ESPGHAN PAC

Winter Council Update

2020

ESPGHAN

Spink.

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

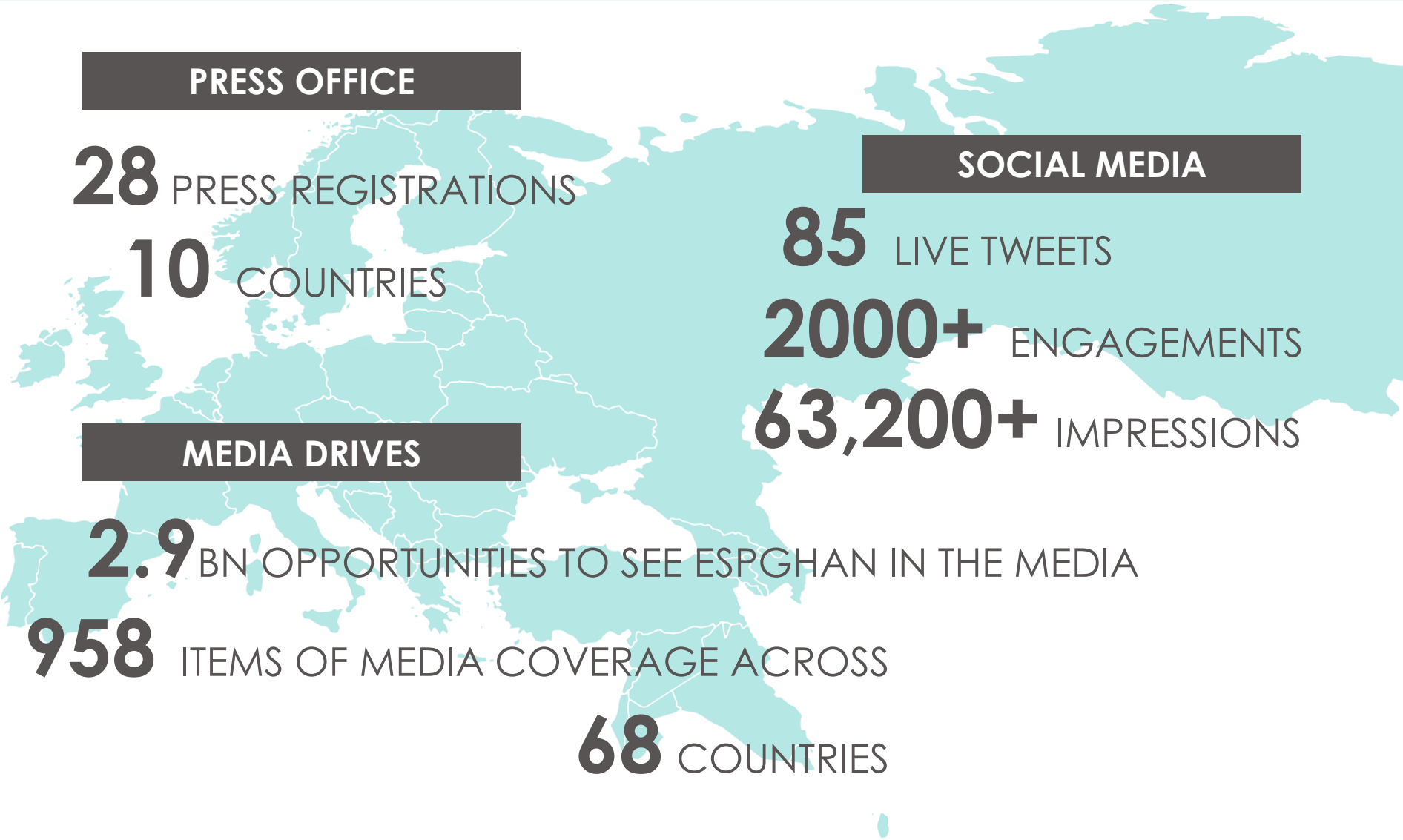
3000+ USES OF #WORLDIBDDAY FOR WORLD IBD DAY

ACTIVITY: ESPGHAN 52nd ANNUAL MEETING

GLASGOW, UNITED KINGDOM
JUNE 5-8, 2019

- PRESS OFFICE
- MEDIA DRIVES
- SOCIAL MEDIA CONTENT

ESPGHAN
52nd ANNUAL MEETING
of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition



