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# Training in pediatric hepatology across Europe: a survey of the National Societies Network (2016-2019) of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition

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## Abstract

**Background** The widely recognized burden of liver diseases makes training in pediatric hepatology (PH) imperative. The aim of this survey, which was part of a global survey on training in pediatric gastroenterology, hepatology and nutrition (PGHN) across Europe, was to assess the PH and liver transplantation (LT) infrastructure, staff and training programs in PGHN training centers.

**Method** Standardized questionnaires were collected from training centers via the presidents/representatives of the National Societies Network of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) from June 2016 to December 2019.

**Results** A total of 100 PGHN training centers participated in the survey (14/100 were national referral centers in PH and/or LT). Dedicated PH clinics were available in 75%, but LT clinics in only 11%. Dedicated beds for PGHN inpatients were available in 47/95 (49%) centers. Full-time or part-time specialists for PH care were available in 31/45 (69%) and 11/36 (31%) centers, respectively. Liver biopsies (LB) were performed in 93% of centers by: a PGHN specialist (35%); an interventional radiologist (26%); a pediatric surgeon (4%); or a combination of them (35%). Dividing the annual number of LBs in the centers performing LBs by the number of trainees gave a median (range) of 10 (1-125) per trainee. Transient elastography was available in 60/92 (65%) of centers.

**Conclusions** The survey highlighted the differences and shortcomings in PH training across Europe. ESPGHAN should take initiatives together with National Societies to ensure the acquisition of PH knowledge and skills according to the ESPGHAN curriculum.

An infographic is available for this article at: <http://www.annalsgastro.gr/files/journals/1/earlyview/2022/Infographic-Hepatology-training-paper.pdf>

**Keywords** Hepatology, children, training, pediatric gastroenterology, nutrition

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## Introduction

Hepatobiliary diseases have a significant impact on pediatric patients. Therefore, trainees in pediatric gastroenterology, hepatology and nutrition (PGHN) should be familiar with their pathophysiological mechanisms and be fully engaged in their diagnosis and management [1,2] so that future pediatric gastroenterologists become independent, qualified and competent specialists in these diseases [3-5].

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Trainees should be exposed to a sufficient number of patients and a sufficient number of procedures and be able to develop and implement a plan for the diagnosis, management and treatment of patients with such diseases using a multidisciplinary approach [3-5]. The progressive maturation of pediatric hepatology (PH) has led to the determination of a hepatology-focused curriculum and educational content for PGHN training programs, as well as training requirements for those who wish to pursue further training in this specific area. The aim of our survey was to assess the PH-related infrastructure, staff and patient volumes of the various PGHN training centers across Europe.

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Conflict of Interest: None

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## Materials and methods

This study constitutes a subgroup analysis of a major project to examine the infrastructure, staffing, patient and procedure volume and organization of PGHN training in PGHN training centers across Europe. Questions related to PH and liver transplantation (LT) were included in the standardized questionnaires (Supplementary Appendix 1) created by the members (AP, AB and CRC) of the Executive Committee of the National Societies Group 2015-2017 of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and sent to the presidents/representatives of the ESPGHAN National Societies, who distributed them to the heads of PGHN training centers in their countries and collected the responses. In countries where no official National Society representative participated in the survey (Italy, Portugal and Switzerland), a volunteer among ESPGHAN members from that country was asked to distribute and collect the questionnaires (Italy and Switzerland), or individual centers provided their data after direct communication with the study coordinators (Portugal). The project was approved by the ESPGHAN Council in 2016 and supported by ESPGHAN. It was implemented from 1 June 2016 to 31 December 2019. The manuscript was sent for review and constructive comments to the former ESPGHAN President, former Chair of the ESPGHAN Hepatology Committee and Public Affairs Committee, Professor of Pediatric Hepatology, DK.

## Statistical analysis

Appropriate statistical analysis was performed with the use of IBM SPSS software. Descriptive statistics was performed to characterize study groups. Continuous data were tested for normality using the Kolmogorov-Smirnov test and graphical methods (histogram, Q-Q plot). For normally distributed variables, the Student's *t*-test was used to assess differences between groups, and the Mann-Whitney *U* test for skewed variables. For categorical data, the  $\chi^2$  test was used, or the Fisher exact test where data were not suitable for  $\chi^2$  testing. ANOVA or the Kruskal-Wallis test was used to test for differences in continuous variables among more than 2 groups, depending on the variables' distribution. Correlations among continuous variables were analyzed using Spearman's or Pearson's test, depending on the variables' distribution. Factors found to be statistically significant in univariate analyses were included in the multivariate analyses to identify independent associations, if any. All statistical analyses were performed with the statistical package SPSS Statistics 21 (SPSS, Inc., Chicago, IL, USA). Statistical significance at  $P < 0.05$  will be assumed.

## Results

A total of 100 training centers from 17 European countries, Turkey and Israel (Supplementary Appendix 2), participated in the survey. Seventy of these were national referral centers—43

in PGHN (Group 1), 14 in PH and/or LT (Group 2), and 13 in pediatric gastroenterology (PG; Group 3)—and 30 were regional referral centers. Thirty training centers were in the capital cities of the 19 countries: 29 were national referral centers (20 in PGHN, 4 in PH and/or LT and 5 in PG), while one was a regional referral center.

