



ESPGHAN

Working Group - Report for Gastroenterology Committee Strategy Day

Working Group Title: Coeliac Disease Special Interest Group

(date of completion 12 August 2019; Carmen Ribes-Koninckx)

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	2012	x		Chair	June 2017-
Steffen Husby	2012		x	Treasurer	June 2017 – (Chair till May2017)
M ^a Luisa Mearin	2012	x		Secretary	June 2017-
Raanan Shamir	2012	x		Steering Committee	June 2017-
Sibylle Koletzko	2012	x		Steering Committee	June 2017-
Riccardo Troncone	2012	x		Steering Committee	June 2017-
Kalle Kurppa	2014	x		Steering Committee	June 2017-
Ilma Korponay-Szabo	2012	x		Steering Committee	June 2017-
Renata Auricchio	2016	x		Core group	
Jernej Dolinsec	2016	X		Core group	
Alina Popp	2016	x		Core group	
Margret Wessels	2016	x		Core group	

Executive Committee : 3 members

Steering Committee: 5 members

Core group: 22 members



Summary of Activities in 2019

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	PreventCD 21th Progress Meeting . Close Meeting
Location	Leiden (The Netherlands)
Date	January 24-25, 2019
Main Points / Activities	<p>January 24 Agenda</p> <p>13.00 – 13.30 Welcome and program overview <i>Luisa Mearin, LUMC, Leiden</i></p> <p>13.30 – 14.00 Updated analysis PreventCD cohort <i>Caroline Meijer, LUMC, Leiden,</i></p> <p>14.00 – 14.30 GROWTH data paper <i>Renata Aurricchio, UNINA, Naples. Italy</i></p> <p>14.30 – 15.00 Children with high risk for coeliac disease: clinical benefit from early diagnosis and treatment. Paper <i>Caroline Meijer, LUMC, Leiden,</i></p> <p>15.30 – 16.00 Single cell RNAseq work on PreventCD PBMCs <i>Aaron Ramirez-Sanchez and Xiaojing Chu, UMCG Groningen, the Netherlands</i></p> <p>16.00 – 16.30 Viral infections and coeliac disease development <i>Bana Jabri and/or Valentina Discepolo, University of Chicago, USA</i></p> <p>16.30 – 17.00 Update from Groningen: PreventCD from a molecular biology perspective <i>Iris Jonkers, UMCG, Groningen, the Netherlands</i></p> <p>17.00 – 17.30 Conclusions on the first day. Food for thoughts <i>Luisa Mearin</i></p> <p>January 25 Agenda</p> <p>9.00 – 9.30 Predictive models for CD screening in children with first degree relatives with CD (paper) <i>Caroline Meijer, LUMC, Leiden, the Netherlands</i></p> <p>9.30 – 10.00 Progress on NeoCel cohort <i>Renata Auricchio, UNINA, Naples. Italy</i></p> <p>10.00 – 10.30 BM CD others versus non CD mothers related to CD <i>Paula Crespo / Maria Roca, Hulafe, Valencia,</i></p> <p>11.00 – 11.30 PreventCD CyTOF <i>Yvonne Kooy-Winkelaar, IHB, LUMC, the Netherlands</i></p> <p>11.30 – 12.00 Update from Groningen: PreventCD from a molecular biology perspective <i>Iris Jonkers, UMCG, Groningen, the Netherlands</i></p> <p>12.00 – 12.30 Single cell RNAseq work on PreventCD PBMCs <i>Aaron Ramirez-Sanchez, UMCG Groningen, the Netherlands</i></p> <p>12.30 – 13.00 I-FABP as early marker of inflammation for CD in the PreventCD cohort <i>Anita Vreugdenhill, University Medical Center Maastricht, the Netherlands</i></p> <p>14.00 – 14.30 AiDA <i>Katharina Werkstetter, LMU, Munich, Germany</i></p> <p>14.30 – 15.00 Role of ThermoFisher Sigrid <i>Sjölander/Peter Szillat, Thermofisher, Freiburg,</i></p> <p>15.00 – 16.00 Discussion and agreements <i>Luisa Mearin, LUMC, Leiden, the Netherlands</i></p>

Meeting	4th Meeting of the CD Special Interest group - Close Meeting
Location	Leiden The Netherlands
Date	January 26, 2019 (8.30H- 17h)
Main Points / Activities	<p><u>Agenda</u></p> <p>Coeliac Disease Diagnosis Guidelines</p> <p>08.30 – 11.30 Coeliac Disease Diagnosis Guidelines Working Group (chair</p>