PRESS OFFICE

28 PRESS REGISTRATIONS

10 COUNTRIES

SOCIAL MEDIA

85 LIVE TWEETS

2000+ ENGAGEMENTS

63,200+ IMPRESSIONS

MEDIA DRIVES

2.9 BN OPPORTUNITIES TO SEE ESPGHAN IN THE MEDIA

958 ITEMS OF MEDIA COVERAGE ACROSS

68 COUNTRIES

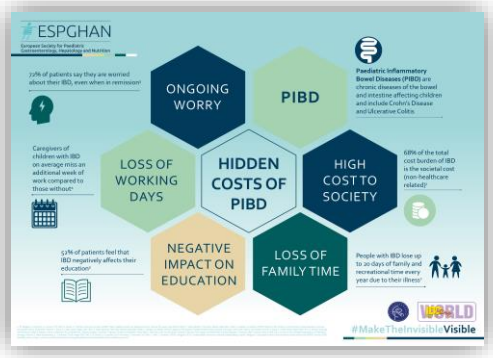
ACTIVITY: WORLD IBD DAY

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




Jan Král @KralJan · May 12
Brilliant Infographic. Celebrate World IBD Day on 19th of May and learn about Hidden Costs of IBD. Well Done! #UEGambassador #IBD #IBDadvocacy #WorldIBDDay2019 @my_ueg @ESPGHANSociety @D_ECCO_IBD

ESPGHAN @ESPGHANSociety
#WorldIBDday is just one week away. Our goal with @efcca this year is to #MakeTheInvisibleVisible by shining light on the hidden costs of #IBD. View our infographic to learn more about the impact this burden can have

