

EGID Survey Results

Summary of Results

We had 48 respondents to our survey. We found that 30% of respondents had more than 1 child with EGID and that both the child's parents and child's siblings also suffered from possibly related conditions such as food allergies and intolerances, hay fever, gastro problems like IBS etc

Interestingly, only 54% showed signs of illness in first 3 months of life. Pain was rated as the most significant symptom, with poor sleep, stomach bloating, tiredness and exhaustion, constipation and vomiting following.

It took families years to get a diagnosis with 23% saying it took 5 years or more! 71% in our survey had to see more than one consultant to get a diagnosis, with 25% seeing 4 or more. 77% of parents said the diagnosis was made by a consultant /paediatrician that were based at a hospital that was not local to them.

Misdiagnosis was common with reflux and 'over anxious' mother being most frequently mentioned.

33% of children were experiencing up to 6 flare-ups a year, 25% were experiencing 7-20 a year and 21% were experiencing over 21 a year!

Most children were on a dietary change of some sort and the most commonly excluded foods were dairy, soya, egg and wheat.

Since starting treatment for EGID, 40% say their children have improved a lot or 'significantly', 12.5% are just the same as they were and 15% have got worse. The most frequently listed symptoms which have not improved since starting treatment were tiredness and exhaustion, joint and limb pain, poor appetite, stomach bloating, poor sleep, mucous in stools, recurrent infections and illnesses and stomach pain.

Overall, 71% of parents are happy with the treatment their child is currently receiving. However, parents were asked to rate the support they have received from medical professionals since their child became unwell and results showed parents rated midwives, health visitors, social services, feeding teams and dieticians quite poorly.

29% of parents have had to pay privately to get medical help and support because they couldn't get it through the NHS. Sadly, **85%** of respondents said at some point they had felt they weren't believed about their child's medical problems.

Parents rated stress and anxiety, distress from lack of information and lack of support from the medical profession, and loneliness as a significant problem. They also rated stress, fear and anxiety and food aversions/eating disorders as significant problems for their child with EGID.

Of the school aged children, significant amounts were missing school; 13% had missed 9-20 weeks and 13% had missed more than 21 weeks.

One parent left a quote which we feel really reflects the findings of the survey:

“ there is a real feeling of trial and error with the treatment of this disease and I realise this is because little research has been done on it but as a parent trying to look after your child day in day out this approach is very hard work.”

Full Results

General:

50% said they had sons with the condition. 42% said they had daughters, the rest chose not to answer. The average current age of their child with the condition was 8.3 years. As babies, 29.2% of the children were breast fed, 20.8% were bottle fed and 44% were mixed fed.

Family history

Interestingly 30% of respondents have more than 1 child with EGID – in fact 20.8% said they have 2 kids with it and 10% have 3 kids with it.

The prevalence of related conditions was quite high amongst parents and siblings as shown below

	Parents	Siblings
Asthma	33%	21%
Hay fever	56%	29%
Food allergies / intolerances	48%	33%
Eczema	42%	29%
EGID	4%	30%
Other gastro problems incl: IBS, Crohn's	44%	17%

First signs of illness

54% of respondents said their child first became ill within 0-3 months from birth. 19% became ill at 4-12months, 8% became ill at 1-2 years and 8% said their child first became ill between 5 and 10 years of age.

Parents rated the severity of their child's symptoms before diagnosis and the results were (1 mild - 5 severe):

Stomach pain	4.4
Poor sleep	4
Stomach bloating	4
Tiredness and exhaustion	3.9
Constipation	3.9
Vomiting	3.8
Poor appetite	3.8
Diarrhea	3.8
Acid reflux	3.7
Food/drink refusal	3.7
Joint and limb pain	3.6
Passing mucus in stools	3.6
Failure to thrive	3.4
Difficulty swallowing	3.3
Passing blood in stools	3.1
Malnutrition	3.0
Mouth ulcers	3.0

Pain was rated as the most severe symptom.

Parents also listed other medical problems that they believed were related to their child's EGID and these are listed here:

Reflux, asthma, hyper mobility, arthritis, headaches, Reynaud's, psoriasis, challenging behaviour, Ehlers-Danlos 3, Enuresis, anaphylaxis, persistent chesty cough, poor sleeping and feeding, pain in feet and joints, congenital sucrase isomaltase deficiency, glue ear and persistent blocked nose, skin rashes, hypermobility.

