

# ESPGHAN PAC

*Winter Council Update*

# 2020

# KEY COMMUNICATIONS HIGHLIGHTS 2019

**958** ITEMS OF COVERAGE FOR EPSGHAN ANNUAL MEETING



**68** COUNTRIES REACHED THROUGH MEDIA COVERAGE



**1200+** VIEWS OF THE WORLD IBD DAY VIDEO



**3** MAJOR FEATURES SECURED INCLUDING WITH THE EUROPEAN MEDICAL JOURNAL

**14** NATIONAL SOCIETIES ENGAGED THROUGH HCP ADVICE GUIDES



**800+** ENGAGEMENTS WITH THE HCP ADVICE GUIDES



**299,400** TOTAL TWITTER IMPRESSIONS



**3000+** USES OF #WORLDIBDDAY FOR WORLD IBD DAY

# ACTIVITY:

# ESPGHAN 52<sup>nd</sup> ANNUAL MEETING

GLASGOW, UNITED KINGDOM  
JUNE 5-8, 2019

- PRESS OFFICE
- MEDIA DRIVES
- SOCIAL MEDIA CONTENT

## PRESS OFFICE

**28** PRESS REGISTRATIONS

**10** COUNTRIES

## MEDIA DRIVES

**2.9** BN OPPORTUNITIES TO SEE ESPGHAN IN THE MEDIA

**958** ITEMS OF MEDIA COVERAGE ACROSS

**68** COUNTRIES

## SOCIAL MEDIA

**85** LIVE TWEETS

**2000+** ENGAGEMENTS

**63,200+** IMPRESSIONS

 **ESPGHAN**

**52<sup>nd</sup> ANNUAL MEETING**

of the European Society for Paediatric  
Gastroenterology, Hepatology and Nutrition

# ACTIVITY:

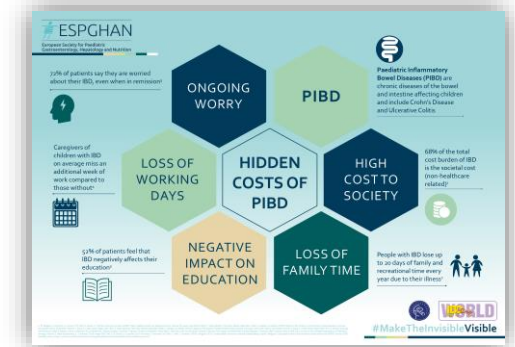
# WORLD IBD DAY

May 19, 2019

- MANIFESTO FOR CHANGE
- INFOGRAPHIC DEVELOPMENT
- SOCIAL MEDIA CONTENT
- MEP ENGAGEMENT
- PATIENT ORGANISATION ENGAGEMENT
- NATIONAL SOCIETY ENGAGEMENT
- MEDIA ACTIVITY

- Video translated into **5 languages**
- 1200+ views of the World IBD Day Video on YouTube
- Manifesto translated into **4 languages**
- 55+ manifesto engagements
- Infographic translated into **4 languages**
- 120+ Infographic engagements

- Support from 20 key stakeholders, including UEG, EFAD and ESPID across social media
- Shared on **3+ Member Society and Patient Organisation** websites
- 3000+ uses** of #WorldIBDDay and #MakeTheInvisibleVisible, including by MEP Daniel Dalton