The age limit for patient care by most of these centers is 18 years. However, the center in Innsbruck cares for children up to the age of 16 years, while 2 centers (in Rome and Zagreb) care for patients up to the age of 21 years. Dedicated clinics for PH and/or LT were present in 68/91 (75%) centers: 49/64 (77%) of the national referral centers that answered the relevant question and 19/27 (70%) of the regional centers. Among the groups of national referral centers, dedicated clinics for PH and/or LT were present in 25/37 (68%) centers in Group 1, in 14/14 (100%) in Group 2 and in 10/13 (77%) in Group 3. However, dedicated clinics for LT were available in only 9/84 (11%) centers, 8 of which were national referral centers: 0/31 (0%) in Group 1, 7/12 (58.3%) in Group 2 and 1/12 (8%) in Group 3 (jointly with a national PH/LT referral center). Furthermore, dedicated clinics for PH and/or LT were present in 20/28 (71%) of the training centers established in European capitals that answered the relevant question.

Dedicated beds for pediatric gastroenterology and hepatology inpatients were available in 37/69 (54%) of the national referral centers that answered the relevant question in the total cohort, and in 10/14 (71%) of the national referral centers for PH. Full-time specialists for PH care were available in 31/45 (69%) of centers and part-time specialists in 11/36 (31%) of training centers (Table 1). Liver biopsies (LB) were performed in 85 training centers (Table 2). The performers of LBs in different training centers were the following: PGHN specialists in 35% of training centers, interventional radiologists in 26%, surgeons in 4%, and

a combination of them in 35% (Table 1). Transient elastography was available in 60/92 (65%) training centers (Table 1).

The annual number of procedures in the training centers of the total cohort is shown in Table 1. Annual numbers of LBs >100 were reported by 6 national referral centers for PH and LT (King's College Hospital, London, UK; Birmingham Children's Hospital, UK; Saint-Luc University Hospital, Catholic University de Louvain, Brussels, Belgium; Papa Giovanni XXIII Hospital, Bergamo, Italy; Woman Mother Child Hospital, Lyon, France; Schneider Children's Medical Center of Israel, Petah Tiqva, Israel). Ten LBs or fewer per year were reported by 61% of regional centers compared to 30% of national referral centers ( $P=0.022$ ; Table 2). A multinomial logistic regression analysis showed that national PH referral centers were more likely to perform large numbers of LBs (51-100 or >100 liver biopsies per year) than any other centers ( $P<0.001$ ; Table 2). No significant differences in procedure volume were found between training centers located in European capitals and other cities ( $P=0.377$ ; Table 2). The annual procedural volume in the training centers of the total cohort, according to the number of outpatients, is shown in Table 3. Thirty-two of 85 (38%) training centers reported a low number ( $\leq 10$ ) of LBs per year (Table 3). Low ( $\leq 10$ ) annual numbers of LBs were reported by 60% of centers with less than 1500 outpatients per year, but also by 19% of those centers with the highest (>5000) annual numbers of outpatients (Table 3).

Dividing the total number of LBs performed at the training center per year by the number of trainees, the median (interquartile range, range) annual number of LB per trainee in the cohort of centers performing LBs, is 10 (5-28, 1-125). Significant differences were found between national referral centers and regional centers ( $P=0.06$ ) and between different categories of training centers ( $P=0.005$ ), with trainees in PH national referral centers having the greatest exposure to LBs.

**Table 1** Availability of specialists for PH care, availability of transient elastography and liver biopsy operators in PGHN training centers

Specialists	National referral centers in PGHN (n=43)	National referral centers in PH (n=14)	National referral centers in PG (n=13)	Regional centers (n=30)	Centers in European capitals (n=30)	Centers in other cities (n=70)
Availability of full-time/part-time specialist for PH care						
Full-time	13/21 (62%)	9/9 (100%)	5/8 (63%)	4/7 (57%)	11/15 (73%)	20/30 (67%)
Part-time	5/16 (31%)	3/6 (50%)	1/7 (14%)	2/7 (29%)	4/9 (44%)	7/27 (26%)
Liver biopsy operator						
PGHN specialist only	17/40 (43%)	4/12 (33%)	3/11 (27%)	8/29 (28%)	12/28 (43%)	20/64 (31%)
Interventional radiologist only	9/40 (22%)	0/12 (0%)	3/11 (27%)	12/29 (41%)	7/28 (25%)	17/64 (27%)
Pediatric surgeon only	3/40 (8%)	0/12 (0%)	0/11 (0%)	1/29 (3%)	2/28 (7%)	2/64 (3%)
PGHN specialist and interventional radiologist	6/40 (15%)	5/12 (42%)	2/11 (18%)	6/29 (21%)	4/28 (14%)	15/64 (23%)
PGHN specialist and pediatric surgeon	3/40 (8%)	3/12 (25%)	3/11 (27%)	2/29 (7%)	1/28 (4%)	10/64 (16%)
Interventional radiologist and pediatric surgeon	2/40 (5%)	0/12 (0%)	0/11 (0%)	0/29 (0%)	2/28 (7%)	0/64 (0%)
Availability of transient elastography						
Transient elastography	24/39 (62%)	9/13 (69%)	8/11 (73%)	19/29 (66%)	15/25 (60%)	45/67 (67%)

PGHN, pediatric gastroenterology, hepatology and nutrition; PG, pediatric gastroenterology; PH, pediatric hepatology; The numerators indicate the number of centers that answered the corresponding question and the denominators indicate the total number of centers

