

## Improving the dialogue with a Family Education Day

- **ESPGHAN 54TH ANNUAL MEETING**
- **COPENHAGEN, 23-25 JUNE 2022**

### HELPING CHILDREN AND THEIR FAMILIES

How do you ensure that children with autoimmune diseases and their families are informed about the disease in the best way possible? 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



Photo: Wonderful Copenhagen



Photo: Wonderful Copenhagen

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.

**Medical expert, former member of the local organising committee, and designer of the Family Education Day, Anders Pærregaard, commented:**

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

### 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, **the Danish Society for Paediatric Gastroenterology, Hepatology, and Nutrition (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



## Strategic goals and societal needs

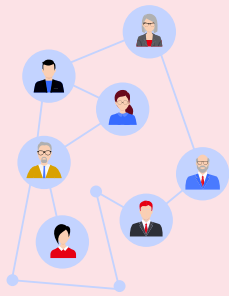
The two UN Sustainable Development Goals (SDGs) this conference showed commitment to was:

- #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.



## Activities

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.



## 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 Gastroenterology Hepatology and Nutrition (DaSPGHaN) stand throughout the congress. Flyers with information about the Research Fund were distributed among the participants.



## Outcomes (+6-12 months - changed behaviour)

**Family Education Day:** Two-way communication between the patient and the doctor is important for both parties to understand how to treat the disease. The doctor may have a plethora of practical and theoretical knowledge but is not the one with the actual symptoms. Likewise, the patient needs the help of a health professional to understand the different symptoms and what they mean in terms of treatment etc. The activity reiterated this with the majority of participants answering that they had learned something new about their disease.

**Talent Workshop:** The participants showed interest in doing a PhD or postdoc in Denmark on the topic. It is still to be seen if some of the participating students will join PREDICT.

**Research Fund:** DaSPGHaN has since the congress made a project plan for the establishment of a research fund. A minimum of one million DKK is required to kickstart the National Research Fund – the first of its kind.



## Impact (+1 year – societal value)

**Family Education Day:** DaSPGHaN is in contact with the ESPGHAN Public Affairs Committee (PAC) about integrating the Family Education Day concept as part of future congresses. DaSPGHaN has, in collaboration with Copenhagen Legacy Lab, completed a playbook explaining the concept, which has been handed over to the ESPGHAN PAC. If the concept from Copenhagen is adopted, it is likely to affect even more families on a global scale. Copenhagen Legacy Lab will follow the development.

**Talent Workshop:** Copenhagen Legacy Lab will be able to estimate the societal value in terms of GDP and tax revenue if some of the participants convert into talents in the future.

**Research Fund:** Since the congress, DaSPGHaN has received help to concretize the foundation's articles of association and rules of procedure with support from Copenhagen Legacy Lab. DaSPGHaN is still applying for funding, and when the funding is place, the research fund will be established with the aim of supporting young PhD researchers studying gastrointestinal and liver diseases in children.



## Potential legacy (+1-3 years and beyond)

All activities support the strategic objective of closing the research and talent gap. The Family Education Day was a success but will need to be developed further, taking the participants' feedback into account. The Talent Workshop was a single event which was made for this special occasion. The success of The Research Fund is still to be seen, but the surplus money from the conference supports the ongoing process of legalising the fund.