TWEETS POSTED **33**

3156 #WORLDIBDDAY MENTIONS

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

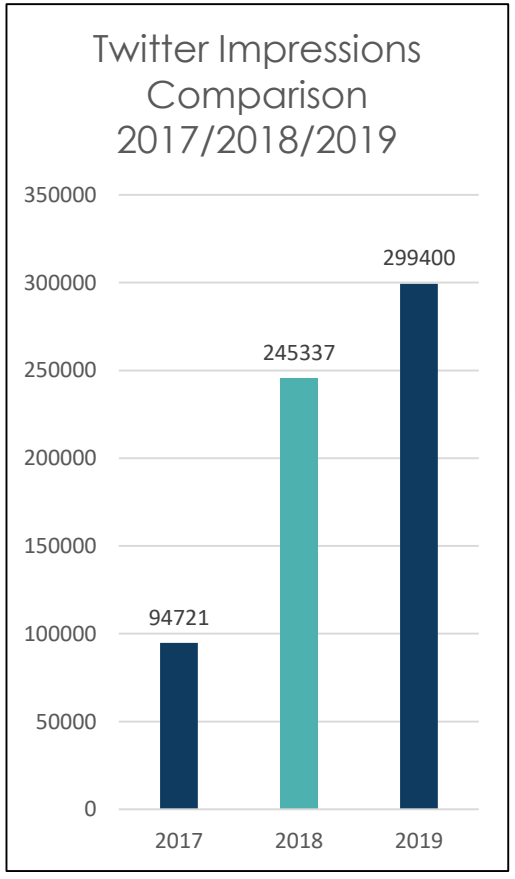
858 TOTAL ENGAGEMENTS

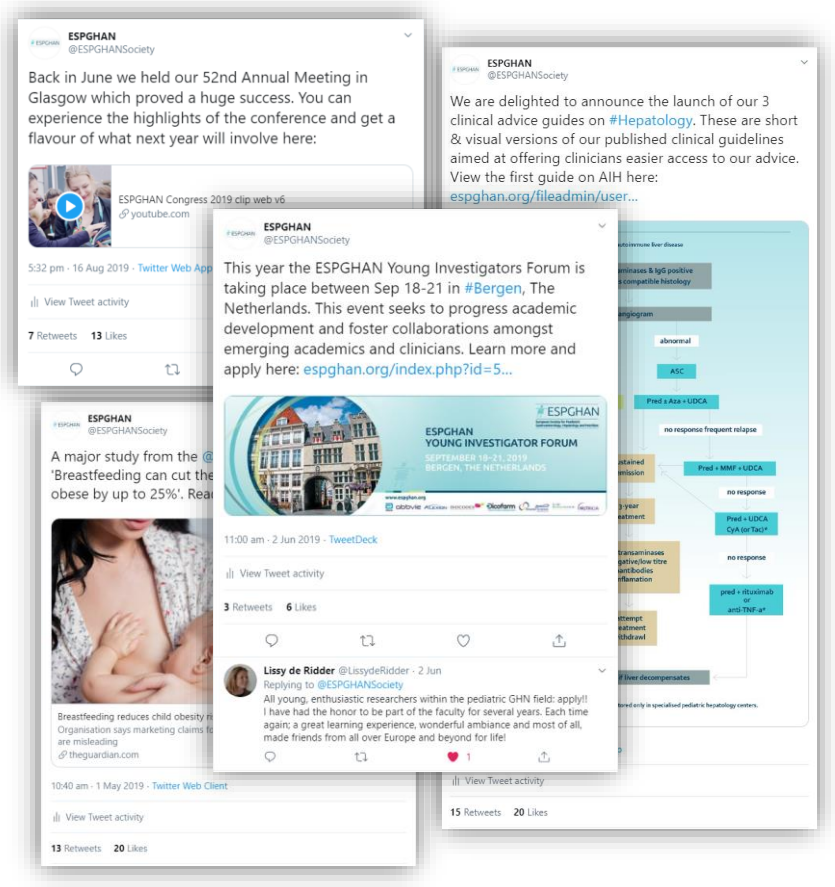
ACTIVITY: ONGOING SOCIAL MEDIA

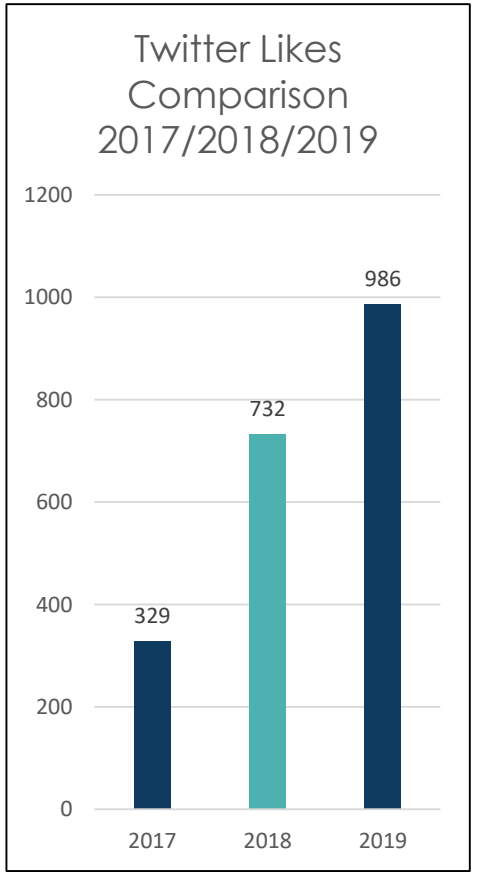
- MANAGEMENT OF ESPGHAN TWITTER ACOUNT
- ASSET AND CONTENT CREATION
- STAKEHOLDER ENGAGMENT
- EVENT AND NEWS PROMOTION

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

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 provided suggestions for new Parliament Childhood Guarantee
- Parliament's Internal Market committee to consider sub-speciality recognition


ESPGHAN

Improving Paediatric Health Across Europe

The European Union is home to over 106 million children* who make up the future of every European nation. This paper, by the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and its patient and parent association partners, identifies some of the key issues facing paediatric care and outlines the key steps that policy makers can proactively take to deliver better lifelong health across the continent.

The Priority Issues Facing Paediatric Care Across Europe

Paediatric care in a paediatric setting:
Across Europe, children are not always cared for in paediatric units - some are treated in adult hospitals and by adult doctors. All children should be seen by a paediatric specialist in a paediatric setting.

The importance of effective transitional care:
Transferring from paediatric to adult care is a critical time and, if not done properly, impacts education, leads to mental health issues and poor management of disease. All European countries should focus on improving transitional care arrangements.

Earlier diagnosis and treatment for a better quality of life:
Earlier diagnosis of chronic conditions leads to better growth and development, improved disease management, longer life expectancy, improved quality of life and lower healthcare costs in adult life. Diagnosing chronic conditions earlier in childhood should be a political priority.

