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 52nd 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

▪ PRESS OFFICE
▪ MEDIA DRIVES
▪ SOCIAL MEDIA

CONTENT
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

#WORLDIBDDAY MENTIONS 3156

OPPORTUNITIES TO SEE 5,467,000+

TOTAL ENGAGEMENTS 858
ONGOING SOCIAL MEDIA

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

TOTAL TWITTER IMPRESSIONS
299,400

Twitter Impressions Comparison 2017/2018/2019

Twitter Likes Comparison 2017/2018/2019
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
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
- LINKED 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
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
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:**

- **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**

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**HCP ADVICE GUIDES – GI**

**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)**

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

- Malnutrition, malabsorption, constipation, diarrhea, feeding issues, difficulty swallowing, vomiting
- Nutritional and metabolic abnormalities

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

- Nutritional component of the medical management of children with neurological impairments
- Feeding issues, difficulty swallowing, constipation, diarrhea, malnutrition, malabsorption

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

- Identification of nutritional and metabolic issues
- Feeding issues, constipation, diarrhea, malnutrition, malabsorption

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Common gastrointestinal problems in children with neurological impairment (NI) include issues such as malnutrition, malabsorption, constipation, diarrhea, feeding difficulties, and difficulty swallowing. Nutritional and metabolic abnormalities are also prevalent. The dietetic management of children with neurological impairments focuses on the nutritional component of their medical management, addressing feeding issues, constipation, diarrhea, and malnutrition, malabsorption. Recommendations for nutritional management emphasize identifying nutritional and metabolic issues and addressing feeding difficulties, constipation, diarrhea, and malnutrition, malabsorption.
ACTIVITY: SOCIAL MEDIA

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

**ESP GHAN 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
“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.”

Anders Paerregaard
President of DASPGHAN

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

Sue Protheroe,
President of BSPGHAN
“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 PedGastos