

Media Release

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New blood test on horizon for the 1 in 10 children who suffer common liver disease

(Glasgow, 8 June, 2019) A new blood test could become clinical practice within five years, reducing the need for a liver biopsy in the management of paediatric Non-Alcoholic Fatty Liver Disease (NAFLD), as a major new international paediatric liver registry collaboration yields early results¹.

Researchers are today presenting findings, at the 52nd Annual Meeting of the European Society of Paediatric Gastroenterology, Hepatology and Nutrition, which indicate that blood tests could replace the need for a liver biopsy in children suffering with NAFLD. Currently, if a doctor is concerned a child has scarring or inflammation of the liver they may recommend a liver biopsy. The study looked at 67 children with NAFLD and found that different types of fats in the blood were associated with features of fatty liver on liver biopsy, allowing researchers to determine the presence of inflammation and scarring – also known as non-alcoholic steatohepatitis and fibrosis.

Non-Alcoholic Fatty Liver Disease affects around one in 10 children² and is the most common paediatric liver disorder³. It can progress to advanced scarring (cirrhosis), liver failure, and liver cancer. Despite this, the natural history of the condition is poorly understood and there are currently no approved treatments or drugs in clinical trials for children. In response to this, researchers from across Europe have come together to pool resources in order to better understand the condition and how to treat it.

Liver biopsy is currently the most accurate test for NAFLD and the only method routinely used in practice for assessing the presence of scarring or inflammation^{4,5}. However, biopsy is invasive, resource intensive, costly, prone to sampling error and carries a small risk of significant complications⁶. Therefore, the availability of an accurate and non-invasive marker to replace the need for liver biopsy, both in routine practice and in a clinical trial setting, is a major breakthrough for children, parents and healthcare professionals.

To date, all European drug trials^{7,8} and assessments of non-invasive markers⁹ in paediatric NAFLD have been single-centre studies, which limits the generalisability of findings. This is particularly pertinent given the variation in clinical practice at different centres.

This research is the first major finding to be reported from the European Paediatric Non-Alcoholic Fatty Liver Disease Registry (EU-PNALFD registry), an international collaboration of 11 specialist and non-specialist centres in six European countries, led by Dr. Jake Mann. When fully operational, the registry will have enrolled up to 2,000 children, including 500 with biopsy-proven paediatric NAFLD, and follow-up will continue for up to 30 years.

Commenting on the findings, registry co-ordinator Dr. Jake Mann said:

"It is early days but the results of the research are promising and could help shift the way we understand and manage paediatric NAFLD: saving resources, time, and stress for children and their parents. The new multi-centre registry provides us with an opportunity to tackle these challenges. The EU-PNAFLD registry will facilitate recruitment into interventional clinical trials as well as imaging, biomarker, and translational studies, plus allow greater understanding of the long-term natural history of NAFLD. The ultimate aim is to understand the condition sufficiently to intervene and slow disease progression so we can reduce the number of patients requiring liver transplantation later in life."

Alison Taylor Chief Executive of the Children's Liver Disease Foundation (CLDF) added:

"It is great to hear that the registry, supported through CLDF research funds is already yielding such fantastic insights to improve the diagnosis and care of children affected by NAFLD. In particular, it is wonderful to see such progression in the development of non-invasive tests which will positively impact children, young people and their families at a time that is incredibly stressful. We know that further significant developments in care will come via the European Paediatric Non-Alcoholic Fatty Liver Disease Registry (EU-PNALFD registry) and we are proud to be supporting the initiative."

