

## Working Group - Report for Gastroenterology Committee Strategy Day

Working Group Title: Coeliac Disease Special Interest Group

(date of completion 31 August 2021; Carmen Ribes-Koninckx )

### Working Group Members and Mandates

Name	Date of entry	1 <sup>st</sup> Term	2 <sup>nd</sup> Term	Positions held within WG (e.g. Secretary treasurer etc.)	Dates held of these positions
Carmen Ribes	2012		X	Chair	Sept 2021-
Steffen Husby	2012		x	Treasurer	Till August 2021
M <sup>a</sup> Luisa Mearin	2012		x	Secretary	Sept 2021-
Ketil Stordal	2021	x		Treasurer	Sept 2021-
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-

**NB :**

**Structure and Organization of the CD SIG has been amended according to the GIC / Council recommendations . These amendments will be reflected in the TOR of the CD SIG**

**Executive Committee : 3 members**

**Core Group ( previous Steering Committee) : 5 members**

**Task Force ( previous ) Core group: 26 members**

## Summary of Activities in 2021

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

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

<b>Meeting</b>	<b>25<sup>th</sup> PreventCD Progress Meeting . Close Meeting</b>
<b>Location</b>	<b>ONLINE Meeting ( Virtual meeting )</b>
<b>Date</b>	Thursday, January 14 9:30 – 13:30 hr.
<b>Main Points / Activities</b>	<p><b>AGENDA</b></p> <p><b>9:30-9:50</b> Welcome, update on PreventCD Luisa Mearin, LUMC, Leiden, the Netherlands</p> <p><b>9:50-10:10</b> Updated analysis PreventCD cohort Caroline Meijer, LUMC, Leiden, the Netherlands</p> <p><b>10:10-10:30</b> Progress on the NeoCel cohort Renata Auricchio, UNINA, Naples, Italy</p> <p><b>10:30-10:50</b> BREAK</p> <p><b>10:50-11:10</b> Paper “Predictive models for celiac disease development in children from risk families: data from 10 years follow up of the PreventCD cohort” Caroline Meijer, LUMC, Leiden, the Netherlands</p> <p><b>11:10-11:30</b> Biomarker detection at molecular and cellular level with PreventCD; an update from Groningen Iris Jonkers, UMCG, Groningen, the Netherlands</p> <p><b>11:30-12:10</b> BREAK</p> <p><b>12:10-12:30</b> Plasma inflammatory protein profiling in pediatric intestinal disease Janneke Samsom, ErasmusMC, Rotterdam, the Netherlands</p> <p><b>12:30-12:50</b> Update Virus project collaboration Chicago/Harvard Valentina Discepolo, University of Naples Federico II, Naples, Italy</p> <p><b>12:50-13:20</b> (Potential) new project intervention with anti-CD3 in high-risk children Luisa Mearin, Riccardo Troncone</p> <p><b>13:20-13:30</b> Discussion, conclusions and agreements Luisa Mearin</p>

<b>Meeting</b>	<b>9th Meeting of the CD Special Interest group - Close Meeting</b>
<b>Location</b>	<b>ONLINE Meeting ( Virtual meeting )</b>
<b>Date</b>	January 15, 2021 ( 09 h - 13h )
<b>Main Points / Activities</b>	<p>Agenda</p> <p>0900-09:15h: Opening C. Ribes, chair SIG-CD</p> <p>09:15--09:30h : Enquiry on follow-up and management on in Europe, Margreet Wessels/Jernej Dolinsek/Luisa Mearin</p> <p>09:30-09:50: CD in Focus <i>Jernej Dolinsek</i></p> <p>09:50-10:00 ESPGHAN 2<sup>o</sup> Master Class on CD . Announcement and Preliminary programme Steffen Husby</p> <p>10.00 h – 12 h WORKING IN GROUPS : Parallel sessions</p> <p>A ) ESPGHAN recommendations for a gluten free diet Paula Crespo and Anita Vreugdenhill</p> <p>B ) Development of position paper on follow-up and management of CD in</p>