Three Steps For MEPs

1. Raising awareness of early-years is critical to lifelong health: MEPs can help champion the need for better child health and shine a spotlight on the inequalities and disparities within Europe. For example the lack of recognition of paediatric sub-specialties and the lack of paediatric research.
2. A new EU health policy focused on healthier children: MEPs can hold the Commission to account to ensure that the new strategic plan for health fully recognises the importance of early years in delivering a healthier continent and improving childhood diagnosis, treatment and care.
3. Advocating for the voice of children: MEPs can meet & work with European and national paediatric medical societies and patient and parent organisations to ensure that children's voices are represented in all of the relevant decision-making and advisory bodies of the European Union.

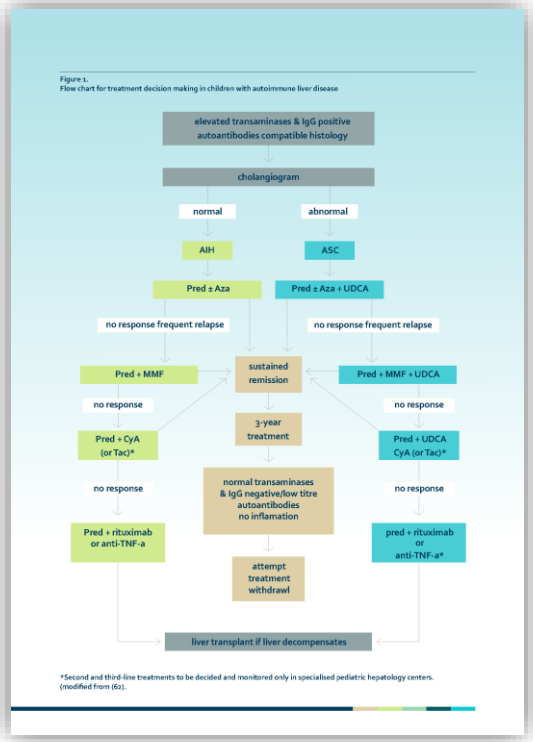
The European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) is a multi-professional organisation whose aim is to promote the health of children with gastrointestinal, liver and nutritional diseases, through knowledge creation, dissemination of science based information, promotion of best practice in the delivery of care and the provision of high quality education in Europe and beyond.

CONTACT US:
Prof Deirdre Kelly CBE | Chair of the ESPGHAN Public Affairs Committee | office@espghan.org

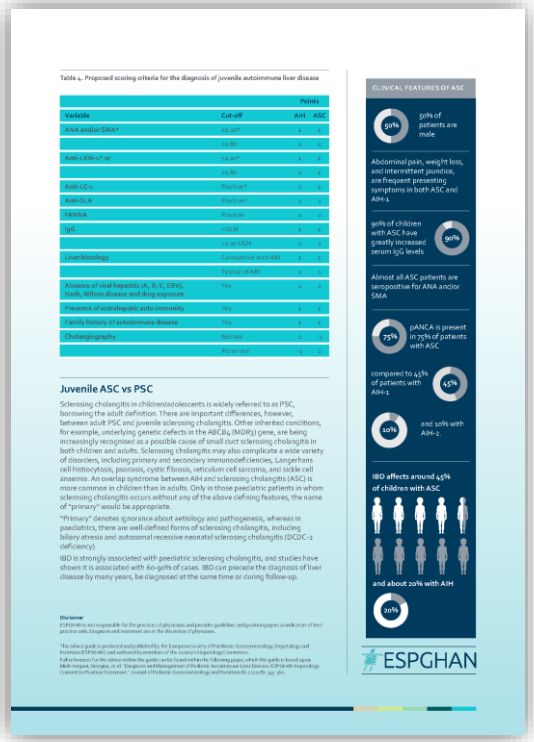
ACTIVITY: HCP ADVICE GUIDES – HEPATOLOGY