TWEETS POSTED **33**

**3156** #WORLDIBDDAY MENTIONS

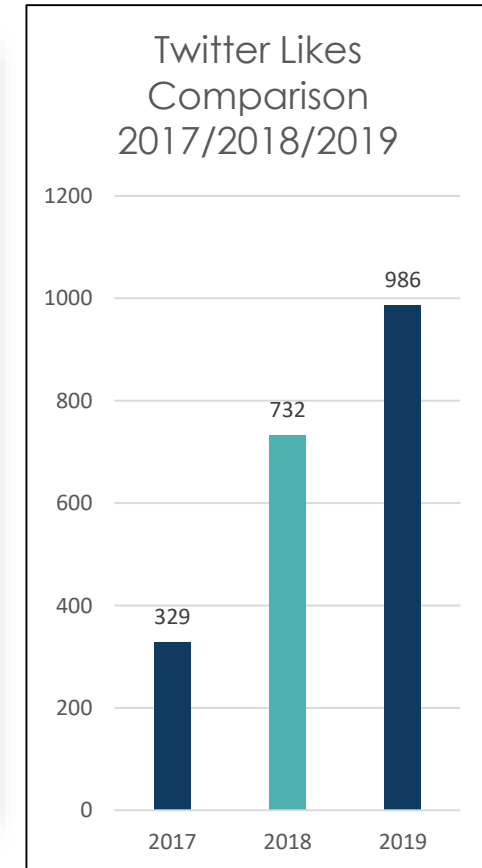
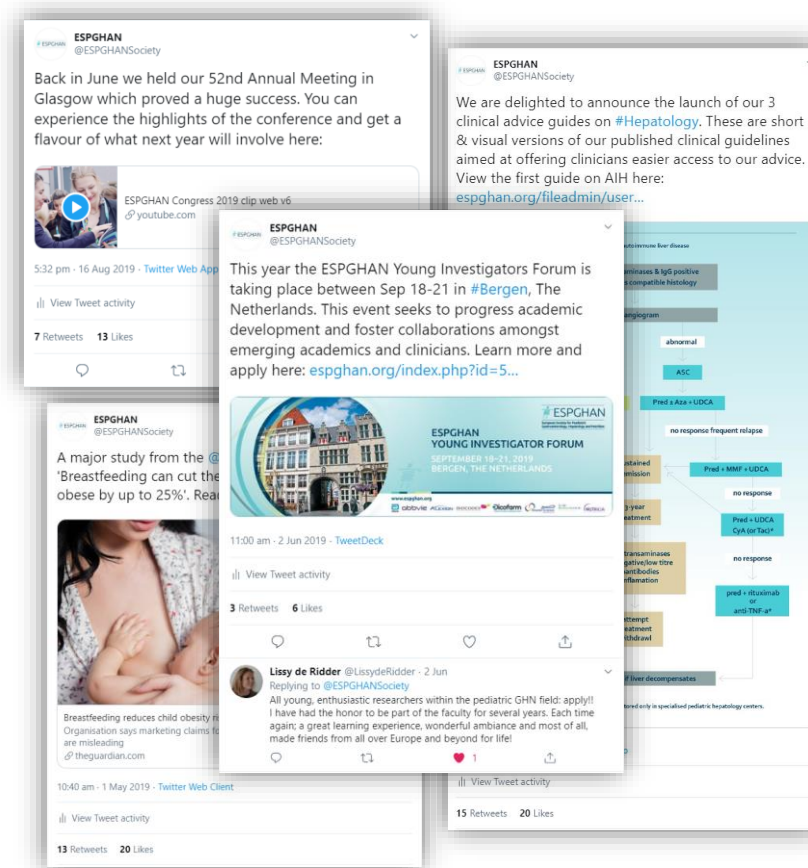
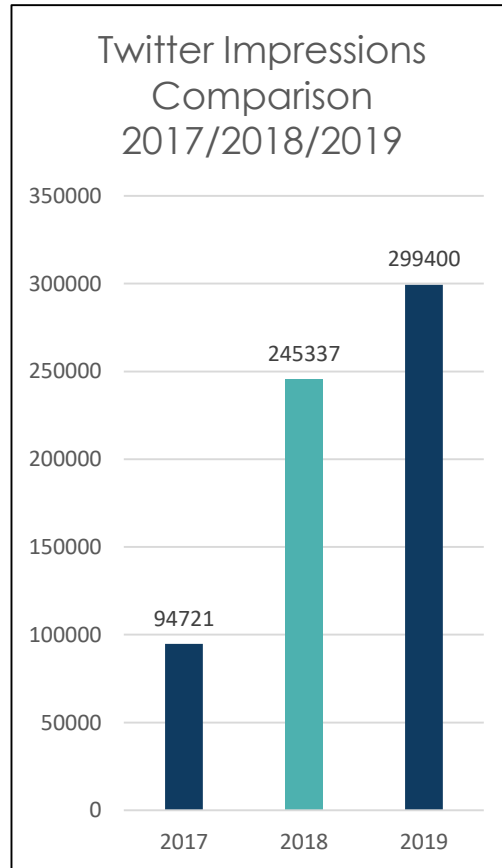
OPPORTUNITIES TO SEE **5,467,000+**

**858** TOTAL ENGAGEMENTS

# ACTIVITY:

# ONGOING SOCIAL MEDIA

- MANAGEMENT OF ESPGHAN TWITTER ACCOUNT
- ASSET AND CONTENT CREATION
- STAKEHOLDER ENGAGEMENT
- EVENT AND NEWS PROMOTION



TOTAL TWITTER IMPRESSIONS

299,400



# ACTIVITY:

# ONGOING PRESS OFFICE

- ONGOING PROACTIVE AND REACTIVE PRESS OFFICE

## Features & News Coverage

### Features secured in:

- European Medical Journal (EMJ)
- Northern Irish, Welsh and Scottish Healthcare Review
- Netdoctor

### News Coverage secured in:

- Irish Independent
- News Medical

## Independent.ie

Irish children consuming 250pc of recommended daily maximum of sugar

## EMJ

MAKING THE INVISIBLE VISIBLE: THE HIDDEN COST OF PAEDIATRIC INFLAMMATORY BOWEL DISEASE

05 DECEMBER 2019 | GASTROENTEROLOGY | DOWNLOAD AS PDF



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### Abstract

This year, the European Society for Gastroenterology, Hepatology and Nutrition (ESPGHAN) joined forces with the European Federation of Crohn's & Colitis Associations (EFCCA) to drive awareness of the hidden costs of paediatric inflammatory bowel diseases (IBD) and make the invisible visible. This feature puts the hidden cost of paediatric IBD in the spotlight and the author makes the case for policy makers to recognise the invisible cost of paediatric IBD. He pledges to take four key steps to reduce the burden of the diseases on society and improve the lives of children and their families.

