



European Society for Paediatric
Gastroenterology, Hepatology and Nutrition

ESPGHAN

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Gastroenterology, Hepatology and Nutrition

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1201 Geneva, Switzerland
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Working Group - Report for GI Committee Strategy Day

Working Group Title: Polyposis working group

(date of completion 18 Aug 2024 Hyer)

Working Group Members and Mandates

Name	Positions held within WG (e.g. Secretary treasurer etc.)		Dates held of these positions	
	2015	2015		
Warren Hyer	2015	2015	chair and convenor	2015 - current
Dominique Schluckebier	2023	-	Deputy chair	2024
Shlomi Cohen	2015	2015	R and D and Registry	2024-current
Andrew Latchford	2016	2016	InSight representative and guideline advisor	2016-current
Carol Durno	2017	2017	NASPGHAN representative and guideline advisor	2023
Thomas Attard	2017	2017	NASPGHAN representative and core group	2023
Avi Lemberg	2024		Australia Representative	2024
Philip Robinson	2024		Young ESPGHAN rep	
Mike Thomson	2015	2015	Endoscopy Working group lead and WG advisor	2023
Fiona Cargill Marin	2024	2024	AHP representative	
Johannes Spalinger	2015	2015	Member, contributor	-
Jerome Viala	2015	2015	Member, contributor	-
Merit Tabber	2018	2018	Member, contributor	-
Emmanual Mas	2017	2018	Link to GIC	2023
Panayiota Protopapa	2022	2022	Organiser endoscopy training	2023
Doug Fishman	2019	2022	Endoscopy advisor/lead	2023



Filippo torroni	2023	-	Member, contributor	-
Renato Tambucci	2023	-	Member, contributor	-
Luigi Delloglio	2023	-	Member, contributor	-
Victor manuel navas-lopez	2023	-	Member, contributor	-
Ari Silbermintz	2023	-	Member, contributor	-
Oscar Segarra	2023	-	Member, contributor	-
Tamara Caldaro	2023	-	Member, contributor	-
Anastasia Konidari	2023	-	Member, contributor	-
Matilde Pescarin	2023	-	Member, contributor	-
Dominique Schluckebier	2023	-	Member, contributor	-
Katrien Mertens	2023	-	Member, contributor	-
Mordechai Slae	2023	-	Member, contributor	-
Dariia Voroniak	2023	-	Member, contributor	
Oren Leder	2023	-	Member, contributor	
Christos Tzivinikos	2023	-	Member, contributor	
Anca Miu	2023	-	Member, contributor	
Elizabeth Hechavarria	2023	-	Member, contributor	
Vasiliki Spyropoulou	2023	-	Member, contributor	
Usha Krishnan	2023	-	Member, contributor	
Marcus Auth	2016	2016	Member , contributor	-
Joseph Machtu	2024		Member , contributor	
Jan Bukowski	2024		Member , contributor	



Duypu Skender	2024		Member , contributor	
Thomas Kriser	2024		Member , contributor	
Geta Cowbelli	2024		Member , contributor	
Tomaz krencnik	2024		Member , contributor	
Noam Zevit	2024		Member , contributor	
Alex krauthammer	2024		Member , contributor	
Anan Martinex	2024		Member , contributor	
Yona Amar	2024		Member , contributor	
Kelissa Ilhan	2024		Member , contributor	
Krasimmira volera	2024		Member , contributor	
Hristo naydenov	2024		Member , contributor	
Alex nedelcheva	2024		Member , contributor	
Paulo de Angelis	2024		Member , contributor	
Maria Pastore	2024		Member , contributor	
Filippo Torrini	2024		Member , contributor	



Summary of Activities in 2024

A. WG meetings (date and any main points/activities)

(one table per meeting – please just copy and paste the tables as often as needed)

