



March/April 2013 Survey

TOPIC: LIVING WITH AN EGID

Total Started Survey: 52

Total Finished Survey: 52

1. Does your EGID child (or EGID you) take a supplement?

answered question 35

skipped question 17

	<i>Percentage</i>	<i>Votes</i>
Multi-Vitamin	45.7%	16
Calcium	34.3%	12
Iron	22.9%	8
B-Vitamins	8.6%	3
Probiotics	42.9%	15
Other :		16
<i>Custom mixed vitamin, protein supplements (vegan), Cod Liver Oil, Fish Oils, Magnesium, Zinc, Vit C, Vit D</i>		

2. Are you or your child a picky eater?

answered question 52

skipped question 0

	<i>Percentage</i>	<i>Votes</i>
Yes	59.6%	31
No	21.2%	11
Sometimes	19.2%	10

3. What impact does EGID have on your life?

answered question 51

skipped question 1

	<i>Percentage</i>	<i>Votes</i>
I often have to have additional time off work	52.9%	27
I find it difficult to integrate with others (non EGID) socially	49.0%	25
I feel tired and/or depressed sometime	70.6%	36
I see a psychologist for this specifically	13.7%	7
It has created a strain on my relationship with my partner or immediate family	35.3%	18
It has little or no impact on my life	9.8%	5

4. Name one or two things that could dramatically improve your way of life living with an EGID

answered question 40

skipped question 12

There needs to be a far greater awareness of EGID in Australia, the medical profession needs to be more aware of it, there is many medical staff and even some doctors who have hardly even heard of it, much less know what to do about it. another great thing would be if there was much more food products available that are completely chemical free.

Team approach with knowledge of EoE. Recognition. support. being able to join in what's considered normal activities with others. financial assistance.

Easier way to test rather than scope to help determine safe foods and progress with diet.

More community awareness

Support, understanding and knowledge from gp. Better communication between specialists.

More food selection in supermarkets and reasonable prices.

We don't fully understand yet which food stuffs affect my daughter other than dairy, and knowing what to avoid would help a lot

Greater understanding of what causes sudden episodes of pain & vomiting & seemingly equally sudden recovery.

Financial support to help with speech, OT, feeding groups etc More help around the house

Just for ppl to be more understanding

Easier/quicker way of contacting specialists when needed & if more medical people (pharmacists/GP's etc) knew something about it

Being able to afford a thermomix. Easier access to speciality foods (postage costs make food super expensive as they are expensive anyway)

Knowing where to go for further help and to specialists in Australia NSW who actually deal with this disorder and can test for triggers etc. There is little or no information about the gastroenteritis but alot more of the esophageal conditions.

Food being in the shop

It would be great if it was easier to negotiate in cafes etc

Public understanding, medical condition and not picky eater!!!

More understanding/support from medical and government departments Ability to work less to reduce stress on myself and family due to days off for illness and medical/ hospital appts

Get better-dont like taking medications

Curing it!

Understanding the cause and prevention

More suitable nutritious short-cut meals. Better access to information from experts in the field - imagine a quarterly newsletter from Dr Frances Connor, Dr Pete Smith, etc with updates on EGID?

More accurate allergy testing so we could be sure what foods could be eaten without causing reactions

Not having a drama at each meal time Make it easier to buy products ie one stop shop

Working out exactly what causes the flare ups. It must be food related but as yet haven't pinpointed the exact cause

A personal chef! :)

Understanding and support.

Being able to eat without pain.

Recommended experienced drs, pysch, OT etc in my area so I hadn't wasted 3 years looking for the right team (and wasted all of that money).

Money for medications & appointments & food

I would love there to be more top eight free food available. Also it would be immensely helpful for EGID to be recognised by Centrelink for Carers allowance.

More awerness and understanding along with better funding

Increasing others awareness so that they believe you that a child can be allergic to all foods. Better money from centrelink to reduce financial stress

Eligible for carers allowance and Case conferencing between drs

More comprehensive food labelling. More community awareness of just how important it is for children with food allergies to not come into contact with those foods.

Less bloating and pain and Finding out what triggers an attack.

Prepackaged foods for emergencies, that you can take on a plane or o/seas trip. That don't have to be refrigerated. Also options that don't need heating. Sometimes I just want to go out without having to prepare/cook food 1st! Just once, please :)

Social understanding of EGID and for outsiders to know we are not over reacting!

5. What could ausEE specifically do to further support you and/or your family?

answered question 30

skipped question 22

I think the main thing is that there is more awareness on what is successful in managing the EGID.

Raise awareness of levels of care EoE can present to whole family to medical & govt agencies. profile success & hard work required. cost out financial burden faced by families.

Doing a great job. One area of concern is about of time kids miss school due to symptoms/reactions. Also impact socially for them. Have answered Q 3 above as missing work to cover this. Tiredness also key factor during reactions for my teen. Maybe these could be included in future surveys.

Perhaps run specialist camps or age appropriate activities for kids who suffer along with their siblings. Would be great for my son to make friends and even go away on camp with others who also have this disease.

Recipes, information about cures and professional help.

Maybe more info on exactly what tests can be done to determine what foods cause reaction. I am aware skin prick won't work for us, but my doc has not spoken of any other methods other than elimination.

Keep pushing research.

Nothing specifically - possibly canvassing gov for Medicare rebates for speech etc if referred by gastro or allergist

Find something that helps

Local support groups so social events could be organised

Have more information available for the gastroenteritis. Have reports on tests and specialists that can help.

Maybe we could make a book for fundraising with recipies that submitted form ausEE families.

AusEE is fabulous! A great resource. We are much better advocates for our son because we are better informed and have a team of experienced advisers through ausEE. Thank you!

Create more information brochures for schools/ drs/ extra curricular activities that have medical specialist comments and suggestions,

Find a cure :)

Information, hearing others experiences

Push for a one-day family conference on EGID every second year?? A new hand-out on on EGID on the ausEE website that explains the daily practicalities of EGID for grandparents, family, friends, school teachers?

I think ausEE is doing a great job especially with the forums as it helps to read of others experiences and solutions that worked for them

We're already grateful that you do so much. I can't think of anything else.

Ausee is a huge support to me! Knowing there are others out there experiencing similar situations reduces the feeling of isolation and frustration. Thank you!!

Just keep getting the word out so people understand what I am talking about - you guys are awesome xx

Push For recognition with Centrelink. I just feel there has to be a link we can use with Diabeties or other illnesses that are diet related which must be followed otherwise it causes organ damage. In EGID case being the gastrointestinal tract.

Maybe a more family based brochure for people not used to medical talk just simpler to understand

Government advocacy

Improve GPs awareness of the condition - symptoms, treatments etc.

Supply me with information. My specialist just told me that there is no cure and not life threatening.

We love what you do!!