## netdoctor

The telltale signs you might be gluten intolerant

As sales of gluten-free products continue to rise, we separate the wheat from the chaff.

By Claire Chamberlain, 20/05/2019



### PAEDIATRIC COELIAC DISEASE: A TALL ORDER?

Coeliac disease is a frequent and life-long autoimmune condition, caused by an abnormal reaction of the immune system to gluten – a group of proteins found in grains such as wheat, barley and rye – that are common in the European diet. Despite its significant prevalence, many people are unaware of just how common it has become. Luisa Mearin, Secretary of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition, investigates how by boosting our understanding, we can reduce complications and pave the way for a brighter future for our young patients dealing with it.



Luisa Mearin

**WHAT IS PAEDIATRIC COELIAC DISEASE?**  
Coeliac disease can occur at any age, including in babies during weaning (when gluten has been introduced in their diet), in children, and in adolescents. When a child with coeliac disease eats gluten, their immune system reacts by damaging the lining of the small intestine.  
Paediatric coeliac disease is now the most common food-related chronic disease among children in Europe, with one in 100 children in the majority of European countries, and in one of eight children in the USA. However, most children with coeliac disease are not properly diagnosed due to the complex clinical picture of the disease. (1) With the strong prevalence, intelligent paediatric coeliac disease has a large population at risk of developmental issues and long-term associated health complications.

It is urgent to raise awareness that paediatric coeliac disease was considered a rare condition among children until very recently. The reality is that it is a common entity among children of all ages, including adolescents, and this trend is likely to continue moving into the future.

**RISK FACTORS OF PAEDIATRIC COELIAC DISEASE**  
Coeliac disease is a hereditary autoimmune condition. It is a five-degree relative with the condition makes one up to at least 10 times more likely to have the disease if you are female. (4) Additionally, having type 1 diabetes, autoimmune thyroid disease, Williams syndrome, or autoimmune liver disease, increases the chance of having paediatric coeliac disease. (2)  
Until recently, we had no knowledge of how many paediatric coeliac disease from developing, finding an association with breast feeding (protective), selective or formula feeding, for instance. Prospective observational research projects have shown that it was possible to lower the risk by either a later introduction of gluten, or the dose of young children.  
Other national studies have also shown that the breast-feeding. However, more studies with paediatric coeliac disease indicate that there may be ways to lower the risk of developing the condition through the diet. New research presented at the 2019 European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) Annual Meeting held in June of this year suggested that high fibre intake during pregnancy reduces the risk of paediatric coeliac disease in children. (6) The Norwegian study, which covered over 100,000 children between 1995-2009, found that the risk of the condition was eight per cent lower per 10g increase in fibre intake during pregnancy. ESPGHAN look forward to

Further studies in this field. Secondary prevention by early diagnosis and treatment is also possible and as the prevalence we should look to drive this forward. Screening programmes for young children offer an effective step in achieving this.

**SIGNS AND SYMPTOMS OF PAEDIATRIC COELIAC DISEASE**  
Paediatric coeliac disease may present with a large variety of non-specific signs and symptoms. It is worth noting the importance of diagnosis among those children with histological symptoms, or all of those with chronic gastrointestinal malnutrition. (7) Symptoms will not necessarily be severe, and in fact many children with the condition only present mild symptoms, such as abdominal pain, constipation, occasional vomiting, and diarrhoea. (8)  
Key symptoms, which also act as the high-risk complications associated with paediatric coeliac disease, include chronic or intermittent diarrhoea, growth problems, weight loss, delayed puberty, anaemias, iron-deficiency anaemia, nausea or vomiting, chronic abdominal pain, osteoporosis, chronic stomatitis, chronic constipation, chronic fatigue, recurrent mouth ulcers, and abnormal liver tests.

# ACTIVITY:

# ESPGHAN LOBBY DAY

- ORGANISATION OF 4 MEP MEETINGS
- DEVELOPMENT OF ESPGHAN LOBBY MANIFESTO
- SECURED SUPPORT OF 4 PATIENT ORGANISATIONS

## CALLS TO ACTION INCLUDING:

- Sub-specialty recognition
- Earlier diagnosis
- Effective transitional care
- Paediatric care in a paediatric setting

## MEP MEETINGS

### MEPs MET:

- Manuel Pizzaro (Por)
- Klara Dobrev (Hun)
- Sara Weiner (Aus)
- Petra De Sutter (Bel)

### FORWARD ACTIONS:

- ESPGHAN to provide suggestions for new Parliament Childhood Guarantee
- Parliament's Internal Market committee to consider sub-specialty recognition