Getting a Diagnosis:

We looked at how long it was taking for children to get a diagnosis and found that for 15% it took up to 5 months, for 4% it took 6-12 months, for 23% it took between 1 and 2 years, for 21% it took 3-5 years and for 23% it took over 5 years.

Diagnosis by was following an endoscope in 77% of cases but 17% said it was by diagnosed/suggested from symptoms.

77% of parents said the diagnosis was made by a consultant /paediatrician that were based at a hospital that was not local to them.

In order to get a diagnosis, most of the families in our survey said they had to see more than one consultant / paediatrician. In fact, 14.6% of these had to see 2 consultants, 31% had to see 3, 8.3% had to see 4 and 17% had to see more than 5 before they got a diagnosis!

Misdiagnosis

Before a correct diagnosis, many families were given other incorrect diagnoses and these are all listed below:

Reflux and 'over anxious' mother were mentioned most frequently. Other things included: milk allergy, Munchausen's, Crohn's disease, ulcerative colitis, pyloric stenosis, food intolerance, celiac disease, abdominal migraine, chronic fatigue syndrome, colic, stress, psychological, IBS, unknown allergies, constipation, cystic fibrosis, mega colon, delayed motility, toddler diarrhoea, attention seeking baby.

Illnesses

60% said their child gets ill more often than their peers and 56% said it takes their child longer to recover from illnesses than their peers.

Of those children on prophylactic antibiotics, 12% said it helped a little, 4% said it helped a lot and 8% said it didn't help at all.

Drug Treatments

We asked parents which drug treatments their child was on and the following were the results:

Antihistamines	54%
Other medications for related symptoms	48%
Special milks / formulas	42%
Vitamins / supplements	37%
Amino-salicyclates	23%
Sodium cromoglicate	27%
Prophylactic antibiotics	23%
Immunosuppressant's	21%
Steroids	19%
Leukotriene inhibitors	17%

We asked families how many flare ups their child was averaging a year and found that 8% were getting 1-2 a year, 25% were getting 3-6 a year, 19% were getting 7-12 a year, 6% were getting 13-20 a year and a shocking 21% were experiencing more than 21 flare ups a year!

We asked how many courses of steroids each child had been given in the last 12 months and found that 15% had 1 or 2 courses, 6% had been given 3-4 courses and 8% had more than 5 courses.

42x% of respondents said their child was experiencing side effects from their drug treatment. The kinds of side-effects varied and are summarised below:

Diarrhoea, allergic reaction, ulcers, thrush, tummy ache, shaking, headaches, sickness, blisters, fatigue, behaviour issues, drowsiness, irritability, weight gain, reflux, stunted growth, mood changes, depression, loss of appetite, hair loss, nausea, bloating, sleep disturbance, immunosuppression.

Dietary Treatments

Most children were on a dietary change of some sort and the most commonly excluded foods were dairy, soya, egg and wheat (in that order).

Other more unusual foods that children were having to avoid included: tomato, citrus fruit, sugar, fish, beef, shellfish, apple, carrot, corn, rye, maize, vinegar, tapioca, meat, rice, sesame, all grains, additives, preservatives, cabbage, banana, peas, beef and much more.

69% of the children in our survey were being fed orally, 10% by gastroscopy and 2% by NG and 2% by IV/TPN.

Treatment Success

We asked parents to rate the improvement their child had made since receiving treatment for EGID. 15% had got worse, 12.5% were just the same, 21% had improved a little, 40% had improved a lot or significantly.

We asked parents which of their child's symptoms haven't improved much since starting treatment and the results showed that the 12 most frequent symptoms that haven't improved are (in order); tiredness and exhaustion, joint and limb pain, poor appetite, stomach bloating, poor sleep, mucous in stools, recurrent infections and illnesses, stomach pain, emotional and sensitivity problems, food/drink refusal, mouth ulcers, behavioural problems.

We asked parents if their child has needed any surgery in relation to their EGID and the following:

G-Peg insertion, pyloric stenosis following misdiagnosis, polyp removed and bowel repaired and biopsies being taken.

Medical Information and Support

We asked parents overall if they are happy with the treatment their child is currently receiving and 71% said yes.