**Table 2** Annual numbers of liver biopsies performed at the PGHN training centers across Europe

No of liver biopsies	National referral centers in PGHN (n=38/43)	National referral centers in PH (n=13/14)	National referral centers in PG (n=11/13)	Regional centers (n=23/30)	Centers in European capitals (n=24/30)	Centers in other cities (n=61/70)
≤10	12/38 (32%)	0/13 (7.1%)	6/11 (55%)	14/23 (61%)	8/24 (33%)	24/61 (39%)
11-50	20/38 (53%)	5/13 (36%)	5/11 (46%)	9/23 (39%)	10/24 (42%)	29/61 (48%)
51-100	3/38 (8%)	5/13 (36%)	0/11 (0%)	0/23 (0%)	3/24 (13%)	5/61 (8%)
>100	3/38 (8%)	3/13 (21%)	0/11 (0%)	0/23 (0%)	3/24 (13%)	3/61 (5%)

The numerators indicate the number of centers that answered the corresponding question and the dominators indicate the total number of centers

PGHN, pediatric gastroenterology, hepatology and nutrition; PG, pediatric gastroenterology; PH, pediatric hepatology

**Table 3** Annual procedural volume of liver biopsies performed by training centers according to the annual numbers of outpatients

Annual No of outpatients	≤10	11-50	51-100	>100
≤500 (n=3*)	3/3 (100%)	0/3 (0%)	0/3 (0%)	0/3 (0%)
501-1500 (n=12*)	6/12 (50%)	5/12 (42%)	1/12 (8%)	0/12 (0%)
1501-3000 (n=28*)	12/28 (43%)	11/28 (39%)	4/28 (14%)	1/28 (4%)
3001-5000 (n=24*)	8/24 (33%)	13/24 (54%)	0/24 (0%)	3/24 (13%)
>5000 (n=16*)	3/16 (19%)	8/16 (50%)	3/16 (19%)	2/16 (13%)

\*The numbers indicate the number of centers that answered the question about the center's outpatient volume per year and the annual number of liver biopsies performed

No significant differences were found between centers located in capital cities compared to other cities ( $P=0.659$ ; Table 4).

We were interested in finding out if there are differences between countries in the frequency with which LBs are performed in the population aged 0-19 years. The number of LBs per 100,000 population aged 0-19 years performed annually by all training centers in countries where training centers are fully represented in the survey is shown in Fig. 1. The population aged 0-19 years is from the international database of the United States Census Bureau [6]. Although countries with a larger number of children aged 0-19 years reported a higher number of LBs ( $r_s=0.714$ ;  $P=0.047$ ), the number of LBs per 100,000 population aged 0-19 years did not correlate with the number of children per country ( $r_s=-0.071$ ;  $P=0.867$ ). We were also interested in knowing the procedural volumes of the major centers in each country among those participating in the survey, to identify potential training centers in each country and at a European level. The annual number of LBs performed by the PGHN centers with the largest procedural volumes among the participating centers in each country is shown in Fig. 2. Twelve of the 18 centers were pediatric liver transplant centers. The total number of PGHN specialists in the top 6 centers (i.e., those with the highest number of LBs) was 52 (37 fulltime), while it was 22 (13 fulltime) in the 6 centers with the lowest number of LBs and 38 (29 fulltime) in the 6 centers with a medium number of LBs. The centers with the highest numbers of procedures had a larger outpatient volume, as 5/6 (83%) of the top 6 centers reported >3000 outpatients per year (3/6, >5000), which was not the case for the centers with a medium or the lowest number of LBs, as only 2/6 (33%) of the centers with a medium number and 2/6 (33%) of centers with the lowest number of LBs have reported >3000 outpatients per year.

## Discussion

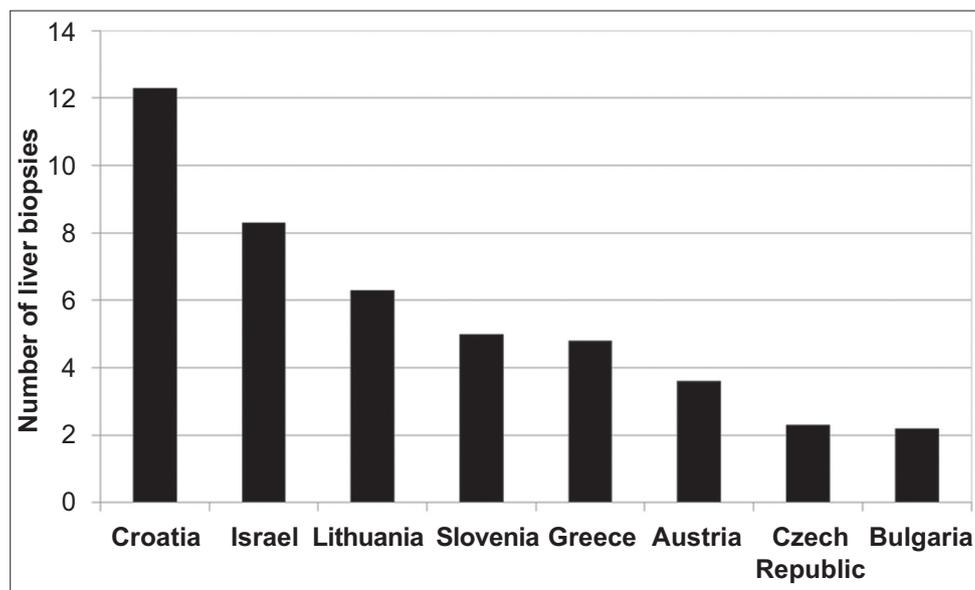
The survey shows that the infrastructure, staff, training program, patients and procedural volumes related to PH vary widely across PGHN training centers in Europe. Dedicated clinics for PH were present in 3/4 of the training centers, while dedicated clinics for LT were present in only one tenth. Full-time specialists to care for PH patients were reported by 2/3 of the training centers and part-time specialists by almost 1/3. Dedicated beds for pediatric gastroenterology and hepatology inpatients were reported by half of the training centers. The number of LBs varied considerably among the different training centers, as 38% of them performed 10 LBs or fewer per year, while 6 national reference centers for PH and LT performed more than 100 LBs per year. Trainees on fellowship at the latter centers were exposed to double to quadruple the number of LBs. The latter training centers also had the largest outpatient volumes, with 2/5 of them exceeding 5000 outpatients per year. In about 1/3 of the training centers LBs were performed only by PGHN specialists, in 1/4 only by interventional radiologists, while in about 1/3 LBs involved a combination of different specialists (PGHN, interventional radiologists or pediatric surgeons).