# ACTIVITY:

# HCP ADVICE GUIDES – HEPATOLOGY

- EDITED AND CONDENSED PUBLISHED GUIDELINES INTO NEW USER FRIENDLY, VISUAL FORMAT

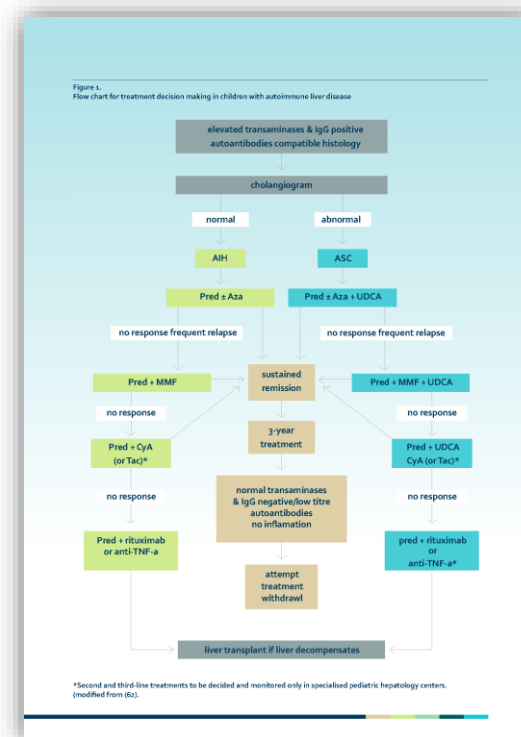
- LIAISON WITH EXPERTS

- DEVELOPMENT OF DESIGN AND GRAPHICS

- DISTRIBUTION TO NATIONAL, HEPATOLOGY AND SISTER SOCIETIES, AND PATIENT ORGANISATIONS

- TRANSLATIONS AND DISCLAIMER BADGE

## Diagnosis and Management of Paediatric Autoimmune Hepatitis (AIH)



## Diagnosis and Management of Paediatric Autoimmune Sclerosing Cholangitis (ASC)

**Table 1. Proposed scoring criteria for the diagnosis of juvenile autoimmune liver disease**

Feature	Child/Adol.	AIH	ASC
Yellowish discoloration	0-2	2	2
Abnormal ALT	1-2	2	2
Abnormal ALP	0-2	2	2
Abnormal GGT	0-2	2	2
Abnormal GAMA1	1-2	2	2
Abnormal ALP > 2.5 x ULN	0-2	2	2
Abnormal GGT > 2.5 x ULN	0-2	2	2
Abnormal ALP > 2.5 x ULN & GGT > 2.5 x ULN	0-2	2	2
Abnormal ALP > 2.5 x ULN & GAMA1 > 2.5 x ULN	0-2	2	2
Abnormal ALP > 2.5 x ULN & GAMA1 > 2.5 x ULN & GGT > 2.5 x ULN	0-2	2	2
Abnormal ALP > 2.5 x ULN & GAMA1 > 2.5 x ULN & GGT > 2.5 x ULN & Abnormal histology	0-2	2	2
Abnormal histology	0-2	2	2
Presence of autoantibodies ANA, ASMA,AMA	0-2	2	2
Presence of autoantibodies ANA/AMA/ASMA	0-2	2	2
Presence of autoantibodies ANA/AMA/ASMA & Abnormal histology	0-2	2	2
Presence of autoantibodies ANA/AMA/ASMA & Abnormal histology & Abnormal ALP > 2.5 x ULN	0-2	2	2
Presence of autoantibodies ANA/AMA/ASMA & Abnormal histology & Abnormal ALP > 2.5 x ULN & Abnormal GGT > 2.5 x ULN	0-2	2	2
Presence of autoantibodies ANA/AMA/ASMA & Abnormal histology & Abnormal ALP > 2.5 x ULN & Abnormal GGT > 2.5 x ULN & Abnormal GAMA1 > 2.5 x ULN	0-2	2	2
Presence of autoantibodies ANA/AMA/ASMA & Abnormal histology & Abnormal ALP > 2.5 x ULN & Abnormal GGT > 2.5 x ULN & Abnormal GAMA1 > 2.5 x ULN & Abnormal ALP > 2.5 x ULN & Abnormal GGT > 2.5 x ULN & Abnormal GAMA1 > 2.5 x ULN & Abnormal histology	0-2	2	2

**Juvenile AIH vs PSC**

Sclerosing cholangitis in childhood/onset is widely referred to as PSC, borrowing the adult definition. There are important differences, however, between adult PSC and juvenile sclerosing cholangitis. Other shared conditions, for example, underlying genetic defects in the ABCG5/ABCG8 gene, are being increasingly recognized as a possible cause of small duct sclerosing cholangitis in both children and adults. Sclerosing cholangitis may also complicate a wide variety of disorders, including primary and secondary immunodeficiencies, Langerhans cell histiocytosis, psoriasis, cystic fibrosis, reticulum cell sarcoma, and sickle cell anemia. An overlap syndrome between AIH and sclerosing cholangitis (ASC) is more common in children than in adults. Only in those paediatric patients in whom sclerosing cholangitis occurs without any of the above defining features, the name of "primary" would be appropriate.

