

**ESPGHAN**European Society for Paediatric
Gastroenterology, Hepatology and NutritionRue Pellegrino Rossi 16
1201 Geneva, Switzerland
www.espghan.org**Working Group - Report for Gastroenterology Committee Strategy Day****Working Group Title: Coeliac Disease Special Interest Group****((date of completion 12 July 2024, Carmen Ribes-Koninckx & Ketil Stordal)****Working Group Members and Mandates**

Name	Date of entry	1 st Term	2 nd Term	Positions held within WG (e.g. Secretary treasurer etc.)	Dates held of these positions
Carmen Ribes-Koninckx	2021		X	Chair	Sept 2021- Sept 2024
Ketil Stordal	2021	x		Treasurer	Sept 2021- Sept 2024
M^a Luisa Mearin	2012		x	Secretary	Sept21-Sept 2023
Renata Auricchio	2023	x		Secretary	Sept 2023-
Margreet Wessels	2023	x		Research Coordinator	Sept 2023-
Francesco Valitutti	2023	x		Communication & Dissemination Coordinator	Sept 2023-

Core group: 37 members

Total CD SIG members: 96

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	31st PreventCD Progress Meeting. Closed Meeting
Location	Leiden, The Netherlands
Date	January 26, 2024 9:00 – 17:30 hr.
Main Points / Activities	<p>AGENDA :</p> <ul style="list-style-type: none"> • Welcome and program overview Luisa Mearin, LUMC, Leiden, The Netherlands • Follow up PreventCD Cohort: Presentation of the Actual Situation after the Infographic Action to encourage participation <p><u>CHAIR: Riccardo Troncone</u></p> <ul style="list-style-type: none"> • Update Analysis PreventCD cohort Caroline Meijer, LUMC, The Netherlands • PreventCD Transient and Potential CD participants Caroline Meijer, LUMC, The Netherlands • Preliminary Results Hormonal Determinations as appraisal of Puberty in the PreventCD Cohort Caroline Meijer, LUMC, The Netherlands • PreventCD the Way Ahead Luisa Mearin, LUMC, The Netherlands <p><u>CHAIR: Raanan Shamir</u></p> <ul style="list-style-type: none"> • Update Human milk oligosaccharides in the breast feeding of the mothers of the PreventCD birth cohort Kelly Dingess, Danone Nutricia Research, The Netherlands • Update on Organoid and Organ-on-Chip work in Groningen Sebo Whitoff, UMCG, The Netherlands <p><u>CHAIR: Hania Szajewska</u></p> <ul style="list-style-type: none"> • The Law on Mass Screening of Childhood Coeliac Disease in Italy Riccardo Troncone, Italy • Real life case -finding of coeliac disease by standard of care at the Preventive Children Health Centers in the Netherlands Lucy Smit, Kennemerland, The Netherlands • Discussion and agreements Luisa Mearin, LUMC, Leiden, The Netherlands



Meeting	14th Meeting of the CD Special Interest group - Closed Meeting
Location	Leiden, The Netherlands
Date	January 27, 2024 9:00 – 17:30 hr.
Main Points / Activities	<p>AGENDA</p> <p><u>Chair: Carmen Ribes, La Fe Hospital, Spain</u></p> <ul style="list-style-type: none"> • <i>Opening</i> Carmen Ribes, chair CD-SIG, La Fe Hospital, Spain • <i>Management update:</i> Carmen Ribes • <i>Secretary:</i> Renata Auricchio • <i>Financial Issues.</i> Ketil Størdal • <i>Communication:</i> Francesco Valitutti • <i>Research:</i> Margreet Wessels <p><u>Chair: Ketil Størdal. Report of Working groups</u></p> <ul style="list-style-type: none"> • <i>Prevent CD.</i> Luisa Mearin, Leiden, The Netherlands • <i>IgA deficiency and CD Project.</i> Esther Donat, La Fe Hospital, Valencia, Spain • <i>Guideline for diagnosis in T1D.</i> Magreet Wessels, Rijnstate Hospital, The Netherlands • <i>Clinical utility of TTG Staining .</i> Raanan Shamir, Schneider Children's Medical Center, Petach-Tikva, Israel <p><u>Chair: Francesco Valitutti Report of Working groups</u></p> <ul style="list-style-type: none"> • <i>New Proposal: Restaurant staff awareness and knowledge of celiac disease: is it always a safe gluten-free experience?</i> Carlo Catassi, Università Politecnica delle Marche, Ancona, Marche, Italy • <i>CD in Focus project</i> Jernej Dolinsek, University Medical Centre Maribor, Slovenia • <i>Endpoints Clinical Trials Task Force.</i> Riccardo Troncone, University of Naples Federico II, Naples, Italy • <i>Draft ESPGHAN position paper on gluten introduction and the risk of coeliac disease: Systematic Review .</i> Hania Szajewska, The Medical University of Warsaw, Poland & Raanan Shamir, Schneider Children's Medical Center, Petach-Tikva, Israel <p><u>Chair: Margreet Wessels. Top 3 research priorities for the future</u></p> <ul style="list-style-type: none"> • <i>Daniel Agardh</i> • <i>Riccardo Troncone</i> • <i>Iris Jonkers</i> <p><u>Chair: Luisa Mearin. What is going in CD outside the CD SIG?</u></p> <ul style="list-style-type: none"> • <i>Screening for diabetes and celiac disease in Italy (Carlo Catassi)</i> • <i>Potential fecal markers in CD (Laura Kivela)</i> • <i>On-going intervention studies to prevent pediatric CD (Carin Aronsson)</i> <p><i>New proposals</i></p> <p><i>General Conclusion and Farewell</i></p> <p><i>Carmen Ribes, La Fe Hospital, Valencia, Spain</i></p>