Williams *et al* highlighted the increasing burden of liver diseases and specific problems in hepatology training in the UK [7]. In 2013, the Hepatology Advanced Training Program was launched to provide clinicians with the opportunity to obtain a subspecialty certificate in hepatology, with only 20 posts available each year [8]. The PGHN training curriculum proposed by both ESPGHAN [3,4] and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) [5] provides a broad knowledge of hepatobiliary diseases. In addition, NASPGHAN envisages

**Table 4** Median (IQR; range) number of trainees in training centers performing liver biopsies and median (IQR; range) annual number of liver biopsies per trainee

Center	No of trainees (median IQR; range)	No of LBs per trainee (median IQR; range)	P-value
National referral center (n=70)	2 (1-5; 0-10)	13* (6-33; 1-125)	
Regional center (n=30)	2 (1-3; 0-10)	10** (5-13; 2-20)	* vs. ** 0.06
National referral center in PGHN (n=43)	2 (1-3; 1-6)	10^ (5-30; 1-83)	
National referral center in PH (n=14)	2 (1-2; 0-5)	38^^ (28-70; 3-125)	
National referral center in PG (n=13)	2 (1-5; 0-10)	8^^^ (5-15; 3-20)	^ vs. ^^ vs. ^^ 0.005
Centers in capitals (n=30)	2 (1-5; 1-10)	13# (6-31; 1-83)	
Centers in other cities (n=70)	2 (1-2; 0-7)	10## (5-20; 2-125)	# vs. ## 0.659

IQR, interquartile range; PGHN, pediatric gastroenterology, hepatology and nutrition; PG, pediatric gastroenterology; PH, pediatric hepatology; LBs, liver biopsies

**Figure 1** Annual number of liver biopsies per 100,000 population aged 0-19 years [7] in countries with full representation of the pediatric gastroenterology, hepatology and nutrition training centers

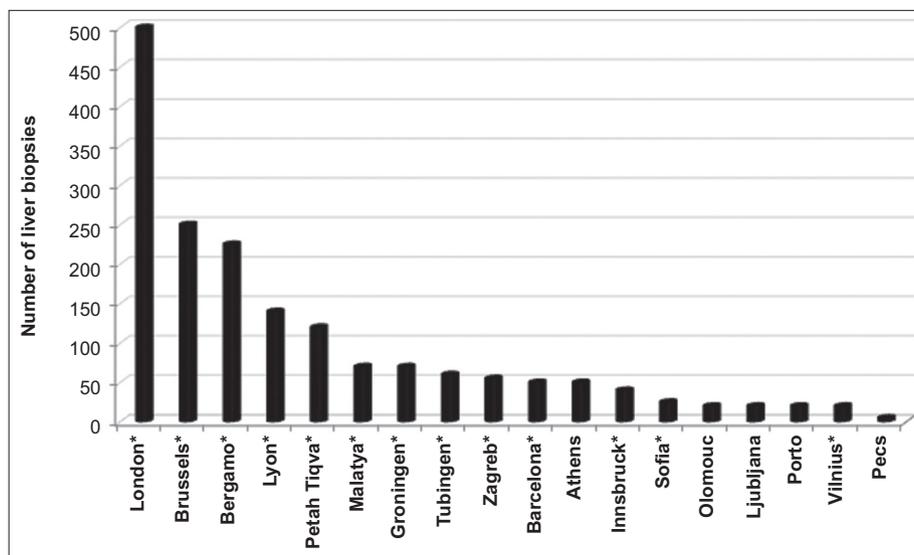
a special PH fellowship program to improve expertise in pediatric PH and LT [5].

There is reportedly a variety of training opportunities in hepatology in the UK, even for adult specialists [9], and the Lancet Commission proposed the establishment of dedicated liver centers in district general hospitals to improve training in this important area [7]. Early identification of training fellows interested in hepatology can provide future specialists with the necessary knowledge, experience and skills to provide the best possible care to patients with hepatobiliary diseases [10,11].

Our survey showed that the age range of the children cared for by the different centers varied: it ranged from 16 years in Innsbruck to 21 years in Rome and Zagreb PH and LT centers. However, it is common knowledge that patients with chronic diseases need medical care into adulthood. Health care transition should be understood as a targeted, planned transition of adolescents with chronic diseases from a child-centered to an adult-centered healthcare system [12], taking into account that this particular

patient age group is at high risk for developmental and psychosocial problems. A successful transition program can limit some of the psychosocial effects of chronic illness by improving self-efficacy and autonomy, as well as treatment adherence [13-15].