- 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

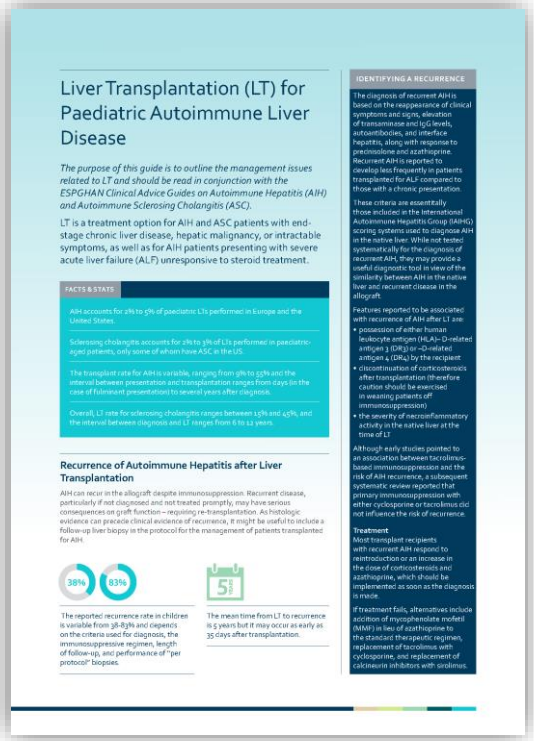
Diagnosis and Management of Paediatric Autoimmune Hepatitis (AIH)



Diagnosis and Management of Paediatric Autoimmune Sclerosing Cholangitis (ASC)



Liver Transplantation (LT) for Paediatric Autoimmune Liver Disease



ACTIVITY: SOCIAL MEDIA

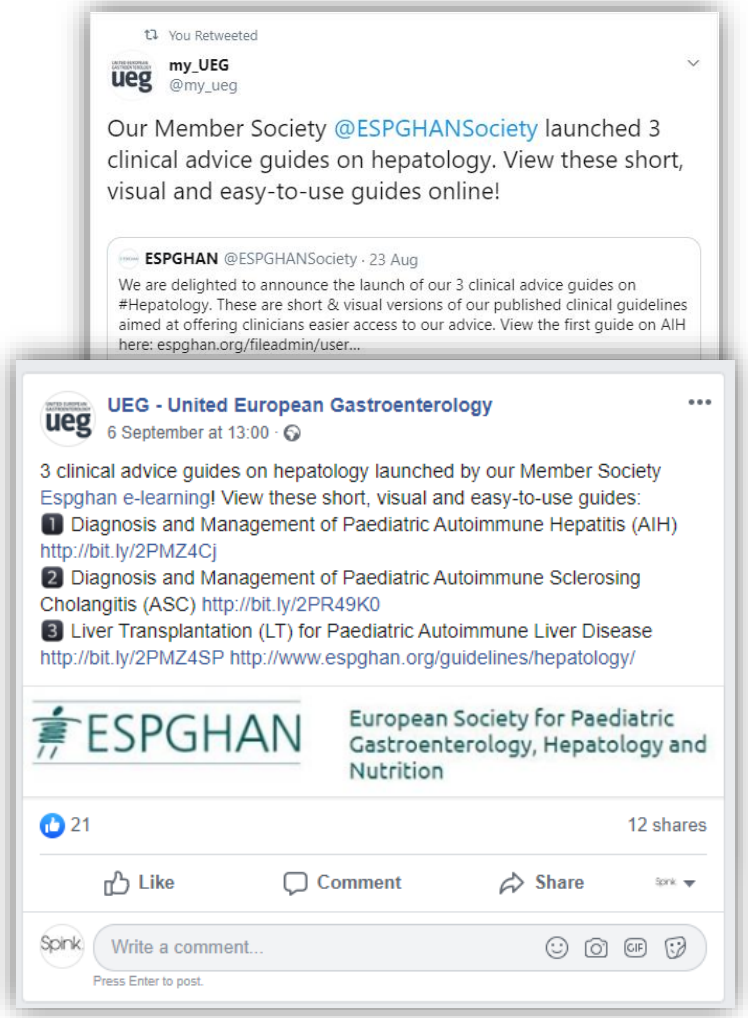
- POSTED TWEETS TO LAUNCH AND PROMOTE ADVICE GUIDES
- LNIKED GUIDES TO ENCOURAGE ENGAGEMENT WITH KEY STAKEHOLDERS