	<p>children and adolescents Luisa Mearin</p> <p>12.00 h -12. 30 Report of the working groups 12.30 -13 h Discussion and conclusions Carmen Ribes</p>
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<b>Meeting</b>	<b>PreventCD 26th Progress Meeting – Close Meeting</b>
<b>Location</b>	<b>ONLINE Meeting ( Virtual meeting )</b>
<b>Date</b>	Thursday June 2nd, 2021 (09:30 – 12.00 hr.)
<b>Main Points / Activities</b>	<p>9:30-9:50 Welcome, update on PreventCD Luisa Mearin, LUMC, Leiden, the Netherlands</p> <p>9:50-10:10 Updated analysis PreventCD cohort Caroline Meijer, LUMC, Leiden, the Netherlands</p> <p>10:10-10:30 MedAll chip results in German and Hungarian PreventCD participants Ilma Korponay, HP, Budapest, Hungary</p> <p>10:30-10:50 BREAK</p> <p>10:50-11:10 Paper ‘Predictive models for celiac disease development in children from risk families: data from 10 years follow up of the PreventCD cohort’ Caroline Meijer, LUMC, Leiden, the Netherlands</p> <p>11:10-12:00 Discussion, conclusions and agreements - Till what age? How? - ProMISe goes CASTOR - Next meeting: January 21st – 22nd 2022 ( TBC ) Luisa Mearin,</p>

<b>Meeting</b>	<b>10th Meeting of the CD Special Interest group - Close Meeting</b>		
<b>Location</b>	<b>Online Meeting ( Virtual meeting )</b>		
<b>Date</b>	Monday 2 <sup>th</sup> June 2021 , 12h-17h		
<b>Main Points / Activities</b>	<p><u>Agenda</u></p> <p><b>Whole Group</b></p> <p><b>1. Introduction, Carmen Ribes (chair)</b></p> <ol style="list-style-type: none"> <li>1. Terms of reference (TOR)</li> <li>2. Turnover of the Executive Committee of the SIG-CD <ul style="list-style-type: none"> <li>- The new Executive Committee starts September 2021</li> </ul> </li> <li>3. Summary of activities 2020-2021</li> </ol> <p><b>2. ESSCD, Report on activities of ESSCD Renata Auricchio</b></p> <p><b>3. CD on Focus (CD SIG-WG), Jernej Dolinsek</b></p> <p><b>15-16.30h Parallel sessions. Working groups</b></p> <table border="1" style="width: 100%; margin-top: 10px;"> <tr> <td><b>WG ESPGHAN Position Paper for CD Follow-up and Management on CD</b> Luisa Mearin</td> </tr> <tr> <td><b>WG ESPGHAN Recommendations for a Gluten Free Diet</b></td> </tr> </table>	<b>WG ESPGHAN Position Paper for CD Follow-up and Management on CD</b> Luisa Mearin	<b>WG ESPGHAN Recommendations for a Gluten Free Diet</b>
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<b>WG ESPGHAN Recommendations for a Gluten Free Diet</b>			

	<p>Paula Crespo/Anita Vreugdenhill</p> <p><b>16.30 Proposal new SIG Projects</b></p> <p><b>1. Quality of Life and CD patients, Henedina Antunes</b>  Henedina Antunes proposed to expand a quality in life in CD patients which is currently being done in Portugal to all European countries.  <u>Henedina will make a proposal protocol and send it to the whole group.</u></p> <p><b>2. IgA deficiency &amp; CD, Ester Donat</b>  A draft protocol was presented by E Donat and discussed. Application for ESPGHAN research and Networking grant was agreed</p> <p><b>17 h Summary and closing Carmen Ribes (chair)</b>  <i>A Face to face meeting to be organized January February 2022 in Leiden</i></p> <p><b>Thu, 03 June 2021 WCPGHAN Annual Meeting 2021</b>  09:45 – 11:45  <b>Parallel Symposium: Coeliac disease</b>  Chairs: Riccardo Troncone (Italy), Alina Popp (Romania)  120 minutes  09:45 – 10:07 Is coeliac disease a virus induced disease? Valentina Discepolo (Italy)  10:07 – 10:17  <b>Abstract:</b> Gluten ingestion in the first years of life is a risk factor for celiac disease in children genetically predisposed Renata Auricchio (Italy)  10:17 – 10:39 Towards a “global diagnosis” of coeliac disease? Are the ESPGHAN algorithms applicable worldwide? Marina Orsi (Argentina)  10:39 – 10:49  <b>Abstract:</b> Endomysial antibodies positivity among children and adolescents with high positive anti-tissue transglutaminase type 2 IgA antibodies  Amir Ben Tov (Israel)  10:49 – 11:11 ESPGHAN advice for coeliac disease management and follow-up  Luisa Mearin (The Netherlands)  11:11 – 11:21 <b>Abstract:</b> Poor adherence to coeliac diagnostic guidelines: Results from The German Celiac Registry (GeCeR) Sibylle Koletzko (Germany)  11:21 – 11:43 Gluten related disorders in children: how common they are? Carlo Catassi (Italy)</p>
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<b>Meeting</b>	WG ESPGHAN position paper for <b>CD follow-up and Management</b>
<b>Location</b>	<b>Online Meetings and TCs</b>

