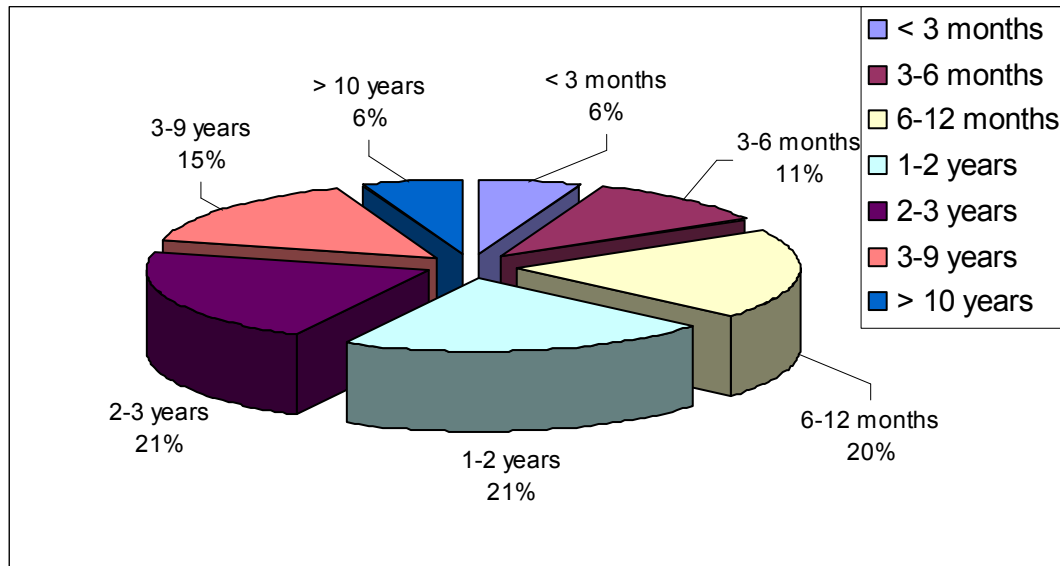
Diagnosis

Eosinophilic esophagitis was the most common diagnosis, closely followed by eosinophil associated gastrointestinal disorders involving other areas of the GI tract.



How much difficulty did you encounter finding a diagnosis?

Delays in diagnosis were common, with nearly half of respondents reporting 2 years or longer to obtain a correct diagnosis. Many of you also travel for medical care. Of the 50 families traveling more than 100 miles each way for care, nearly half report traveling over 500 miles to their medical center.



Time to diagnosis from onset on symptoms

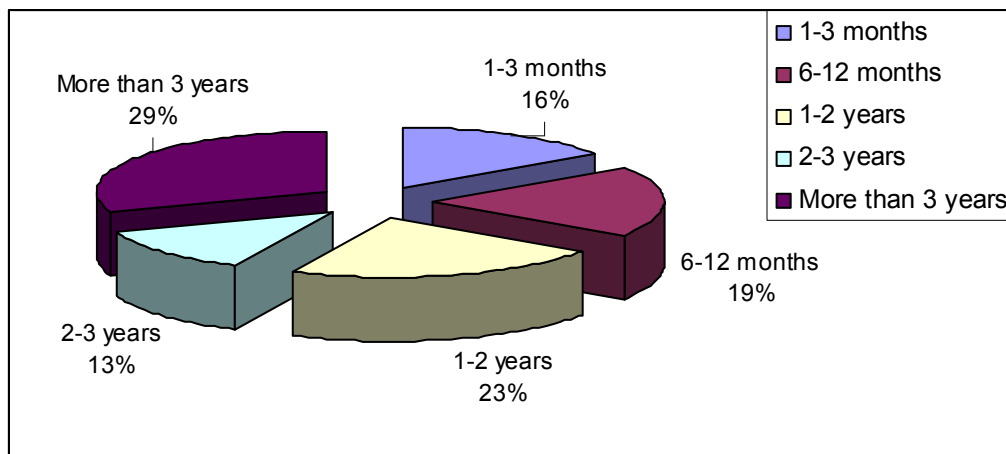
Treatment

Treatment was varied, in part due to the numerous diagnoses represented. The most common treatments involved dietary therapy (restricted or elemental), often in conjunction with medications. An example of a topical steroid is Flovent inhaler, swallowed. An example of a systemic steroid is prednisone. Therapies are shown in the table below:

Treatment	
Respondents	N=136
Restricted Diet	31
Restricted Diet + Steroids (topical)	19
Restricted + systemic steroids	2
Elemental Diet	42
Elemental + topical steroids	3
Elemental + systemic steroids	1
6MP, Azathioprine	2
Systemic Steroids , diet Not specified	9
Singularair	5
Topical Steroid , Diet not specified	16
No treatment, remission	1
Cromolyn	1
Neurontin	1
Acupuncture	1

Additional Treatment Observations	
Total Parental Nutrition, in conjunction with other therapy listed above	2
Ketotifen in Conjunction with other therapy above	3
Treatment Response	
Elemental diet with symptom resolution	25
Elemental diet without symptom resolution	16
Restricted diet with symptom resolution	9
Restricted diet without symptom resolution	13
	N=63
Steroids or Formula	
Steroids, topical or systemic	50
Formula, with/without other therapy	46

Once a diagnosis was made, improvement in symptoms also took time. Nearly 30% reported ongoing symptoms despite 3 or more years of treatment.



Time from diagnosis to resolution of symptoms

What is important to you?

On a scale of 1 to 5, Education and research were rated as top priorities for APFED. The survey indicates areas of need for education at the community level to decrease delays in diagnosis and reduce the need to travel for medical care. Development of consistent and effective treatment recommendation for each of the eosinophilic disorders is also needed.

Education	4.91
Research	4.56
Conference	4.32
Support	4.3
Awareness	4.24
Family Fund	3.75

Please take a few moments to take our latest survey.

<http://www.apfed.org/survey.htm>