Meeting	ESPGHAN 2024
Location	Milan
Date	May 24
Main Points / Activities	Polyposis SIG WG meeting Day 1 – 32 attendees Polyposis clinic session Day 4, last session of the meeting. Presenting work in new aspects of Paediatric polyposis (63 participants despite being the last session of the meeting) Highest score abstract presentation by Cohen et al

Meeting	ESPGHAN Polyposis SIG core group
Location	On line
Date	Aug 24
Main Points / Activities	Meeting of core group to look at this years research priorities

Meeting	InSight
Location	barcelona
Date	June 24
Main Points / Activities	Hyer and Latchford presenting ESPGHAN successes to the International Group on inherited cancers. Seeking a paediatric session for Meeting 2026



B. Educational activities

(i) Educational Events (if applicable)

(one table per event – please just copy and paste the tables as often as needed)

Full Event Name	ESPGHAN 2024
Location	Milan
Date	May 24
Organizer	ESPGHAN
Email Organizer	
EPP	<input type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> No
more information if available	<p>Polyposis SIG WG meeting Day 1 – 32 attendees Polyposis clinic session Day 4, last session of the meeting. Presenting work in new aspects of Paediatric polyposis (63 participants despite being the last session of the meeting) Highest score abstract presentation by Cohen et al</p> <p>Presenting work in new aspects of Paediatric polyposis (63 participants despite being the last session of the meeting) Highest score abstract presentation by Cohen et al</p>

Full Event Name	Insight -
Location	Barcelona
Date	June 24
Organizer	Insight Co ordinators
Email Organizer	
EPP	<input type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> No
more information if available	<p>Hyer and Latchford presenting ESPGHAN successes to the International Group on inherited cancers. Seeking a paediatric session for Meeting 2026</p>

Full Event Name	WCPGHAN
Location	Buenos Aires
Date	Dec 24
Organizer	WCPGHAN committee
Email Organizer	
EPP	<input type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> No
more information if available	Polyposis session – presenters from ESPGHAN SIG throughout



Full Event Name	NASPGHAN
Location	San Diego
Date	Oct 23
Organizer	NASPGHAN
Email Organizer	
EPP	<input type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> No
more information if available	A full one day mono thematic session on paediatric polyposis. Co Ordinator Tom Attard. 125 attendees. Great success

Full Event Name	ESPGHAN endoscopy learning
Location	Athens
Date	July 24
Organizer	Alexandra Papadoulos and team
Email Organizer	
EPP	<input type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> No
more information if available	A huge success. One day allocated to paediatric polyposis. Excellent feedback. Superb endoscopy models.

(ii) E-Learning (if applicable)

(one table per project – please just copy and paste the tables as often as needed)

Full Project Name	Polyposis Podcast
Project Timeline	Completed
Project Leader	ESPGHAN
more information if available (applied for UEG support? Etc)	Recorded on site at Hyer and Cargill Marin



C. WG Publications / Guidelines / Position Papers

(i) **Completed**

(one table per publication – please just copy and paste the tables as often as needed)

Publication ID <i>(to be filled in by Office)</i>	Cohen S, Yerushalmy-Feler A, Rojas I, et al. Juvenile polyposis syndrome in children: the impact of <i>SMAD4</i> and <i>BMPR1A</i> mutations on clinical phenotype and polyp burden. <i>J Pediatr Gastroenterol Nutr.</i> 2024; 79: 161-167			
Full Publication Title	Juvenile polyposis syndrome in children: the impact of <i>SMAD4</i> and <i>BMPR1A</i> mutations on clinical phenotype and polyp burden			
Authors	Cohen S, Yerushalmy-Feler A, Rojas I, et al			
Publication Type	<input type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
Journal, Year, Volume, Page Numbers	<i>J Pediatr Gastroenterol Nutr.</i> 2024; 79: 161-167			
More information if available	ESPGHAN networking grant			



(ii) **future topics considered in 2024/25**
(one table per publication – please just copy and paste the tables as often as needed)