<b>Date</b>	
<b>Main Points / Activities</b>	<p>Coordinator : Luisa Mearin</p> <p>Beside 2 Virtual meetings held in the context of the CSD SIG meetings, different Teleconferences were organised by the Coordinator ( Luisa Mearin ) to discuss specific aspects of the work in progress.</p> <p>A draft paper has been produced pending of Voting among co-authors ( Statements &amp; Recommendations)</p>

<b>Meeting</b>	WG ESPGHAN position Paper for : <b>Recommendations for a gluten free diet</b>
<b>Location</b>	<b>Online Meetings and TCs</b>
<b>Date</b>	
<b>Main Points / Activities</b>	<p>Coordinators; Paula Crespo/Anita Vreugdenhill</p> <p>Beside 2 Virtual meetings held in the context of the CSD SIG meetings, different Teleconferences were organised by the Coordinators to discuss specific aspects of the work in progress. The huge amount of information and publications available was a real challenge ; different strategies were implemented so a final sorting has now been completed</p>

<b>Meeting</b>	
<b>Location</b>	
<b>Date</b>	
<b>Main Points / Activities</b>	

<b>Meeting</b>	
<b>Location</b>	
<b>Date</b>	
<b>Main Points / Activities</b>	

## B. Educational activities

### (i) Educational Events

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

	CD Master class ( Sept 2021 , Denmark) Cancelled

### (ii) E-Learning

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

<b>Full Project Name</b>	
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<b>Project Timeline</b>	
<b>Project Leader</b>	
<b>more information if available</b> (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)

<b>Publication ID</b> <i>(to be filled in by Office)</i>	
<b>Full Publication Title</b>	<b>Circulating miRNAs as potential biomarkers for celiac disease development</b> Authors: Ineke Luise Tan, Rodrigo Coutinho de Almeida, Rutger Modderman, Anna Stachurska, Jackie Dekens, Donatella Barisani, Caroline Renee Meijer-Boekel, María Roca, Eva Martinez-Ojinaga, Raanan Shamir, Renata Auricchio, Ilma R Korponay-Szabó, Gemma Castillejo, Hania Szajewska, Sibylle Koletzko, Alexandra Zhernakova, Vinod Kumar, Yang Li, Marijn C Visschedijk, Rinse K Weersma, Riccardo Troncone, M Luisa Mearin, Cisca Wijmenga, Iris Jonkers, Sebo Withoff
<b>Publication Timeline and Status of Paper</b>	Frontiers in Immunology , section Autoimmune and Autoinflammatory disorders Under review
<b>Publication Type</b>	<input type="checkbox"/> <input type="checkbox"/> Guideline <input type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input checked="" type="checkbox"/> Other
<b>More information if available</b>	