\*Primary\* denotes ignorance about aetiology and pathogenesis, whereas in paediatrics, there are well defined forms of sclerosing cholangitis, including biliary atresia and autosomal recessive neonatal sclerosing cholangitis (DCCDC-2 cell-amyloid).

IBD is strongly associated with paediatric sclerosing cholangitis, and studies have shown it is associated with 10-20% of cases. IBD can precede the diagnosis of liver disease by many years, be diagnosed at the same time or during follow-up.

**CLINICAL FEATURES OF ASC**

- 60% of patients are male
- Abnormal (pale, weight loss, and interstitial pulmonary) are frequent presenting symptoms in both ASC and AIH.
- 90% of children with ASC have greatly increased serum GGT levels.
- Almost all ASC patients are seropositive for AMA and/or AMA.
- 75% pANCA is present in 25% of patients with ASC.
- 65% compared to 45% of patients with AIH.
- IBD affects around 45% of children with ASC and 20% with AIH.
- 90% and about 20% with AIH.

**ESPGHAN**

## Liver Transplantation (LT) for Paediatric Autoimmune Liver Disease

### Liver Transplantation (LT) for Paediatric Autoimmune Liver Disease

The purpose of this guide is to outline the management issues related to LT and should be read in conjunction with the ESPGHAN Clinical Advice Guides on Autoimmune Hepatitis (AIH) and Autoimmune Sclerosing Cholangitis (ASC).

LT is a treatment option for AIH and ASC patients with end-stage chronic liver disease, hepatic malignancy, or intractable symptoms, as well as for AIH patients presenting with severe acute liver failure (ALF) responsive to steroid treatment.

**FACTS & STATS**

- AIH accounts for 3% to 6% of paediatric LTs performed in Europe and the United States.
- 65% of patients with AIH receive LT.
- 70% of patients with AIH receive LT.
- AIH accounts for 3% to 6% of paediatric LTs performed in Europe and the United States.
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- 70% of patients with AIH receive LT.

**IDENTIFYING A RECURRENCE**

The diagnosis of recurrent AIH is based on the reappearance of clinical symptoms and signs, elevation of transaminase and IgG levels, autoantibodies, and interface hepatitis, along with response to prednisolone and azathioprine. Recurrent AIH is reported to develop less frequently in patients transplanted for ALF compared to those with a chronic presentation.

These criteria are essentially those included in the International Autoimmune Hepatitis Group (IAIHG) scoring systems used to diagnose AIH in the native liver. While not tested systematically for the diagnosis of recurrent AIH, they may provide a useful diagnosis in view of the similarity between AIH in the native liver and recurrent disease in the allograft.

Features reported to be associated with recurrence of AIH after LT are:

- possession of at least 2 autoantibodies (AMA, ANA, anti-LKM1, anti-SMA, anti-DNAse b, anti-gp100, anti-p200, anti-LGP3, anti-LGP5, anti-LGP6, anti-LGP7, anti-LGP8, anti-LGP9, anti-LGP10, anti-LGP11, anti-LGP12, anti-LGP13, anti-LGP14, anti-LGP15, anti-LGP16, anti-LGP17, anti-LGP18, anti-LGP19, anti-LGP20, anti-LGP21, anti-LGP22, anti-LGP23, anti-LGP24, anti-LGP25, anti-LGP26, anti-LGP27, anti-LGP28, anti-LGP29, anti-LGP30, anti-LGP31, anti-LGP32, anti-LGP33, anti-LGP34, anti-LGP35, anti-LGP36, anti-LGP37, anti-LGP38, anti-LGP39, anti-LGP40, anti-LGP41, anti-LGP42, anti-LGP43, anti-LGP44, anti-LGP45, anti-LGP46, anti-LGP47, anti-LGP48, anti-LGP49, anti-LGP50, anti-LGP51, anti-LGP52, anti-LGP53, anti-LGP54, anti-LGP55, anti-LGP56, anti-LGP57, anti-LGP58, anti-LGP59, anti-LGP60, anti-LGP61, anti-LGP62, anti-LGP63, anti-LGP64, anti-LGP65, anti-LGP66, anti-LGP67, anti-LGP68, anti-LGP69, anti-LGP70, anti-LGP71, anti-LGP72, anti-LGP73, anti-LGP74, anti-LGP75, anti-LGP76, anti-LGP77, anti-LGP78, anti-LGP79, anti-LGP80, anti-LGP81, anti-LGP82, anti-LGP83, anti-LGP84, anti-LGP85, anti-LGP86, anti-LGP87, anti-LGP88, anti-LGP89, anti-LGP90, anti-LGP91, anti-LGP92, anti-LGP93, anti-LGP94, anti-LGP95, anti-LGP96, anti-LGP97, anti-LGP98, anti-LGP99, anti-LGP100)
- the severity of pre-transplant inflammatory activity in the native liver at the time of LT.

