

Improving the dialogue with a Family Education Day

How can children with autoimmune diseases and their families be better informed?

This was one of the focus areas that The European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) wanted to look at as part of its 54th Annual Meeting in Copenhagen.

The conference had more than 4.000 delegates from around 100 countries and had special attention on the pediatric treatment of gastrointestinal tract, liver, and nutritional diseases. The conference facilitated demonstration models and hands-on techniques such as endoscopy with different types of instruments.

The vision of ESPGHAN was to disseminate know-how and mitigate research and talent gaps, and three legacy activities supported this vision:

- Family Education Day; increasing knowledge for children and their families

- Talent Workshop; diminishing the talent gap
- Research Fund; diminishing the research gap

Information is a cornerstone

When children get sick, it affects the whole family. It can be difficult for the patients and their families to navigate the illness and understand the symptoms, which is why it is instrumental that they have access to the best possible information. Information that is easily understood by the patients and their families. When it comes to autoimmune diseases, they may develop very differently and, therefore, must be treated in a very personalised way.

As a legacy activity, the conference opened its doors for a Family Education Day with about 100 children, parents, and nutritional experts. The activity included

presentations by several international experts and conversations between these experts, the children, and their families. Medical professionals acted as ‘translators’ during the conversations to ensure smooth communication between the two groups. This provided a better understanding of the problems seen from different perspectives and contributed to a positive connection between the patient associations, patients, and their families.

The evaluation feedback from the families was very positive. The most important output was learning about the latest science, practice, and new therapies from experts in the field. The questions and the debates were highly appreciated, and the children were all offered tickets to the Copenhagen amusement park “Tivoli” after the activity.

"The first experience in Denmark has been positive, and the researchers, the kids, and their families learned a lot from the dialogue"

Anders Pærregaard
Medical expert and designer
of the Family Education Day.

Diminishing the gaps

The legacy activities in Copenhagen also included a Talent Workshop for young researchers, organised by Center for Molecular Prediction of Inflammatory Bowel Disease (PREDICT). This workshop presented the research centre's activities and possibilities for future collaboration.

Finally, there was an initiative from the local organising committee (DaSPGHaN) to establish a fund supporting young PhD researchers studying gastrointestinal and liver diseases in children. This will be funded by sponsors and surplus money from the conference and will be activated when it reaches one million DKK.

Looking ahead, the legacy activities at ESPGHAN have the potential to grow in the future.



Legacy process

Objective

Strategic alignment

The two UN Sustainable Development Goals (SDGs) this conference showed commitment to was:

#3 Good Health and Well-being

#4 Quality Education

Objective

- The conference aimed to promote the health of children with focus on the gastrointestinal tract, liver, and nutritional status, through knowledge creation and closure of research and talent gaps within this field.

Stakeholder involvement

Copenhagen Legacy Lab facilitated two creative workshops together with the local organising committee (DaSPGHaN). The workshops involved 15 relevant stakeholders such as patient organisations, universities, private companies and more.

Activity

The legacy activities at the conference were:

- A Family Education Day where families with children could listen to experts talking about new developments within pediatric gastroenterology, hepatology, and nutrition. The activity provided the families with new knowledge about the disease and opened for a dialogue with international experts. Each table had a medical professional translate and explain the questions and answers.
- Center for Molecular Prediction of Inflammatory Bowel Disease (PREDICT) offered a Talent Workshop for young researchers, allowing them to learn about state-of-the-art research within the field.
- The establishment of a Research Fund was suggested by the Local Organising Chair, Professor Steffen Husby. The surplus money from the conference will be transferred to the fund.

Evaluation

Outputs (immediately after the activity)

- **Family Education Day:** A total amount of 100 children, parents, and experts attended the activity, of which 23 respondents took part in the survey. The speakers and helpers were satisfied with the debate, which was not only between the experts and the families, but also between families at the tables.
- **Talent Workshop:** A handful of people attended the workshop and everyone responded to the survey.
- **Research Fund:** Approximately 100 people visited the Danish Society for Paediatric Gastro- enterology Hepatology and Nutrition (DaSPGHaN) stand throughout the congress. Flyers with information about the Research Fund were distributed among the participants.

Legacy process

Evaluation

Outcomes (after 6 to 12 months)

- **Family Education Day:** After the event, Copenhagen Legacy Lab and DaSPGHAN compiled the key learnings into a playbook for successfully replicating the Family Education Day concept. The playbook has since been handed over to the ESPGHAN Public Affairs Committee (PAC), enabling them to continue the concept at future ESPGHAN congresses.
- **Talent Workshop:** PREDICT continued the dialogue with the talents who expressed interest in pursuing a PhD or postdoc in Denmark.
- **Research Fund:** Since the congress, a project plan was created to establish the Danish research fund named “Fonden for Børnemaver.” Based on this, DaSPGHAN and Copenhagen Legacy Lab have successfully secured funding from three foundations. By 2025, DKK 1,770,000 has been raised - enough for the Department of Civil Affairs to approve the fund and its bylaws.

Impact and legacy (after a year)

- **Family Education Day:** ESPGHAN PAC are considering adopting the Family Education Day, to support children and families in other congress host cities.
- **Talent Workshop:** Any potential hiring of participants will create societal and economic benefits for Denmark, as there is still a talent gap.
- **Research Fund:** “Fonden for Børnemaver” will be established in 2026, with the first scholarships expected in summer 2026.

“Fonden for Børnemaver” will support PhD researchers studying gastrointestinal and liver diseases in children, advancing knowledge in the field and directly contributing to the objective of closing the research and talent gap, thus creating an important legacy in Denmark.

Fonden For Børnemaver

The Foundation aims to:

- Advance the diagnosis and treatment of paediatric gastrointestinal and liver diseases, while improving children's quality of life through research.
- Support early-career clinical researchers in paediatric gastroenterology, hepatology, and nutrition.
- Increase knowledge and awareness of paediatric gastroenterology, hepatology, and nutrition.

More info ➔

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Copenhagen Legacy Lab is an award-winning strategic initiative under Copenhagen Convention Bureau that drives positive long-term impact from congresses and events.

For more information and additional cases, visit
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