#### (ii) in progress

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

<b>Publication ID</b> <i>(to be filled in by Office)</i>	
<b>Full Publication Title</b>	Prediction models for celiac disease development in children from risk families: data from long term follow up of the PreventCD cohort C.R. Meijer1*, R. Auricchio2*, H. Putter3, G.Castillejo4, P. Crespo5, J. Gyimesi6, C. Hartman7, S. Kolacek8, S. Koletzko9, I. Korponay-Szabo6, E. Martinez Ojinaga10, I Polanco10, C. Ribes-Koninckx11, R. Shamir7, H. Szajewska12, R. Troncone2, V. Villanacci13, K. Werkstetter9 and M. L. Mearin1
<b>Publication Timeline and Status of Paper</b>	Under review
<b>Publication Leader</b>	
<b>Publication Type</b>	<input type="checkbox"/> Guideline <input type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input checked="" type="checkbox"/> Other
<b>More</b>	

information if available	
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Publication ID <i>(to be filled in by Office)</i>	
Full Publication Title	<b>Children with high risk for coeliac disease: clinical benefit from early diagnosis and treatment</b>
Publication Timeline and Status of Paper	Writing process ongoing .
Publication Leader	<i>L MEARIN &amp; 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 &amp; 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	<b>I-FABP as early marker of inflammation for CD in the PreventCD cohort</b>
Publication Timeline and Status of Paper	Writing process ongoing .
Publication Leader	<i>Joanna Kreutz &amp; A Vreugdenhil , University Medical Center Maastricht,</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	

(iii) **future topics considered in 2022**

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

<b>Full Publication Title</b>	Recommendations for a Gluten free diet in Children and adolescents with Coeliac disease				
<b>Publication Timeline and Status of Paper</b>	In progress Publication planned for 2022				
<b>Publication Leader</b>	Paula Crespo , Anita Vreugdenhil				
<b>Publication Type</b>	<input type="checkbox"/> Guideline	<input checked="" type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other	
<b>More information if available</b>					

<b>Full Publication Title</b>	CD follow-up and Management				
<b>Publication Timeline and Status of Paper</b>	In progress Publication planned for 2021-22				
<b>Publication Leader</b>	M L Mearin				
<b>Publication Type</b>	<input type="checkbox"/> Guideline	<input checked="" type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other	
<b>More information if available</b>					

<b>Full Publication Title</b>					
<b>Publication Timeline and Status of Paper</b>					
<b>Publication Leader</b>					
<b>Publication Type</b>	<input type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other	
<b>More information if available</b>					

**D. Financial Report / Budget for 2021: Will be added by EPGHAN Office**

<b>All in Euros</b>	<b>Allocated</b>	<b>Used so far</b>
<b>Expenses</b>	<b>Will be added by EPGHAN Office</b>	<b>Will be added by EPGHAN Office</b>
Activity 1		
Activity 2		
Activity 3		
Activity 4		
Activity 5		
Activity 6		
Activity 7		
Activity 8		
<b>TOTAL Expenses 2017</b>		
<b>Income</b>	<b>Please also add funding from other sources if applicable</b>	



Activity 1		
Activity 2		
Activity 3		
Activity 4		
Activity 5		
<b>TOTAL Income 2020</b>		

## Outlook on Planned Activity for 2022

### 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)

<b>Meeting</b>	<b>PreventCD 27th Progress Meeting . Close Meeting</b>
<b>Location</b>	Leiden ( The Netherlands)
<b>Date</b>	<b>January 21-22, 2022</b>
<b>Main Points / Activities</b>	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

<b>Meeting</b>	<b>CD-SIG Executive Committee Meeting Close Meeting</b>
<b>Location</b>	Leiden ( The Netherlands)
<b>Date</b>	<b>January 21, 2022</b>
<b>Main Points / Activities</b>	Planning the tasks of the Executive Committee Financial issues

<b>Meeting</b>	<b>11th Meeting of the CD Special Interest group - Close Meeting</b>
<b>Location</b>	Leiden The Netherlands)
<b>Date</b>	January 22, 2022
<b>Main Points / Activities</b>	1.Updating on the ongoing ESPGHAN Positions papers: A) CD follow-up and Management Coordinator; Luisa Mearin B) Recommendations for a gluten free diet Coordinators; Paula Crespo/Anita Vreugdenhill 2. New Working groups and Activities : To be undertaken in 2022 3. WGs Parallel working sessions 4. Summing up from the WGs 5. Conclusions / Agreements

<b>Meeting</b>	<b>PreventCD 28th Progress Meeting – Close Meeting</b>
<b>Location</b>	<b>June 22 - 25, 2022</b> in Copenhagen, Denmark. ( Annual ESPGHAN Meeting 2022 )
<b>Date</b>	TBD
<b>Main Points / Activities</b>	Further analysis on the follow up of the Prevent CD cohort .