Parents were asked to rate the support they have received from medical professionals since their child became unwell. 1 was not happy and 5 was very happy. The results were:

Midwife	1.6
Health visitor	1.8
Social services (if applicable)	1.9
GP	3.3
Dietician	2.6
Speech and language therapist (if applicable)	3.2
Local paediatrician / consultant	2.8
Specialist gastro consultant/ paediatrician	3.8
Feeding team / specialist	2.4

We asked parents if they've ever had to pay privately to get medical help and support because they couldn't get it through the NHS and 29% said yes they had.

Only 31% of respondents successfully receive carer's allowance.

85% of respondents said at some point they had felt they weren't believed about their child's medical problems.

Parents rated how severely (on scale of 1-5 with 5 being severe) they had felt the following symptoms and problems during their child's illness:

Stress and Anxiety	4.3
Distress from lack of information from medical profession	4
Distress from lack of support from medical profession	3.8
Loneliness	3.3
Depression	3
Distress from lack of emotional support from family/friends	2.8
Marital difficulties due to stress of caring for an ill child/children	2.7
Low self-esteem	2.6

We asked how the child with EGID has been affected by their illness and parents used a scale of 1-5 where 5 is severe. The average ratings were:

Stress	3.5
Fear and Anxiety	3.3
Food aversions and eating disorders	3.2
Behavioral difficulties	3.1
Low self esteem	2.4
Bullying in relation to their medical problems (where relevant)	1.7

We wanted to know how EGID is affecting children's leisure time and parents listed the things that their child struggles to do. Some of these things were:

- Struggle with swimming and classes due to tiredness and achy legs
- Eating out affected
- Used to get contact reactions in play areas
- Can't manage contacts sports
- Too tired for any physical activities
- Can't go to social events, on school trips or sleepovers
- Can't swim during flare up as swallowing water will make him sick
- Too achy
- Cant' manage hobbies or clubs
- Everyday life. Eating with friends, pain in joints and he missed 50% school last year
- Can't do P.E
- Still needs a pushchair
- Struggles with school/preschool
- Pain and weakness limits activities

We asked parents how much school their child had missed during the last academic year due to this disorder and found that 23% weren't yet at school but the rest had all missed significant amounts of school. 17% had missed up to 2 weeks. 15% had missed 3-8 weeks, 13% had missed 9-20 weeks and 13% had missed more than 21 weeks.

46% of school aged respondents said their child 'always' or 'sometimes' receives adequate support from their school but 33% said they never or only occasionally receive adequate support.

15% of children had a statement of special education needs. Of those whose children miss enough school to need support from the local authority, approximately 21% said they never or only occasionally got enough support.

What more can be done?

Parents were asked if there is more that the medical profession could do to help them, and their child cope with EGID. Commonly parents said they wanted more information, increased local knowledge and support and simply to be believed. Some of the answers are summarised below:

- “Someone should have listened to me years ago that my child was suffering”
- “ more support from my health visitor”
- “ there is a real feeling of trial and error with the treatment of this disease and I realise this is because little research has been done on it but as a parent trying to look after your child day in day out this approach is very hard work.”
- “Clearer guidance on practical things like food trailing would be really helpful”
- “The DR s are learning at the same pace as us parents. Research needs to be more public
- “Believed us!”
- “Support from health visitor and doctors knowing what egid is and how to care for children with it.”
- “GOSH could have given a lot more time and a better explanation, it was our local pediatrician who spent an hour with us explaining everything,”
- “Support nurse. In the community-- and at gosh..”
- “Have learnt more from Yahoo group than anywhere else. I still feel as though I don't really understand the disease, how her immune system is affected etc. “
- “Needed a more specialist dietician.”
- “speed, we still wait for long periods for changes to be made”
- “More awareness from local medics”
- “provide a detailed explanation of his condition and how to handle the behavior problems”
- “More understanding at the beginning before and just after diagnosis. Expert advice needs to be more accessible. Long waits for appointments.”
- “Listen and believe that our children are in pain”
- “From day 1 I was fobbed off as a "first time mother", had people more knowledge of EGIG it would have been found out sooner and stopped my daughter from being so sick and having terrible diarrhea”
- “I still feel the local hospital do not accept EGID as an illness.”
- “better diet support for extreme allergies”
- “EGID needs to be better publicized amongst health professionals to increase understanding and awareness”
- “...GOS should educate local consultants and GP’s so children have the correct back up locally”
- “...need specialist food on prescription”
- “ I have cried so many tears because of the lack of support from the medical profession”
- “ recognize the pain my daughter is suffering and do more to help us”
- “..understand and believe the child and family, PLEASE”