Meeting	32nd PreventCD Progress Meeting. Closed Meeting
Location	Milano (Annual ESPGHAN meeting 2024)
Date	15th of May 2024, 13.00-14.30
Main Points / Activities	<p>CHAIR: Riccardo Troncone</p> <p>13:00-13:15 <i>Welcome and program overview</i> Luisa Mearin, LUMC, The Netherlands</p> <p>13:15-13:45 <i>Update of the PreventCD cohort</i> Caroline Meijer, LUMC, The Netherlands</p> <p>13:45-14:00 <i>Viral infection in the development of coeliac disease: the results of the VirSCan in the PreventCD cohort.</i> Valentina Discepolo, University of Naples Federico II, Italy</p> <p>14:00-14:30 <i>Proposals, Discussion and Conclusions</i> Luisa Mearin, LUMC, The Netherlands</p>

Meeting	Open Meeting of the CD Special Interest group
Location	Milano (Annual ESPGHAN meeting 2024)
Date	15th of May 2024, 15.00-17.30
Main Points / Activities	<p>AGENDA</p> <p><i>Opening and Management update.</i> Carmen Ribes, chair CD-SIG, Valencia, Spain</p> <p><i>Coeliac Disease: recent papers not to be missed!</i> Luisa Mearin, Leiden, The Netherlands</p> <p><i>Update of SIG activities.</i> Francesco Valitutti, Perugia, Italy</p> <p><i>What is going on in CD outside the CD SIG?</i></p> <ul style="list-style-type: none"> • <i>New strategies for prevention of celiac disease.</i> Carin Andren Aronsson, Sweden. • <i>Screening on Type 1 diabetes and celiac disease in Italy.</i> Carlo Catassi, Italy <p><i>Top 3 priorities in research.</i> Margreet Wessels, Arnhem, The Netherlands</p> <p><i>Patients association point of view: unmet needs and collaboration opportunities</i></p> <p>Tunde Koltai AOECS representative.</p> <p>Discussion</p> <p><i>New proposals: PFAS and autoimmunity</i></p> <p><i>Steffen Husby, Copenhagen, Denmark</i></p> <p><i>Conclusions</i> Carmen Ribes, chair CD-SIG, Valencia, Spain</p>



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	"Coeliac Disease Diagnosis: Talking to your pathologist", Alina Popp, Horia Georgescu
Location	Online webinar
Date	26th of October 2023
Organizer	CD SIO Steering Committee
Email Organizer	
EPP	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
More information if available	<u>63 registered, 48 attending</u>
Full Event Name	"Coeliac Disease Diagnosis: Talking to your immunologist", Renata Auricchio, Ilma Korponay-Szabo
Location	Online webinar
Date	30th of November 2023
Organizer	CD SIG Steering Committee
Email Organizer	
EPP	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
More information if available	<u>178 registered, 80 attending</u>

(ii) E-Learning (if applicable)

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

Full Project Name	
Project Timeline	
Project Leader	
more information if available (applied for UEG support? Etc)	



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>	
Full Publication Title	Gluten-free diet for paediatric patients with coeliac disease: A Position Paper from the ESPGHAN Gastroenterology Committee, Special Interest Group in Celiac Disease.
Authors	Veronica Luque , Paula Crespo-Escobar , Elin M Hård Af Segerstad , Tunde Koltai , Lorenzo Norsa , Enriqueta Roman, Anita Vreugdenhil , Ricardo Fueyo-Díaz , Carmen Ribes-Koninckx
Publication Type	<input type="checkbox"/> Guideline <input checked="" type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input type="checkbox"/>
Journal, Year, Volume, Page Numbers	J. Pediatr Gastroenterol Nutr . 2024 Apr;78(4):973-995. doi: 10.1002/jpn3.12079
More information if available	