<b>Meeting</b>	<b>CD-SIG Executive Committee Meeting Close Meeting</b>
<b>Location</b>	June 22 - 25, 2022 in Copenhagen, Denmark. ( Annual ESPGHAN Meeting 2022 )
<b>Date</b>	TBD
<b>Main Points / Activities</b>	Management & Financial issues / Planning of new activities

<b>Meeting</b>	<b>12 th Meeting of the CD Special Interest group - Close Meeting Close Meeting</b>
<b>Location</b>	June 22 - 25, 2022 in Copenhagen, Denmark. ( Annual ESPGHAN Meeting 2022 )
<b>Date</b>	TBD
<b>Main Points / Activities</b>	Updating of new CD SIG working groups activities ( guidelines & position papers ) WGs Parallel working session

<b>Meeting</b>	<b>Meeting of the CD Special Interest group – Open Meeting ( Annual ESPGHAN Meeting 2022 )</b>
<b>Location</b>	June 22 - 25, 2022 in Copenhagen, Denmark.
<b>Date</b>	TBD
<b>Main Points / Activities</b>	<u>Agenda TBD</u> : (about 100 attendees expected) Welcome to new members Updating on activities of the CD-SIG Opportunity to propose New activities for the CD-SIG
<b>Meeting</b>	Annual ESPGHAN Meeting 2022
<b>Location</b>	June 22 - 25, 2022 in Copenhagen, Denmark.
<b>Date</b>	TBD
<b>Main Points / Activities</b>	Symposium on CD

N B: Additional Virtual meetings will be organized related to the progress of the ongoing Position papers .

## B. Proposed Educational activities

### D. Educational Events

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

<b>Full Event Name</b>	2nd Master class on CD		
<b>Location</b>	Copenhaguen ( TBC)		
<b>Date</b>	TBC		
<b>Organizer</b>	Steffen Husby (TBC)		
<b>Email Organizer</b>			
<b>Applied for EPP</b>	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No	
<b>Applied for UEG Training Support</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
<b>more information if available</b>			

### E. E-Learning

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

<b>Full Project Name</b>	
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<b>Project Timeline</b>	
<b>Project Leader</b>	
<b>more information if available</b> (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)

<b>Full Publication Title</b>	Recommendations for a Gluten free diet in Children and adolescents with CD			
<b>Publication Timeline and Status of Paper</b>	TBD 2022			
<b>Publication Leader</b>	Paula Crespo & Anita Vreugdenhil			
<b>Publication Type</b>	<input type="checkbox"/> Guideline	<input checked="" type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
<b>More information if available</b>				

<b>Full Publication Title</b>	CD follow-up and Management			
<b>Publication Timeline and Status of Paper</b>	TBD 2021-22			
<b>Publication Leader</b>	M <sup>a</sup> Luisa Mearin			
<b>Publication Type</b>	<input type="checkbox"/> Guideline	<input checked="" type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
<b>More information if available</b>				

<b>Full Publication Title</b>	Enquiry and follow-up of CD in children in Europe.. Results of the CD-SIG survey			
<b>Publication Timeline and Status of Paper</b>	TBD 2021			
<b>Publication Leader</b>	Margreet Wessels/Jernej Dolinsek/ L Mearin			
<b>Publication Type</b>	<input type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input checked="" type="checkbox"/> Other
<b>More information if available</b>				

### D. Financial Report / Budget for 2021:

(iv) Kindly attach or copy paste your submitted budget request for 2022

#### 1. Face to Face meeting Leiden ( The Netherlands) 22 January , 2022

11th Meeting of the CD Special Interest group - Close Meeting. Leiden ( The Netherlands)

1 full day meeting .

Attendees around 25-30 CD SIG Core members

Budget (Travel costs up to 300€ + 1 night accommodation + Dinner +Venue ( including Lunch) : Budget 13.000 €

***Total Budget Requested 2022 : 13000 €***

(v) **Additional comments on financial report:**