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	<p>Steffen Husby) (attendants: members of WG) 10.45-11'.30 Communicating the guidelines to EVERYBODY (Justin Wilkes, SPINK) CD-SIG General meeting (attendants: members of WGs) 11.30 – 11.45 Introduction <i>Carmen Ribes Koninckx</i> 11.45 – 12.15 ESPGHAN guidelines for CD follow-up and treatment: draft proposal <i>Coordinator: M. Luisa Mearin</i> 12.15 – 12.45 ESPGHAN recommendations for a gluten free diet: draft proposal <i>Coordinator: Paula Crespo</i> to HAP , 1 representative of the Nutrition Committee, 1 representative of AOECS 12.45 – 13.15 CD on focus <i>Coordinator: Jernej Dolinsek</i> 14.00 – 14.20 PreventCD <i>Luisa Mearin</i> 14.20 – 16.10 Working groups parallel meetings 16.10 - 16.50 Short summary by the coordinators of the new WGs Agreements achieved (10 minutes each) 17.00 Farewell <i>Carmen Ribes Koninckx</i></p>
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Meeting	PreventCD 22th Progress Meeting – Close Meeting
Location	Glasgow (Annual ESPGHAN Meeting)
Date	Wednesday 5 th June 2109 , 10h-12.30h
Main Points / Activities	Welcome, update on PreventCD <i>Luisa Mearin, LUMC, Leiden, the Netherlands</i> 10.00 – 10.30 (Updated) analysis PreventCD <i>Caroline Meijer, LUMC, Leiden, the Netherlands</i> 10.30 – 11.00 Viral infections and coeliac disease development <i>Bana Jabri, University of Chicago, USA and/or Valentina Discepolo, Univ. of Chicago, USA</i> 11.00 – 11.30 IFABP as early marker of inflammation for CD in the PreventCD cohort: update <i>Johanna Kreutz, University Medical Center Maastricht, the Netherlands</i> 11.30 – 12.00 CD Mothers versus non CD mothers related to CD development in their offspring <i>Maria Roca, H U La Fe, Valencia, Spain</i> 12.00 – Conclusions and agreements <i>Luisa Mearin</i>

Meeting	5th Meeting of the CD Special Interest group - Close Meeting
Location	Glasgow Annual ESPGHAN Meeting)
Date	Wednesday 5 th June 2109 , 14h-16h
Main Points / Activities	14.00- 14.15 Opening <i>C Ribes, chair SIG-CD</i> 14.15- 15.15 Parallel Working Groups Session *Evidence Based (EB) ESPGHAN guidelines for CD follow-up and management (proposal) <i>Chair ML Mearin</i> *ESPGHAN recommendations for a gluten free diet <i>Chairs: P Crespo and A Vreugdenhill</i> *Extension of Focus In CD <i>Chair: J Dolinsek</i> 15.15-15.45 Conclusions Working Groups 15.45-16.00 Agreements and Further Planning <i>C Ribes</i>

Meeting	Open Meeting of the CD Special Interest group
Location	Glasgow Annual ESPGHAN Meeting)
Date	Wednesday 5 th June 2109 , 16.15 h-18h



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Main Points / Activities	<p>16.15- 16.30 Opening. TOR of the CD-SIGC <i>Ribes, chair SIG-CD</i></p> <p>16.30- 17.30 Update on Working Groups Activities</p> <p>*ESPGHAN CD Diagnosis Guidelines 2019 <i>S Husby</i></p> <p>*Evidence Based (EB) ESPGHAN guidelines for CD follow-up and management (proposal) <i>ML Mearin</i></p> <p>*ESPGHAN recommendations for a gluten free diet <i>P Crespo and A Vreugdenhill</i></p> <p>*Extension of Focus In CD <i>J Dolinsek</i></p> <p>17.30-18.00 Discussion. Suggestions. Agreements <i>C Ribes</i></p> <p>(75 attendees)</p>
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Meeting	5 th Executive and Steering Committee Meeting
Location	Glasgow Annual ESPGHAN Meeting)
Date	Wednesday 5 th June 2109 , 13 h-14h
Main Points / Activities	<p><i>Chair C Ribes</i></p> <p>TOR of the CD-SIGC. Discussion & Agreements</p> <p>Management proposals: Discussion & Agreements</p> <p>New Activities/ WGs : Discussion & Agreements</p>