Furthermore, differences in the number of procedures per 100,000 population aged 0-19 years were evident between countries, with Croatia reporting the highest number of LBs, while the Czech Republic and Bulgaria report the lowest, although the reasons for these differences are not known. The ESPGHAN Position Paper on LB [16] describes the clinical indications for performing LBs to diagnose liver disease. However, implementation of the guidelines in clinical practice is not always possible. Strategies are needed to improve the adoption, implementation and sustainability of guidelines. At the same time, the most important criterion by which aspects of medical care should be measured is disease outcome, which was outside the scope of this survey, with improvement in outcomes following a particular intervention being the real benefit.



**Figure 2** Annual number of liver biopsies performed by the pediatric gastroenterology, hepatology and nutrition center with the largest procedural volume amongst participating centers in each country. The centers shown in the figure are the following: London (King's College Hospital); Brussels (Saint-Luc University Hospital); Bergamo (Papa Giovanni XXIII Hospital); Lyon (Woman Mother Child Hospital); Petah Tiqva (Schneider Children's Medical Center of Israel); Malatya (Inönü University Faculty of Medicine); Groningen (University Medical Center Groningen); Tübingen (University Children's Hospital, Tübingen); Zagreb (University Hospital Center Zagreb); Barcelona (Vall d'Hebron University Hospital); Athens (Agia Sofia Children's hospital); Innsbruck (Innsbruck Medical University); Sofia (Ivan Mitev Specialized Hospital for Active Treatment of Children's Diseases); Olomouc (Olomouc University Hospital); Ljubljana (Ljubljana University Medical Center); Porto (São João University Hospital); Vilnius (Vilnius University Hospital Santaros Klinikos); Pécs (Pécs University Medical School). (\*) Centers with pediatric liver transplant programs

Regarding training, there are currently no universally accepted recommendations for the training and experience required to qualify a person to perform LBs. The American Association for the Study of Liver Disease recommended a minimum of 40 LBs under supervision [17], while NASPGHAN recommended a minimum of 20 LBs performed independently, of which half should be in infants and children aged <3 years [18]. A similar number of LBs was also recommended by the American Gastroenterology Association in "Training the Gastroenterologist for the Future" [19]. A minimum number of 50 procedures was recommended by the British and Irish Committee on Higher Medical Training [20]. The effect of the experience of the person performing LBs on the adequacy of the obtained liver tissue and on complication rate is poorly defined [21]. An audit carried out by the British Society of Gastroenterology in 1991 reported a slightly higher incidence of complications if the operator had performed <20 LBs compared with >100 (3.2% vs. 1.1%) [22]. Regarding the ability to obtain adequate tissue, one report claimed that physician assistants who observed 10 LBs, practiced on inanimate objects, and then performed 30 LBs under supervision were able to obtain adequate tissue in 99.1% of attempts after a single pass and in 99.8% after 2 passes, with a mean tissue length of 3.2 cm [23]. Another report claimed that, in a series of 101 LBs performed independently by a hepatologist with no prior experience in ultrasound diagnostics, after observing 64 LBs performed by a certified ultrasound technician, no differences in complication rate or in adequacy of the obtained liver tissue were found [24]. The authors of the Position Paper on LB of the ESPGHAN Hepatology Committee suggested that a minimum of 20 LBs should be performed under supervision [16]. Based on the above,

it is reasonable for low procedure volume training centers to work with larger centers within a clinical network. Clinical networks provide opportunities for multidisciplinary team meetings between doctors, surgeons and other professionals, audits and other quality improvement activities, data management, shared information technology protocols and research [25]. They provide access to specialized care, regardless of where patients live, and ensure that access to specialist advice is available by telephone 24/7. Specialist hepatology services and training in hepatology are provided in the UK by 3 leading specialist centers in Leeds, Birmingham and London [25]. Access to these services is by direct referral from primary or secondary services or by referral from the specialist gastroenterology service. Shared care is provided through network arrangements, including outreach clinics organized in close collaboration with local and specialist pediatric consultants, offering joint consultations and agreed local investigations and treatment.

This study had a number of limitations, such as the cross-sectional study design and the variability of the response rate, as there were countries where PGHN training centers were fully represented (Austria, Bulgaria, Czech Republic, Croatia, Greece, Israel, Lithuania and Slovenia), while other countries such as Germany and Turkey had limited representation, as only a few centers participated in the survey. However, the greatest value of this survey is that this first collaborative work of the ESPGHAN National Societies provides the largest set of data on the infrastructure, staffing, number of procedures and training programs in PH across Europe, identifying discrepancies that can help ESPGHAN, together with the National Societies, to develop actions to fill the identified gaps to achieve excellence in training and medical care across Europe.

In conclusion, this survey showed clear differences and deficits in terms of PH infrastructure, staff, patient and procedure volumes, and thus training opportunities, between PGHN training centers across Europe. ESPGHAN, together with the National Societies, should take initiatives for a well-structured training program according to the ESPGHAN curriculum, supporting the rotation of trainees to referral centers with large patient and procedure volumes and their participation in training courses and schools, as well as for developing competence assessment and accreditation measures where these are lacking.

