

**ESPGHAN**European Society for Paediatric
Gastroenterology, Hepatology and NutritionRue De-Candolle 16
1205 Genève, Switzerland
www.espghan.org**Working/Special Interest group - Report for Hepatology Committee****Working Group Title: European Reference Network RARE LIVER**

(date of completion 05.08..2019; ES)

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
Ekkehard Sturm	2017	2018		Coordinator/ chair	2018-
Marianne Hørby Jørgensen	2017	2019		WG secretary	2019
Etienne Sokal	2017				
Emmanuel Gonzales	2017				
Enke Grabhorn	2017				
Mara Cananzi	2017				
Valerie McLin	2017				
Deirdre Kelly	2017				
Bjoern Fischler	2017				
Loreto Hiero	2017				
Ruth DeBruyne	2017				

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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	ERN RARE LIVER MEETING
Location	Hamburg, Germany
Date	January 31- February 1 2019
Main Points / Activities	Aims, use of CPMS, implementation biliary atresia and congenital shunt registry, grant applications
Meeting	WG ERN RARE LIVER MEETING
Location	Glasgow, UK
Date	June 2019, ESPGHAN Annual Meeting
Main Points / Activities	Aims, use of CPMS, implementation biliary atresia, 3 rd line therapy AIH, grant applications, Survey on Paediatric Liver Care across Europe for the EASL Lancet Commission, ESPGHAN Quality of Care initiative, Quality of Care of A1ATD in Europe, Cooperation with MetabERN
Meeting	ERN RARE LIVER MEETING AT EASL
Location	Vienna, Austria
Date	April 2019, EASL meeting
Main Points / Activities	Aims, use of CPMS, implementation liver tumor registry, ERN RARE LIVER Statutes
Meeting	ERN RARE LIVER session at CPLD meeting
Location	Hamburg, Germany
Date	November 2019
Main Points / Activities	Aims, use of CPMS, implementation biliary atresia and alpha1-antitrypsin registry, transition

B. Educational activities

(i) Educational Events

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

Full Event Name	EASL /ESPGHAN School of Rare Liver Disease (proposed)		
Location	Tbd		
Date	Tbd 2020		
Organizer	ERN RARE LIVER management board		
Email Organizer			
EPP	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
UEG Training Support	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
more information if available			

(ii) E-Learning

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

Full Project Name	Use of Clinical Patient Management System (CPMS) as tool for fellow training in ped hepatology (in preparation)
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Project Timeline	Concept ready in Dec 2019
Project Leader	Ekkehard Sturm
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	Position statement on access to care in rare liver diseases: advancements of the European reference network (ERN) RARE-LIVER.
Authors	Bernts LHP, Jones DEJ, Kaatee MM, Lohse AW, Schramm C, Sturm E, Drenth JPH.
Publication Type	<input type="checkbox"/> Guideline <input checked="" type="checkbox"/> Position Paper <input type="checkbox"/> Update of existing paper <input type="checkbox"/> Other
Journal, Year, Volume, Page Numbers	Orphanet J Rare Dis. 2019 Jul 8;14(1):169. doi: 10.1186/s13023-019-1152-z. PubMed PMID: 31287000; PubMed Central PMCID: PMC6615270.
More information if available	

(ii) future topics considered in 2019

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

Full Publication Title	What is the evidence in the pediatric population for third line treatment in autoimmune hepatitis?			
Publication Timeline and Status of Application for Paper	Estimated submission in 2020			
Publication Leader	Marianne Hørby Jørgensen			
Publication Type	<input type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
More information if available				
Full Publication Title	Report EASL Lancet Commission on Liver Disease in Europe.			
Publication Timeline and Status of Application for Paper	Estimated submission in 2020			
Publication Leader	Deirdre Kelly			
Publication Type	<input type="checkbox"/> Guideline	<input type="checkbox"/> Position Paper	<input type="checkbox"/> Update of existing paper	<input type="checkbox"/> Other
More information if available	Deirdre Kelly			



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	ERN RARE LIVER at ESPGHAN Annual Meeting
Location	Copenhagen
Date	
Main Points / Activities	
Meeting	ERN RARE LIVER Spring Meeting
Location	tbd
Date	
Main Points / Activities	

B. Proposed Educational activities

(i) Educational Events

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

Full Event Name	Use of CPMS for fellow training in ped hepatology (in preparation) Concept ready in Dec 2019
Location	
Date	Introduction during ERN RARE LIVER Meeting September 2019, at meeting with Young ESPGHAN and at EASL/ ESPGHAN Annual meetings
Organizer	Ekkehard Sturm, Toni Illhardt
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	

(ii) Scientific Symposia planned for the Annual Meeting

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

Full Symposia Name	Value of registries on rare liver diseases
Project Leader	Henkjan Verkade
more information if available	To be proposed to council for slot at ESPGHAN meeting 2020, Saturday program

C. Proposed Publications / Guidelines / Position Papers

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

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