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



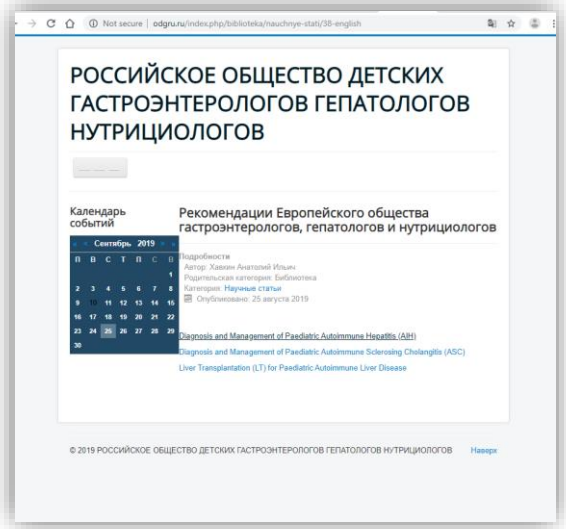
ACTIVITY: KEY STAKEHOLDER ENGAGEMENT

- 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



SEGHNP

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 SEGHNP

ACTIVITY:

HCP ADVICE GUIDES – GI

- EDITED AND CONDENSED PUBLISHED GUIDELINES INTO NEW USER FRIENDLY, VISUAL FORMAT
- LIAISON WITH EXPERTS
- DEVELOPMENT OF DESIGN AND GRAPHICS
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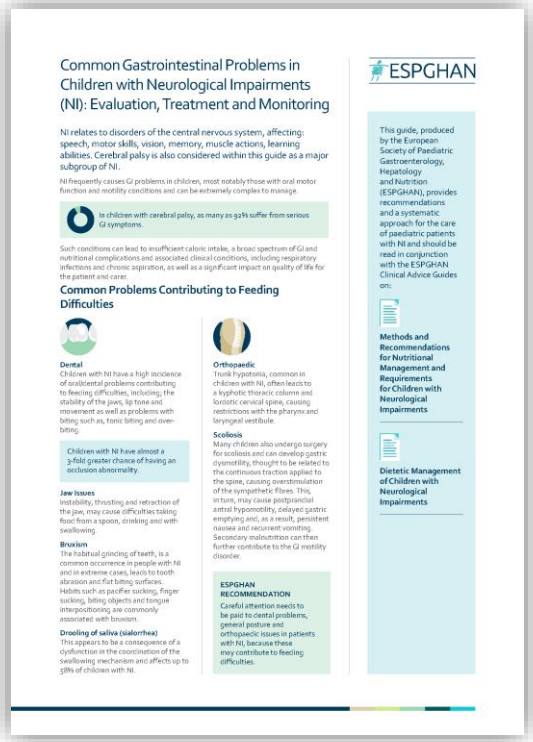
- TRANSLATIONS AND DISCLAIMER BADGE

Common Gastrointestinal Problems in Children with Neurological Impairments (NI)



Dietetic Management of Children with Neurological Impairments (NI)

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

ACTIVITY: SOCIAL MEDIA

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

ESPGHAN launch tweets received:

- **6400+** Impressions
- **430+** Engagements
- **100+** Link clicks

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)

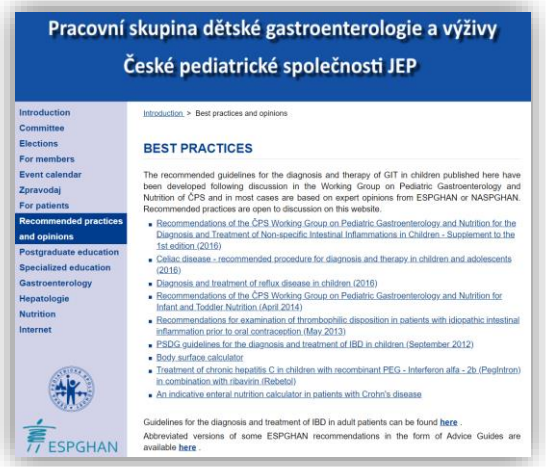
ACTIVITY: KEY STAKEHOLDER ENGAGEMENT

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

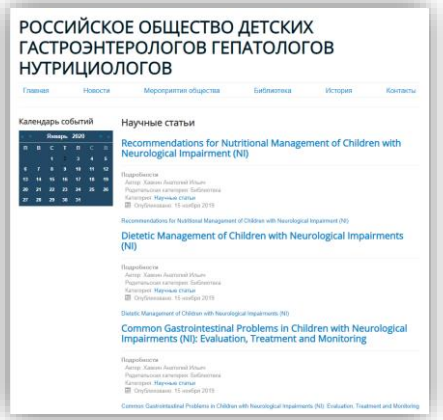
Recognised and shared by:

- 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'Hepatologie 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 DASPGHAN

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