### Summary Box

#### What is already known:

- The goal of the training program in pediatric hepatology is to provide excellent clinical and research training, so that pediatric gastroenterologists become independent, qualified and competent specialists in liver diseases

#### What the new finding is:

- Major differences exist in the infrastructure, staff, training programs, patients, and procedural volumes, between pediatric gastroenterology, hepatology and nutrition training centers across Europe

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## Supplementary material

### Supplementary Appendix 1

#### Questionnaire

#### EUROPEAN SURVEY ON PEDIATRIC GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION TRAINING CENTERS

Name of the Training Center

City:..... Country:.....

Contact Person: Name .....

Position:.....

e-mail:

#### Information on Training Programs

Does the Center provide:

- full training in pedGHN Y  N  number of training places
- training only in gastroenterology Y  N  number of training places ()
- training only in hepatology Y  N  number of training places ()
- training in nutritional care Y  N  number of training places ()
- training in research techniques Y  N  number of training places ()
- Is research mandatory in training? Y  N  but strongly recommended
- training in pancreatic diseases Y  N  number of training places
- training in metabolic diseases Y  N  number of training places
- training in transplantation Y  N  number of training places
- training in nutritional failure Y  N  number of training places
- Maximum number of trainees in post at any given time:

Does your department have a training lead? Y  N

Does your department have training links/relationships with other departments? Y  N

Does your department have a training curriculum? Y  N

Minimum duration of training:....

Which formal body certifies your trainees as competent?.....

Please summarise how trainees are assessed

Global assessment + technical skills + personal project (presentation and publication)

#### GENERAL DATA

Is it a National Referral Center for PGHN

For all GI specialities Y  N

Only for specific subspecialties Y  N  ,

which one(s).....

Is it a Regional Referral Center for PGHN Y  N

Cut off age range for Chronic Gastro Hepatology diseases in the Center

12y  14y  16y  18y  21y

Population served:.....

Number of Specialists: Full Time:..... Part time:.....

How many only Gastro: Full Time:..... Part time:.....

How many only Hepatology: Full Time:..... Part time:.....

How many only Nutrition/Metabolic Diseases: Full Time: Part time:.....

How many only Endoscopy: Full Time:..... Part time:.....

How many others subspeciality ..... Full Time: Part time:.....

Special separate Clinic for:

IBD Y  N

Motility Y  N

Nutrition/Metabolic Y  N

Cystic Fibrosis/Pancreas Y  N

Hepatology/Liver transplantation Y  Hepatology Yes;

Liver transplantation No N

Others (Name.....)

#### ACTIVITY

Number of out patients attended per year (1<sup>st</sup> visit & follow up visits)

< 500  501-1500  1501-3000  3001-5000  >5000

Number of in patients consultations offered per year

< 500  501-1500  1501-3000  >3000

PGHN in patients have: specific separate beds  General pediatrics beds

#### EMERGENCIES

The GHN Unit covers pedGI Emergency on-call: Y  N

< 7 days/month 8-14d/m 15-21 d/m daily

Is there a formal on-call roster? Y  N

The trainees participate in the Emergency calls Y  N

Are you on-call voluntarily Y  N  Everybody must participate to the on-call

#### PROCEDURES & TECHNIQUES

#### ENDOSCOPY

Endoscopy Unit

Free Access: Y  N

Separate Suite attached to the GI training center: Y  N   
Attached to the Adults Endoscopy Unit: Y  N   
Specialised Endoscopy Nurses: Full Time:... Part time:..  
Are they AHP-ESPGHAN members Y  N

Procedures: Diagnostic endoscopy Y  N   
Therapeutic endoscopy: Polypectomy Y  N   
Removal of foreign bodies Y  N   
Gastrostomy placement Y  N   
Balloon dilatation Y  N   
Banding, Clips, sclerotherapy Y  N   
ERCP Y  N  (done by the adult GI)

Who performs the therapeutic endoscopy?  
Pediatric Gastroenterologist  
Pediatric Surgeon  
Adult Gastro/Endoscopist  
Other

Number of procedures per year  
Diagnostic endoscopy Upper GIT: total/year:..  
Diagnostic endoscopy Lower GIT: total/year:..  
Therapeutic endoscopy: total/year: 30  
Anaesthetists involved Y  N

Video capsule performed: Y  N  total number/year:.....

### OTHER TECHNIQUES

Motility Techniques:  
pH/monitoring Y  N  total number/year:..  
pH/Impedance: Y  N  total number/year:..  
Standard Manometry: Y  N  total number/year:..  
High Resolution Manometry: Y  N  total number/year:..

Who performs the Motility Techniques?  
Pediatric Gastroenterologist   
Pediatric Surgeon   
Adult Gastro   
Other

Specialised Endoscopy Nurses: Full Time:... Part time:..  
Are they AHP-ESPGHAN members Y  N

Liver Biopsy  
Y  N  total number/year:..  
Who is involved:  
Pediatric Hepatologist   
Pediatric Surgeons   
Interventional radiologist   
Other

Imaging Techniques  
Fibroscan Y  N   
Other (specify).

Dietitians or doctors trained in nutrition attached to the GHN Unit:  
Y  N  Full Time: Part time:..  
Are they AHP-ESPGHAN members Y  one N  one

Other Specialists attached to the GHN Unit:  
Dietitians  
Pharmacists  
Specialized Nurses  
Administrative staff

### Home Parenteral Nutrition Program

Y  N  <5/year 5-10/year > 10/year

### Home Enteral (tube feeding) Nutrition Program

Y  N  <5/year 5-10/year > 10/year

### Research Activities

Has your Unit a recognised Research Activity Program Y  N   
attached to the Unit   
attached to other Research groups   
Does your unit have research laboratories (wet labs) Yes

### Additional Comments or clarification:

.....  
.....

