



## 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)

<b>Meeting</b>	ESPGHAN Cystic Fibrosis/Pancreas Interest Group meeting
<b>Location</b>	Glasgow, UK
<b>Date</b>	May 2019
<b>Main Points / Activities</b>	<ol style="list-style-type: none"> <li>1. New definition of CFLD (Frank Bodewes)</li> <li>2. Feedback report from the CF-Monothematic in Valencia (Frank Bodewes)</li> <li>3. Contribution of elastography in the diagnosis of CF-related liver disease using Fibroscan, elastography shear wave and MRE (Dominique Debray)</li> <li>4. Proposal for joint manuscript “Diagnostic work-up of ARP and CP in children – Tools for the general GI” (Isabelle Scheers)</li> <li>5. PERT adjustment, lessons learned from the MyCFaPP clinical trial (Joaquin Calvo)</li> <li>6. Pediatric pancreatitis, perspectives from the APPLE Trial (Andreea Parniczky)</li> <li>7. Proposition from the European Pediatric Hereditary Database (Grzegorz Oracz)</li> </ol>

<b>Meeting</b>	ESPGHAN / NASPGHAN guidelines on Cystic Fibrosis associated liver disease
<b>Location</b>	Bethesda, USA
<b>Date</b>	July 2019
<b>Main Points / Activities</b>	<ol style="list-style-type: none"> <li>1. Outline and procedure of definition were discussed and agreed</li> <li>2. 3 subgroups started on writing the individual subheading text including background and references</li> </ol>

### B. Educational activities

#### (i) Educational Events

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

<b>Full Event Name</b>	ESPGHAN Monothematic CF conference	
<b>Location</b>	Valencia, Spain	
<b>Date</b>	April 2019	
<b>Organizer</b>	Carmen Ribes Koninckx	
<b>Email Organizer</b>		
<b>EPP</b>	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
<b>UEG Training Support</b>	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
<b>more information if available</b>		

#### (ii) E-Learning

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

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



### 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>Authors</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>Journal, Year, Volume, Page Numbers</b>	
<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>	Expert consensus on CFLD definitions (ESPGHAN and NASPGHAN collaboration)
<b>Publication Timeline and Status of Paper</b>	Completion by 12/2019
<b>Publication Leader</b>	Frank Bodewes / Michael Narkewicz
<b>Publication Type</b>	<input type="checkbox"/> Guideline <input type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper            X Other
<b>More information if available</b>	

#### (iii) future topics considered in 2019

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

<b>Full Publication Title</b>	Clinical practice guidelines for first line work-up of acute recurrent / chronic pancreatitis			
<b>Publication Timeline and Status of Application for Paper</b>	09/2019 – Define WG members 12/2019 – Meeting, task assignment, paper layout 03/2020 – Discussion of first draft 06/2020 – Review by the members 09/2020 – Submission to JPGN			
<b>Publication Leader</b>	Isabelle Scheers			
<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>				

<b>Full Publication Title</b>	Impact of CFTR modulators on patient dietary advice			
<b>Publication Timeline and Status of Application for Paper</b>	TBA			
<b>Publication Leader</b>	Frank Bodewes / Etna Masip			
<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>				



<b>Full Publication Title</b>	CFTR-gene mutation related pancreatitis network (CFPANET)		
<b>Publication Timeline and Status of Application for Paper</b>	Application for Networking Grant 2019		
<b>Publication Leader</b>	Frank Bodewes Co-leaders: Dominique Debray, Carmen Ribes, Michael Wilschanski, Etna Masip and Isabelle Scheers		
<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 / YTD 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 – Working Group on CFLD definitions – Bethesda, USA – July 2019		
Activity 2 – CF/Pancreas SIG Board meeting – July 2019		
Activity 3		
Activity 4		
Activity 5		
Activity 6		
Activity 7		
Activity 8		
<b>TOTAL Expenses 2019</b>		
Income	Please also add funding from other sources if applicable	
Activity 1		
Activity 2		
Activity 3		
Activity 4		
Activity 5		
<b>TOTAL Income 2019</b>		

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)

<b>Meeting</b>	WCPGHAN
<b>Location</b>	Copenhagen, DK
<b>Date</b>	May 2020
<b>Main Points / Activities</b>	Annual meeting special interest group meeting



## B. Proposed Educational activities

### (i) Educational Events

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

<b>Full Event Name</b>	ESPGHAN/NASPGHAN joint monothematic conference on acute recurrent and chronic pancreatitis in children		
<b>Location</b>	Brussels, Belgium		
<b>Date</b>	2021		
<b>Organizer</b>	Isabelle Scheers		
<b>Email Organizer</b>			
<b>Applied for EPP</b>	<input 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>			

### (ii) Scientific Symposia planned for the Annual Meeting

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

<b>Full Symposia Name</b>	Recent advances in Cystic Fibrosis
<b>Project Leader</b>	Frank Bodewes / Isabelle Scheers / Etna Masip
<b>more information if available</b>	CF and pancreatitis Cystic Fibrosis Liver Disease what's known, how to go forward? Imaging in quantifying fibrosis in CFLD PERT in CF, MyCFApp follow-up

## 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>	Expert consensus on CFLD definitions			
<b>Publication Timeline and Status of Application of Paper</b>	01/ 2020 Paper submission			
<b>Publication Leader</b>	Frank Bodewes / Michael Narkewicz			
<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>				

<b>Full Publication Title</b>	Clinical practice guidelines for first line work-up of acute recurrent / chronic pancreatitis			
<b>Publication Timeline and Status of Application for Paper</b>	09/2019 – Define WG members 12/2019 – Meeting, task assignment, paper layout 03/2020 – Discussion of first draft 06/2020 – Review by the members 09/2020 – Submission to JPGN			
<b>Publication Leader</b>	Isabelle Scheers			
<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 2020:**

- Kindly attach or copy paste your submitted budget request for 2020
  
- Additional comments on financial report:
  
- Any other issues that may be of interest