Meeting	6th Meeting of the CD Special Interest group - Close Meeting
Location	Paris (ICDS)
Date	Saturday 7 th September 2109 , 15.30h-17.30h
Main Points / Activities	<p>15.30- 15.45 Opening <i>C Ribes, chair SIG-CD</i></p> <p>15.45- 17.00 Parallel Working Groups</p> <p>* Evidence Based (EB) ESPGHAN guidelines for CD follow-up and Management and Extension of Focus In CD <i>Chairs ML Mearin & JJ Dolinsek</i></p> <p>*ESPGHAN recommendations for a gluten free diet <i>Chairs: P Crespo and A Vreugdenhill</i></p> <p>17.00-17.20 Conclusions Working Group</p> <p>17.20-17.30 Agreements and Further Planning <i>C Ribes,</i></p>

B. Educational activities

(i) Educational Events

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

(ii) E-Learning

(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	ESPGHAN guidelines for diagnosing coeliac disease 2019
Publication Timeline and Status of Paper	Final review submitted to JPGN August 2019
Publication Leader	Steffen Husby
Publication Type	<input checked="" type="checkbox"/> Guideline <input type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input type="checkbox"/> Other
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	Survey on the 2012 ESPGHAN guidelines for the diagnosis of coeliac Disease in children and adolescents
Publication Timeline and Status of Paper	Writing process currently ongoing . Final version expected September 2019
Publication Leader	Carmen Ribes
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	

Publication ID <i>(to be filled in by Office)</i>	
Full Publication Title	Predictive models for celiac disease development in children from risk families: data from 10 years follow up of the PreventCD cohort.



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Publication Timeline and Status of Paper	Writing process currently ongoing . Final version expected September 2019				
Publication Leader	Luisa Mearin				
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					

Publication ID <i>(to be filled in by Office)</i>					
Full Publication Title	Children with high risk for coeliac disease: clinical benefit from early diagnosis and treatment				
Publication Timeline and Status of Paper	Writing process ongoing .				
Publication Leader	<i>L MEARIN & Caroline Meijer, LUMC, Leiden, the Netherlands)</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					

Publication ID <i>(to be filled in by Office)</i>					
Full Publication Title	CD Mothers versus non CD mothers related to CD development in their offspring				
Publication Timeline and Status of Paper	Writing process ongoing .				
Publication Leader	<i>Maria Roca & C Ribes H U La Fe Valencia</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					

Publication ID <i>(to be filled in by Office)</i>					
Full Publication Title	I-FABP as early marker of inflammation for CD in the PreventCD cohort				
Publication Timeline and Status of Paper	Writing process ongoing .				
Publication Leader	<i>Joanna Kreutz & A Vreugdenhil , University Medical Center Maastricht,</i>				



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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				

(iii) future topics considered in 2019

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

Full Publication Title	Recommendations for a Gluten free diet in Children and adolescents			
Publication Timeline and Status of Paper	Preliminary draft to be discussed in the January-February 2020 7th Meeting of the CD Special Interest group - Close Meeting			
Publication Leader	Paula Crespo , Anita Vreugdenhil			
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				

Full Publication Title	Evidence Based (EB) ESPGHAN guidelines for CD follow-up and Management			
Publication Timeline and Status of Paper	Preliminary draft to be discussed in the January-February 2020 7th Meeting of the CD Special Interest group - Close Meeting			
Publication Leader	M L Mearin			
Publication Type	<input checked="" type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
More information if available				

D. Financial Report / Budget for 2019: 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 2017		
Income	Please also add funding from other sources if applicable	
Activity 1		

Activity 2		
Activity 3		
Activity 4		
Activity 5		
TOTAL Income 2017		

Additional comments on financial report:

Outlook on Planned Activity for 2020

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	PreventCD 23th Progress Meeting . Close Meeting
Location	Leiden (The Netherlands)
Date	TBD, 2020
Main Points / Activities	Update on the CD Prevent cohort follow up. Proposal for new activities inside the group Grants and financial support opportunities Update on publications from the group

Meeting	5rd CD-SIG Executive Committee Meeting Close Meeting
Location	Leiden (The Netherlands)
Date	TBD , 2020
Main Points / Activities	Planning the tasks of the Executive Committee Financial issues

Meeting	8th Meeting of the CD Special Interest group - Close Meeting
Location	Leiden The Netherlands)
Date	TBD , 2020
Main Points / Activities	Updating of new CD SIG working groups activities (guidelines & position papers) WGs Parallel working session

Meeting	PreventCD 24th Progress Meeting – Close Meeting
Location	Copenhagen 2020. (Annual ESPGHAN Meeting 2020)
Date	TBD
Main Points / Activities	Further analysis on the follow up of the Prevent CD cohort .