(ii) in progress

(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>	
Full Publication Title	<i>IgA deficiency and CD</i>
Publication Timeline and Status of Paper	Retrospective study: end 2024
Publication Leader	Ester Donat
Publication Type	<input type="checkbox"/> Guideline <input checked="" type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input type="checkbox"/> Other
More information if available	The retrospective study has just ended and the statistical analysis is completed. Paper is now in preparation Prospective study: will be ongoing for the next 3-4 years

(iii) future topics considered in 2024

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

Full Publication Title	Designing clinical drug trials in Pediatric Celiac Disease
Publication Timeline and Status of Application for Paper	End 2024
Publication Leader	Riccardo Troncone and Sibylle Koletzko
Publication Type	<input type="checkbox"/> Guideline <input checked="" type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input type="checkbox"/> Other
More information if available	This is a joint ESPGHAN NASPGHAN Position Paper establishing the rationale for conducting therapeutic clinical trials with drugs in children as well as the target populations and trial designs specially focusing on outcomes. (ESPGHAN and NASPGHAN writing group includes pediatric gastroenterologists from different European countries (Germany, Italy, Spain, Norway, Finland and Romania), Canada and the United States with expertise in celiac disease as well as in clinical trials in adults with celiac disease. To incorporate the patients’



	perspective 2 members representing the patients associations (AOECS and Celiac Disease Foundation) have also been integrated in the task force and writing group.		
Full Publication Title	Guideline for diagnosis of CD in children with T1D		
Publication Timeline and Status of Paper	In progress . To be expected in 2025		
Publication Leader	Margreet Wessels		
Publication Type	<input type="checkbox"/> Guideline	<input checked="" type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper
More information if available	The aim is to produce a Position Paper / Guidelines for CD diagnosis and management in children with Type 1 Diabetes due to the false positive tTG and EMA in those patients.		

D. Financial Report / Budget for 20XX: 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
Activity 1		
Activity 2		
Activity 3		
Activity 4		
Activity 5		
Activity 6		
Activity 7		
Activity 8		
TOTAL Expenses 20XX		
Income	Please also add funding from other sources if applicable	
Activity 1		
Activity 2		
Activity 3		
Activity 4		
Activity 5		
TOTAL Income 201XX		

Additional comments on financial report:

Outlook on Planned Activity for 2025

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	15th Meeting of the CD Special Interest group – Core Group Meeting
Location	Leiden, The Netherlands
Date	January 27, 2025 9:00 – 17:30 hr.



Main Points / Activities	CD SIG management update Update on the working groups activities Top 3 research priorities Parallel working sessions for the specific WG (Agenda in progress)
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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	3 rd Masterclass on Gastrointestinal Immunology	
Location	Naples, Italy	
Date		
Organizer	R Troncone, V Discepolo , R Auricchio	
Email Organizer		
Applied for EPP	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Applied for UEG Training Support	<input type="checkbox"/> Yes	<input type="checkbox"/> No
more information if available		

Full Event Name	Topic to be determined	
Location	Online webinar	
Date	October 2024	
Organizer	CD SIG Steering Committee	
Email Organizer		
EPP	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
more information if available		

Full Event Name	Topic to be determined	
Location	Online webinar	
Date	November 2024	
Organizer	CD SIG Steering Committee	
Email Organizer		
EPP	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
UEG Training Support	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

(ii) E-Learning (if applicable)

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

Full Project Name	
Project Timeline	



Project Leader	
more information if available (applied for UEG support? Etc)	

C. Proposed Publications / Guidelines / Position Papers

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

Full Publication Title	Clinical utility of TTG Staining in SBB in CD diagnosis			
Publication Timeline and Status of Application for Paper	In progress. To be expected in 2025			
Publication Leader	<i>Raanan Shamir, Schneider Children's Medical Center, Petach-Tikva, Israel</i>			
Publication Type	<input type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input checked="" type="checkbox"/> Other
More information if available				

Full Publication Title	To be defined			
Publication Timeline and Status of Application of Paper	To be expected in 2025			
Publication Leader	TBD			
Publication Type	<input type="checkbox"/> Guideline	<input checked="" type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input checked="" type="checkbox"/> Other
More information if available	EMA testing is not available in all settings and countries challenging the use of EMA as a confirmatory test for the CD diagnosis by a non-biopsy approach. A Task force composed by Core members of the ESPGHAN CD SIG has been constituted to analyse and provide a solution to this problematic situation. Several publications are planned.			

D. Financial Report / Budget for 20XX:

- Kindly attach or copy paste your submitted budget request for 20XX
- Additional comments on financial report:

E. Any other issues that may be of interest