Although early recidivism is not associated with immunosuppression and the risk of recurrence is a subject of systematic review reported that immunosuppression with either cyclosporine or tacrolimus did not influence the risk of recurrence.

**Recurrence of Autoimmune Hepatitis after Liver Transplantation**

AIH can recur in the allograft despite immunosuppression. Recurrent disease, particularly if not diagnosed and not treated promptly, may have serious consequences on graft function—requiring re-transplantation. As histologic evidence can precede clinical evidence of recurrence, it might be useful to include follow-up liver biopsy in the protocol for the management of patients transplanted for AIH.

**Treatment**

Most recurrent patients with recurrent AIH respond to azathioprine or prednisolone, or a combination, which should be implemented as soon as the diagnosis is made.

**Follow-up**

Early detection of recurrence should include monitoring of transaminase levels (ALT and AST) as well as response to the dose of corticosteroids and azathioprine, which should be implemented as soon as the diagnosis is made.

The reported recurrence rate in children is variable from 38-55% and depends on the criteria used for diagnosis. The immunosuppressive regimen, length of follow-up, and performance of "per protocol" biopsies.

The mean time from LT to recurrence is 5 years but may occur as early as 35 days after transplantation.



# ACTIVITY:

# SOCIAL MEDIA

- POSTED TWEETS TO LAUNCH AND PROMOTE ADVICE GUIDES
- LIKED GUIDES TO ENCOURAGE ENGAGEMENT WITH KEY STAKEHOLDERS

## ESPGHAN Launch tweets received:

- 3,131 Impressions
- 372 Engagements
- 90 Link clicks



## Recognised and shared by:

- United European Gastroenterology – who posted in support of the guides
- UEG Journal
- NGO SLAP (Save Liver Association for patients)
- Haemochromatosis UK
- Ukrainian Gastroenterological association
- Pedgastro



# ACTIVITY:

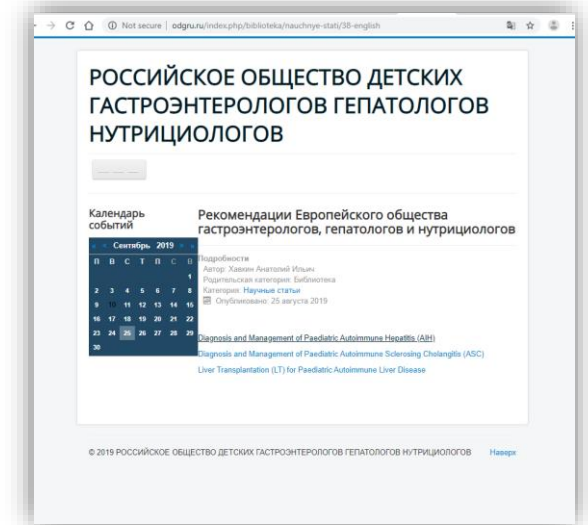
# KEY STAKEHOLDER ENGAGEMENT

- GUIDES DISTRIBUTED TO **114 BODIES** ACROSS NATIONAL & SISTER SOCIETIES, PATIENT ORGANISATIONS AND HEPATOLOGY SOCIETIES
- SYNOPSIS BREAKDOWNS OF EACH GUIDE PROVIDED ALONG WITH LINKS TO THE GUIDES

## Recognised and shared by:

- United European Gastroenterology
- European Society for the Study of the Liver
- The European Society for Primary Care Gastroenterology
- The European Foundation for the Care of Newborn Infants
- + 13 National Societies & 6 Patient Organisations

RUSPGHAN



SEGHP



# ACTIVITY:

# KEY STAKEHOLDER FEEDBACK

*“First of all I would like to congratulate ESPGHAN for your excellent work in the development of such important guidelines. From ESPCG we will be informing accordingly about them in order to have as much impact as possible. I would like to congratulate you for such a good initiative in sharing information among UEG societies”*

**Juan Mendive**  
President of ESPCG



*“I really appreciate this information. These three guides are very easy to read and I am sure they may improve our routine clinical practice. We will share these guidelines across our society website and newsletter”*

**Enriqueta Roman**  
President of SEGHN



# ACTIVITY:

# HCP ADVICE GUIDES – GI

- EDITED AND CONDENSED PUBLISHED GUIDELINES INTO NEW USER FRIENDLY, VISUAL FORMAT
- LIAISON WITH EXPERTS
- DEVELOPMENT OF DESIGN AND GRAPHICS
- DISTRIBUTION TO NATIONAL, GI AND SISTER SOCIETIES, AND PATIENT ORGANISATIONS
- TRANSLATIONS AND DISCLAIMER BADGE

## Common Gastrointestinal Problems in Children with Neurological Impairments (NI)

**Common Gastrointestinal Problems in Children with Neurological Impairments (NI): Evaluation, Treatment and Monitoring**

NI relates to disorders of the central nervous system, affecting speech, motor skills, vision, memory, muscle actions, learning abilities. Cerebral palsy is also considered within this guide as a major subgroup of NI.