**Supplementary Appendix 2** List of participating training centers in pediatric gastroenterology, hepatology and nutrition

Country	City	Center	Head of the GI Unit
Austria	Graz	Medical University of Graz	Almuthe Christine Hauer
	Innsbruck	Medical University of Innsbruck	Thomas Müller
	Vienna	Medical University of Vienna	Wolf-Dietrich Huber
Belgium	Liège	MontLégia CHC Clinic	Colinet Stephanie
	Leuven	Leuven-Gasthuisberg University Hospital	Ilse Hoffman
	Brussels	Saint-Luc University Hospital	Etienne Sokal
	Ghent	Ghent university hospital	Myriam Van Winckel
	Brussels	Reine Fabiola University Hospital	Patrick Bontems
Bulgaria	Sofia	Sofia Specialized hospital for active treatment of child diseases Ivan Mitev	Elena Lazarova
		Acibadem city clinic Tokuda Hospital	Kalin Lisichki
	Varna	St Marina University Hospital for active treatment	Miglena Georgieva
Croatia	Zagreb	Children's Hospital Zagreb	Sanja Kolaček
		University Hospital Center Zagreb	Jurica Vuković
		'Sestre Milosrdnice' University Hospital	Orjena Žaja
	Rijeka	Rijeka University Hospital	Goran Palčevski
Czech Republic	Prague	Pediatric Gastroenterology Unit, Department of Pediatrics, University Hospital Motol and Charles University	Jiri Bronsky
		Pediatric Gastroenterology Unit, Department of Pediatrics, General University Hospital and Charles University	Pavel Fruhauf, Peter Szitanyi
	Olomouc	Pediatric Gastroenterology Unit, Department of Pediatrics, University Hospital Olomouc and Palacký University	Eva Karaskova
France	Le Kremlin-Bicêtre	Pediatric liver disease and pediatric liver transplantation, Paris-Sud University, Medical School	Gonzales Emmanuel
	Le Havre	Department of pediatrics, Jacques Monod Hospital	Valérie Bertrand
	Lille	Department of pediatric gastroenterology, hepatology and nutrition, Lille University Hospital	Frederic Gottrand
	Lyon	Department of pediatric gastroenterology, hepatology and nutrition, Lyon University Hospital	Sophie Heissat
	Nancy	Department of pediatric gastroenterology, hepatology and nutrition, Nancy University Hospital	Emeline Guiot
	Paris	Department of pediatric gastroenterology, hepatology and nutrition, Necker Hospital	Florence Lacaille
		Department of pediatric gastroenterology and nutrition, Robert Debra Hospital	Jean-Pierre Hugot
	Rouen	Department of pediatrics, Rouen University Hospital	Olivier Mouterde
	Strasbourg	Department of pediatric gastroenterology, Strasbourg University Hospital	Julie Rebeuh
	Toulouse	Department of pediatric gastroenterology, hepatology and nutrition, Toulouse Universtary Hospital	Emmanuel Mas <sup>#</sup>
Tours	Department of pediatrics, Tours University Hospital	Stephanie Willot	
Germany	Bremen	Gesundheit Nord, Klinikum Links der Weser, Children's hospital, Bremen	Martin Classen
	Cologne	Department of Pediatrics, University Children 's Hospital, Cologne, Germany	Ilse Broekaert
	Darmstadt	Darmstädter Children's Hospital Prinzessin Margaret, Darmstadt	Andreas Krahl

(Contd...)