Full Publication Title	Desmoid disease in Paediatric polyposis		
Publication Timeline and Status of Application for Paper	Data collection complete. Aim to bring to ESPGHAN 2025; publication 2025		
Publication Leader	Hyer		
Publication Type			<input type="checkbox"/> Other
More information if available	New research		

Full Publication Title	Combined <i>BMPRI1A</i> and <i>PTEN</i> gene mutation in JPS in paediatrics		
Publication Timeline and Status of Application for Paper	Data collection complete. Aim to bring to ESPGHAN 2025; publication 2025		
Publication Leader	Hyer		
Publication Type			<input type="checkbox"/> Other
More information if available	New research		

Full Publication Title	Patients perspective and preferences on medical or surgical choices delaying colectomy in familial adenomatous polyposis		
Publication Timeline and Status of Application for Paper	<p>Joint ESPGHAN and NASPGHAN QOL and psychology questionnaire/ interview First study of it's kind. Will frame future choices in delaying colectomy in patients with FAP</p> <p>Study design in progress 2024 Data collection 2025, aim for presentation and publication 2026</p>		
Publication Leader	Hyer		
Publication Type			<input type="checkbox"/> Other
More information if available	New research		

Full Publication Title	Somatic gene mutations in juvenile hamartomatous polyps in patients with juvenile polyposis syndrome without a disease causing gene mutation		
Publication Timeline and Status of Application for Paper	<p>Novel study Genetics study on the polyp impacting on risk of polyposis syndrome in siblings and parents.</p> <p>Study design in progress 2024 Data collection 2025, aim for presentation and publication 2026</p>		
Publication Leader	Hyer		
Publication Type			<input type="checkbox"/> Other
More information if available	New research		



D. Financial Report / Budget for 2025: Will be added by EPGHAN Office

All in Euros	Allocated	Used so far
Expenses	Will be added by EPGHAN Office	Will be added by EPGHAN Office
Joint ESPGHAN and NASPGHAN QOL and psychology questionnaire/ interview First study of it's kind. Funding request covers access to psychology time and validated questionnaire.	Euro12,000	
Income	Please also add funding from other sources if applicable	
Activity 1	No income	

Additional comments on financial report:

Outlook on Planned Activity for 2024/25

A. Working Group meetings (date and any main points/activities)

(one table per meeting – please just copy and paste the tables as often as needed)

Meeting	Core group meeting/ InSight rep
Location	On line
Date	20 th Aug
Main Points / Activities	Planning ESPGHAN 2026

Meeting	WCPGHAN
Location	Buenos Aires
Date	Dec 25
Main Points / Activities	Conference presentation WG with NASPGHAN



B. Proposed Educational activities

(i) Educational Events (if applicable)

(one table per event – please just copy and paste the tables as often as needed)

Full Event Name	WCPGHAN
Location	Argentina
Date	Dec 24
Organizer	Organisers of WCPGHAN
Email Organizer	
Applied for EPP	<input type="checkbox"/> No
Applied for UEG Training Support	<input type="checkbox"/> No
more information if available	Clinical session in the meeting

Full Event Name	ESPGHAN 2025
Location	Helsinki
Date	June 25
Organizer	Organisers ESPGHAN
Email Organizer	
Applied for EPP	<input type="checkbox"/> No
Applied for UEG Training Support	<input type="checkbox"/> No
more information if available	Clinical session in the meeting. WG SIG face to face



C. Any other issues that may be of interest

ESPGHAN 2025

Building on the success of 2024 educational sessions, we are seeking another Polyposis session at ESPGHAN 2025.

This years theme:

- Preventing Colorectal cancer in at risk groups.
- Towards safer polypectomy

Case presentations in Paediatric Polyposis (very successful in 2024 meeting)

Core group of WG SIG

- More inclusive.
- More Eastern European representation
- Young ESPGHAN and AHP representation