NI frequently causes GI problems in children, most notably those with oral motor function and mobility conditions and can be extremely complex to manage.

In children with cerebral palsy, as many as 94% suffer from serious GI symptoms.

Such conditions can lead to insufficient caloric intake, a broad spectrum of GI and nutritional complications and associated clinical conditions, including respiratory infections and chronic aspiration, as well as a significant impact on quality of life for the patient and carer.

**Common Problems Contributing to Feeding Difficulties**

- Dental** Children with NI have a high incidence of occlusional problems contributing to feeding difficulties, including the stability of the jaw, lip tone and movement as well as problems with biting such as, tonic biting and over-biting.
- Children with NI have almost a 3-fold greater chance of having an occlusion abnormality.**
- Jaw issues** Instability, throbbing and retraction of the jaw, may cause difficulty taking food from a spoon, drinking and with swallowing.
- Bruxism** The habit of grinding of teeth, is a common occurrence in people with NI and in extreme cases, leads to tooth abrasion and flat biting surfaces. Habits such as pacifier sucking, finger sucking, biting objects and tongue interdigitation, are commonly associated with bruxism.
- Drooling of saliva (sialorrhea)** This appears to be a consequence of a dysfunction in the coordination of the swallowing mechanism and affects up to 60% of children with NI.

**Orthopaedic** Torticollis, kyphosis, scoliosis in children with NI, often leads to a kyphotic thoracic column and limited cervical spine, causing restrictions with the pharynx and laryngeal vestibule.

**Scoliosis** Many children also undergo surgery for scoliosis and can develop gastric dysmotility, thought to be related to the continuous traction applied to the spine, causing overstimulation of the sympathetic fibres. This, in turn, may cause postprandial autal hypomotility, delayed gastric emptying and, as a result, persistent nausea and discomfort eating. Secondary malnutrition can then further contribute to the GI motility disorder.

**ESPGHAN RECOMMENDATION** Careful attention needs to be paid to dental problems, general posture and orthopaedic issues in patients with NI, because these may contribute to feeding difficulties.

This guide, produced by the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), provides recommendations and a systematic approach for the care of paediatric patients with NI and should be read in conjunction with the ESPGHAN Clinical Advice Guides on:

- Methods and Recommendations for Nutritional Management and Requirements for Children with Neurological Impairments
- Dietetic Management of Children with Neurological Impairments

## Dietetic Management of Children with Neurological Impairments (NI)

**Dietetic Management of Children with Neurological Impairments (NI)**

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NI frequently causes GI problems in children, most notably those with oral motor function and mobility conditions and can be extremely complex to manage.

In children with cerebral palsy, as many as 92% suffer from serious GI symptoms.

Such conditions can lead to insufficient caloric intake, a broad spectrum of GI and nutritional complications and associated clinical conditions, including respiratory infections and chronic aspiration, as well as a significant impact on quality of life for the patient and carer.

Oral feeding is preferred in children with NI. The duration of a trial of oral feeding though depends on the child's age and severity of malnutrition.

**Type of Diet** The optimal energy content of oral feeds differs according to impairment, mobility and other factors.

To increase total energy content of meals without excessively increasing volume, additional fat or oils, dry milk powders, cream or ice cream may be supplemented.

Fibre intake should be normal e.g. age plus 5 g/day in children older than 2 years.

Composition of the diet should be discussed with specialist dietitians to modify textures and ensure safe and efficient food intake.

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- Methods and Recommendations for Nutritional Management and Requirements for Children with Neurological Impairments
- Common Gastrointestinal Issues for Children with Neurological Impairments: Evaluation, Treatment and Monitoring

## Recommendations for Nutritional Management of Children with Neurological Impairment (NI)

**Recommendations for Nutritional Management of Children with Neurological Impairment (NI)**

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**PATIENT MANAGEMENT GOALS**

- Regular nutritional assessment
- Optimize oral intake but where this is not possible prompt nutritional intervention with non-oral methods
- Multidisciplinary approach and follow-up
- Patients and/or carer given to be involved in decision making – particularly concerning gastrostomy feeding
- Primary focus on improving quality of life for both the child and their family
- Professional ethicist to assist decision making concerning invasive procedures where good ethical dilemmas

**UNDERNUTRITION WARNING SIGNS** In the absence of strict criteria to identify undernutrition, ESPGHAN recommends 1 or more of the following warning signs to aid identification:

- Physical signs of undernutrition, e.g. decubitus ulcers, skin problems and poor peripheral circulation
- Weight for age z score < -2
- Triceps skinfold thickness < 5th centile for age and sex
- Mid-upper arm fat or muscle area < 10th centile
- Faltering weight and/or failure to thrive