Meeting	5th CD-SIG Executive Committee Meeting Close Meeting
Location	Copenhagen 2020. (Annual ESPGHAN Meeting 2020)
Date	TBD
Main Points / Activities	Management & Financial issues / Planning of new activities

Meeting	9th Meeting of the CD Special Interest group - Close Meeting Close Meeting
Location	Copenhagen 2020. (Annual ESPGHAN Meeting 2020)
Date	TBD
Main Points / Activities	Updating of new CD SIG working groups activities (guidelines & position papers) WGs Parallel working session

Meeting	Meeting of the CD Special Interest group – Open Meeting
Location	Copenhaguen 2020. (Annual ESPGHAN Meeting 2020)
Date	TBD
Main Points / Activities	Agenda TBD : (about 100 attendees expected) Welcome to new members Updating on activities of the CD-SIG New proposals

B. Proposed Educational activities

D. Educational Events

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

Full Event Name	
Location	
Date	
Organizer	
Email Organizer	
Applied for EPP	<input type="checkbox"/> Yes <input type="checkbox"/> No
Applied for UEG Training Support	<input type="checkbox"/> Yes <input type="checkbox"/> No
more information if available	

E. E-Learning

(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	Recommendations for a Gluten free diet in Children and adolescents
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Publication Timeline and Status of Paper	TBD			
Publication Leader	Paula Crespo & Anita Vreugdenhil			
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				

Full Publication Title	Evidence Based (EB) ESPGHAN guidelines for CD follow-up and Management			
Publication Timeline and Status of Paper	TBD			
Publication Leader	M ^a Luisa Mearin			
Publication Type	<input checked="" type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
More information if available				

Although we will take the opportunity to meet at the Annual ESPGHAN meeting, only short meetings can be scheduled at that time because of the commitments of delegates with Committees and Scientific activities. This year we had an extra full Working Day in January 2019 which was extremely productive as it was the starting point of **1 Guidelines** (Evidence Based (EB) ESPGHAN guidelines for CD follow-up and Management, coordinated by ML Mearin), **1 Position paper** (ESPGHAN recommendations for a gluten free diet, multidisciplinary approach, coordinated by P Crespo and A Vreugdenhil) and **a new WG: Extension of Focus In CD (JJ Dolinsek)**. All 3 groups have continued with their respective activities, thus discussion of achievements after one year can be crucial to assess and consolidate the progresses made, as well as to agree on the way ahead and establish realistic deadlines for completion and publication dates. For this purpose we plan again a One Day Working Meeting in January- February 2020 (beside a short 2h meeting at the International CD Symposium in Paris, September 2019) attendees being only members actively involved in the 3 WGs.

Eventually an additional restricted meeting could be scheduled by the Executive Committee in the last trimester of 2020 for a restricted number of members provided it is requested and adequately justified by the WG coordinator and for very specific tasks such as for examples writing committees

Teleconferences will be scheduled additionally to assess progress of the activities

Any other issues that may be of interest

Producing Guidelines and Position papers is one of the most rewarding activities of our Society, not only in terms of scientific relevance but also to achieve the **strategic aims of the Society namely to “ build the ESPGHAN brand to become the globally recognised authority on paediatric gastroenterology, hepatology and nutrition by the public, patients and policy makers”**



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In this respect Coeliac disease, beside being one of the foundational pillars of our Society , is the most prevalent paediatric digestive disease worldwide , involving the highest number of paediatric Gastro's . Since the Foundation of our Society, ESPGAN / ESPGHAN has been the world reference for Coeliac disease thanks to ground breaking research in the field by outstanding members of our Society. Our ambition, but also our responsibility, is to maintain this position in the years to come . Recently, promoted by the Executive Committee, a relevant number of **bright young professionals** have enthusiastically joined the CD SIG thus creating a unique opportunity to build a promising future in the field of CD under the umbrella of ESPGHAN. The aim of the CD -SIG Executive Committee is to encourage clinical and basic research by supporting new engaging proposals and facilitating networking . **The budget requested for the year 2020 aims at covering these objectives.**