**Supplementary Appendix 2 (Continued)**

Country	City	Center	Head of the GI Unit
	Eisenach	St. Georg Hospital, Children's Hospital, Eisenach	Benno Kretzschmar
	Erlangen	University Medical Center Erlangen, Department of Pediatrics and Adolescent Medicine, Erlangen	André Hörning
	Stuttgart	Klinikum Stuttgart, Olgahospital, Stuttgart	Söhnke Dammann
	Tübingen	University Children's Hospital Tübingen, Eberhard Karls University Tübingen	Ekkehard Sturm
	Ulm	University Medical Center Ulm, Department of Pediatrics and Adolescent Medicine, Ulm	Carsten Posovszky
Greece	Athens	First Department of Pediatrics, University of Athens, Agia Sofia Children's Hospital, Athens	Alexandra Papadopoulou
		Third Department of Pediatrics, University of Athens, ATTIKON University Hospital	Smaragdi Fessatou
	Thessaloniki	Forth Department of Pediatrics, Aristotle University of Thessaloniki	Maria Fotoulaki
		Third Department of Pediatrics, Aristotle University of Thessaloniki, Hippokration Hospital	Ioannis Xinias
Hungary	Budapest	First Department of Pediatrics, Semmelweis University	Áron Cseh
	Debrecen	University of Debrecen, Clinical Center, Dep. of Pediatrics	Gábor Veres
	Pécs	Department of Pediatrics, University Medical School of Pécs	Andras Tarnok
	Szeged	Department of Pediatrics, University of Szeged	Daniel Szucs
Israel	Haifa	Pediatric Gastroenterology Unit at Ruth Rappaport Children's Hospital, Rambam Medical center	Ron Shaoul
	Jerusalem	Shaare Zedek Medical Center (Hebrew University)	Dan Turner
		Pediatrics Department, Hadassah Mount Scopus - Hebrew University medical center	Michael Wilschanski
	Ramat Gan	Sheba Medical Center (Sackler Faculty of Medicine, Tel Aviv University)	Batia Weiss
	Petach Tiqva	Institute of Gastroenterology, Nutrition and Liver Diseases, Schneider Children's Medical Center of Israel (Tel Aviv University)	Raanan Shamir
Italy	Ancona	Marche Polytechnic University, Ancona University Hospital	Carlo Catassi
	Bergamo	Papa Giovanni XXIII Hospital (affiliated to Milan and Pavia University)	Lorenzo D'Antiga/Emanuele Nicastro
	Florence	Meyer University Hospital	Paolo Lionetti
	Messina	Messina University Hospital	Claudio Romano
	Naples	Intradepartmental Program of Pediatric GI Endoscopy and Motility, Department of Translational Medical Science, Section of Pediatrics	Annamaria Staiano
	Rome	Sapienza University Hospital	Salvatore Cucchiara
		Bambino Gesù Children's Hospital (affiliated to University of Rome La Sapienza · Università Cattolica del Sacro Cuore, Rome · University of Rome Tor Vergata)	Luigi Dall'Oglio
		Bambino Gesù Children's Hospital affiliated to University of Rome La Sapienza · Università Cattolica del Sacro Cuore, Rome · University of Rome Tor Vergata)	Giuseppe Maggiore
Lithuania	Kaunas	Hospital of Lithuanian University of Health Sciences Kauno klinikos	Ruta Kucinskiene
	Vilnius	Center for Pediatrics of Vilnius University Hospital Santaros Klinikos	Vaidotas Urbonas
Portugal	Lisbon	Santa Maria University Hospital Pediatric	Ana Isabel Gouveia Costa
	Porto	São João University Hospital	Jorge Amil Dias (until 2021)
Slovenia	Ljubljana	Ljubljana University Medical Center	Rok Orel
	Maribor	Maribor University Medical Center	Jernej Dolinsek

*(Contd...)*

**Supplementary Appendix 2 (Continued)**

Country	City	Center	Head of the GI Unit
Spain	Barakaldo	País Vasco University Hospital	Iñaki Xarles Irastorza Terradillos
	Barcelona	Vall d'Hebron University Hospital	Jesus Quintero
		San Juan de Dios University Hospital	Javier Martín de Carpi
	Córdoba	Reina Sofia University Hospital	Rafael Gonzalez de Caldas Marchal
	Valencia	La Fe University Hospital	Carmen Ribes-Koninckx
	Las Palmas	Materno-Infantil de Canarias University Hospital	Luis Peña-Quintana
	Madrid	Niño Jesús University Hospital	Rosa Ana Muñoz Codoceo
		La Paz University Hospital	Manuel Molina
	Málaga	Materno Infantil University Hospital	Víctor M. Navas López
Murcia	Virgen de la Arrixaca University Hospital	David Gil Ortega	
Seville	Virgen del Rocio University Hospital	Alejandro Rodriguez Martinez	
Switzerland	Geneva	Pediatric Liver Center, University Hospitals Geneva	Valérie McLin
	Lausanne	Lausanne University Hospital	Andreas Nydegger
	Basel	University Children's Hospital Basel	Raoul I. Furlano
	Lucerne	Children's Hospital of Lucerne	Johannes Spalinger
	St. Gallen	Children's Hospital of Eastern Switzerland in St. Gallen	George Marx / Pascal Müller
The Netherlands	Amsterdam	Emma Childrens Hospital / Academic Medical Center	Marc Benninga
	Groningen	Groningen University Medical Center	Rene Scheenstra
	Rotterdam	Erasmus University MC, Sophia Children's Hospital	Hankje Escher
	Utrecht	Wilhelmina Children's Hospital / Utrecht University Medical Center	Roderick Houwen
Turkey	Ankara	Ankara University School of Medicine	Aydan Kansu
	Izmir	Dokuz Eylul University School of Medicine	Yeşim Öztürk
	Malatya	Inönü University Faculty of Medicine	Mukadder Ayşe Selimoğlu
United Kingdom	Birmingham	Birmingham Children's Hospital (University of Birmingham)	Sue Protheroe
	Bristol	Bristol Children's Hospital	Dharam Basude
	Cambridge	Cambridge University Hospital NHS Foundation Trust	Camilla Salvestrini
	Leeds	Leeds Teaching Hospitals NHS Trust	Suzanne Davison
	Liverpool	Alder Hey Children's NHS Foundation Trust (Liverpool University NHS Foundation Trust )	Marcus KH Auth
	London	Royal London Children's Hospital, Barts Health NHS Trust	Nicholas Croft
		Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK	Nikhil Thapar (until 2019)
		King's College Hospital (London University NHS Foundation Trust)	Jonathan Hind
	Manchester	Royal Manchester Children's Hospital (Manchester University NHS Foundation Trust)	Andrew Fagbemi
	Nottingham	Nottingham University Hospitals NHS Trust	David Devadason
	Oxford	Oxford University NHS foundation trust	Lucy Howarth
	Sheffield	Sheffield Children's Hospital (affiliated to Sheffield Medical School)	Mike Thomson
	Scotland	North of Scotland Pediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN) NHS Grampian, NHS Tayside, NHS Highland, (NHS Orkney, NHS Shetland)	Dagmar Kastner-Cole