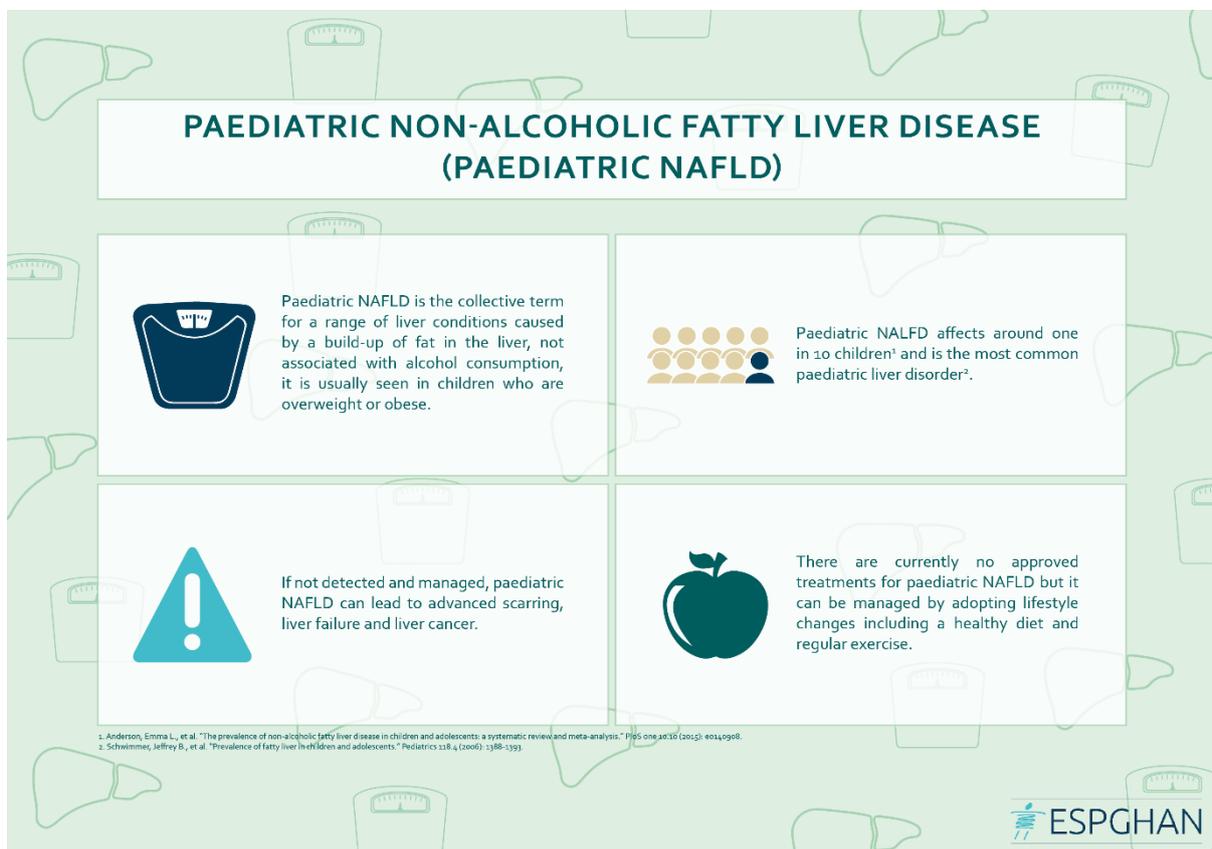
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Notes to Editors

For further information, to speak to Dr. Jake Mann or an ESPGHAN expert, please contact James M. Butcher at media@espghan.org or call +44 (0) 1444 811 099.

INFOGRAPHICS

To view a high-resolution version of ESPGHAN's Paediatric NAFLD infographic, [please click here](#).



About the Expert

Dr. Jake Mann, Wellcome Trust Clinical Research Fellow at the Institute of Metabolic Science, University of Cambridge.

Jake is a paediatrics registrar with an interest in liver fat (hepatic steatosis) and insulin resistance (type 2 diabetes). He is particularly focused on genetic influences that lead to the development of steatosis and non-alcoholic fatty liver disease (NAFLD) spectrum.

His current research focuses are:

- Understanding how gene mutations associated with NAFLD affect the liver and insulin resistance
- Searching for blood tests ('serum biomarkers') that might be useful for predicting who may progress to more advanced liver disease

Dr. Mann is the Registry Co-ordinator for the EU-PNAFLD registry.

About the Registry

The European Paediatric Non-Alcoholic Fatty Liver Disease Registry (EU-PNAFLD) is a multi-centre registry of paediatric NAFLD that serves as a prospective, observational, natural history study and provide a tractable back-bone to support recruitment into subsequent interventional trials. Collection of samples into a bio-repository will facilitate translational studies, including genome sequencing and metabolomics. EU-PNAFLD will work closely alongside the existing adult European NAFLD Registry to obtain data on clinical outcomes after 20–30 years. Through an international, well-characterised large-scale cohort, EU-PNAFLD will address the key questions in paediatric NAFLD and benefit patients with the condition.

The EU-PNAFLD was set up using funding from the European Association for the Study of the Liver (EASL).

Dr Jake Mann and ESPGHAN would like to recognise the significant contribution made by the late Professor Valerio Nobili, who sadly passed away this year and without whom the registry would not have been possible.

About ESPGHAN

The European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) is a multi-professional organisation whose aim is to promote the health of children with special attention to the gastrointestinal tract, liver and nutritional status, through knowledge creation, the dissemination of science based information, the promotion of best practice in the delivery of care and the provision of high quality education for paediatric gastroenterology, hepatology and nutrition professionals in Europe and beyond. Find out more by visiting www.espghan.org

About the 52nd Annual Meeting of ESPGHAN

The 52nd Annual Meeting of ESPGHAN is taking place from 5-8 June 2019, at the SEC in Glasgow, United Kingdom.

Every year the ESPGHAN Annual Meeting attracts over 4,600 experts and key opinion leaders in the field of Paediatric Gastroenterology, Hepatology and Nutrition from 100 countries across Europe and all five continents, turning it into the largest conference of its kind worldwide.

The European Society for Paediatric Gastroenterology, Hepatology and Nutrition 52nd Annual Meeting in Glasgow is being supported by the VisitScotland National Conference Bid Fund and a grant from the Glasgow Convention Bureau. ESPGHAN would like to thank VisitScotland and the Glasgow Convention Bureau for their support.

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For more information about the ESPGHAN Congress, including to view the programme, please visit: <https://www.espghancongress.org/>

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