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- Dietetic Management of Children with Neurological Impairments
- Common Gastrointestinal Issues for Children with Neurological Impairments: Evaluation, Treatment and Monitoring

# ACTIVITY:

# SOCIAL MEDIA

- POSTED TWEETS TO LAUNCH AND PROMOTE ADVICE GUIDES
- LINKED GUIDES TO ENCOURAGE ENGAGEMENT WITH KEY STAKEHOLDERS

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## Recognised and shared by:

- United European Gastroenterology (UEG)
  - Who supported & shared the guides across Twitter & Facebook
- The Latin American Society for Paediatric Gastroenterology, Hepatology and Nutrition (LASPGHAN)



# ACTIVITY:

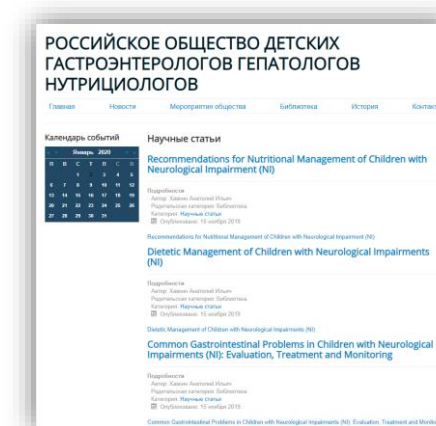
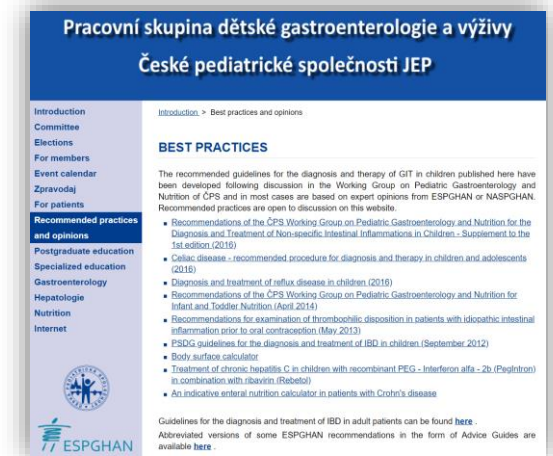
# KEY STAKEHOLDER ENGAGEMENT

- GUIDES DISTRIBUTED TO NATIONAL & SISTER SOCIETIES, PATIENT ORGANISATIONS AND GASTROENTEROLOGY SOCIETIES
- SYNOPSIS BREAKDOWNS OF EACH GUIDE PROVIDED ALONG WITH LINKS TO THE GUIDES

## Recognised and shared by:

- United European Gastroenterology (UEG)
- Commonwealth Association of Paediatric Gastroenterology & Nutrition (CAPGAN)
- + 10 National Societies:
  - BSPGHAN
  - SPGP
  - BeSPGHAN
  - Working Group for Paediatric Gastroenterology, Hepatology and Nutrition of the Czech Paediatric Society
  - RUSPGHAN
  - RoSPGHAN
  - DASPGHAN
  - Finnish PedGastros
  - Groupe Francophone d'Hepatology Gastroenterologie et Nutrition Pediatrique
  - Lithuanian Society for Paediatric Gastroenterology and Nutrition

## Working Group for PGHAN of the Czech Paediatric Society



## RUSPGHAN



# ACTIVITY:

# KEY STAKEHOLDER FEEDBACK

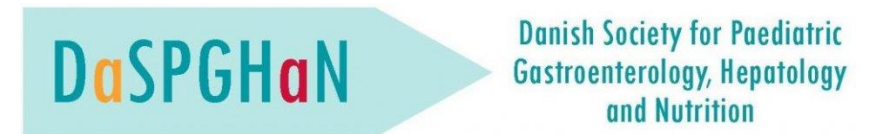
*“These look really excellent and helpful for neurodisability and general paediatricians, dieticians etc as well as gastroenterology teams. Yes we can alert and share with our BSPGHAN members. Thank you very much.”*

**Sue Protheroe,  
President of BSPGHAN**



*“Thanks for these guides within a very clinically relevant area. They appear to be very helpful. I have already shared them with relevant colleagues.”*

**Anders Paerregaard  
President of DASPUGHAN**



# ACTIVITY:

# KEY STAKEHOLDER FEEDBACK CONT.

*“Thank You very much for Your kind letter and those important guides and recommendations. We will forward Your letter to the pediatrics, pediatric gastroenterologists, pediatric neurologists and dietitians in Finland. I am sure this will enhance our understanding on and the management of these conditions.”*

**Taina Arvola,  
President of the Finnish PedGastros**



SUOMEN  
LASTENLÄÄKÄRIYHDISTYS RY  
BARNLÄKARFÖRENINGEN I FINLAND  
FINNISH PAEDIATRIC SOCIETY  
1930–2020

