LEGACY CASE STUDY





ESPGHAN 54th Annual Meeting

COPENHAGEN, 22-25 JUNE 2022

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 also 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 individual-oriented way. But how do you then ensure that the patients and their families are informed in the best way possible every time? 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.

ESPGHAN's Annual Meeting had special attention on the pediatric treatment of gastrointestinal tract, liver, and nutritional diseases. The conference also 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.

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 and the kids 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, just as it contributed to a positive connection to the patients associations, patients and their families.

The evaluation feedback from the families was very positive. The most important output was to learn 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.

It is only recently that legacy targets have been part of ESPGHAN. Medical expert and former member of the local organising committee Anders Pærregaard, who designed the Family Education Day, said:

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

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 to establish a fund supporting young PhD researchers studying gastrointestinal and liver diseases in children. This fund will be funded by sponsors and the conference's surplus money 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.

RESUME

ESPGHAN 54th Annual Meeting had more than 4.000 delegates from around 100 countries. In addition to the congress, three legacy activities supported the strategic objective of closing a research and talent gap within the field of pediatric treatment of gastrointestinal tract, liver, and nutritional diseases:

- Family Education Day
- Talent Workshop
- Research Fund

ESPGHAN will due to the success of the Family Education Day integrate the concept as part of future congresses. A minimum of EUR 130.000 is required to kickstart the Research Fund, while the Talent Workshop was a single event for this special occasion.

TESTIMONIAL

The Local Organising Committee Chair Professor Steffen Husby stated:

"The expectations of the conference were met with a surprising high number of participants and positive feedback on the legacy activities as well as the total event."



SPECIAL THANKS TO







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STEP 1 Strategic goals and societal needs

The local organising committee was chaired by Professor Steffen Husby from the University of Southern Denmark (SDU). The two UN Sustainable Development Goals (SDGs) this conference showed commitment to was:

- #3 Good Health and Well-being
- #4 Quality Education







Objectives

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



Inputs

Two legacy workshops were organised to prepare, decide on, and support the legacy activities.



A Family Education Day, where families with kids could listen to experts talking about new developments on Pediatric Gastroenterology, Hepatology and Nutrition. The activity allowed families with patients to get new knowledge about their disease and have a dialogue with international experts. Each table had a medical professional translate and explain the

questions and answers.

STEP 3 Activities

The legacy activities at the conference were:

Center for Molecular Prediction of Inflammatory Bowel Disease (PREDICT) offered a second legacy activity. It was a Talent Workshop for young researchers, allowing them to learn about state-ofthe-art research within the field.

The third activity was a Research Fund suggested by the Local Organising Chair, Professor Steffen Husby. The surplus money from the conference will be transferred to the fund.

STEP 4 Outputs

Family Education Day

A total amount of 100 children, parents, and experts attended the activity. It resulted in 23 survey responses. 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.



The 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 STEP 5

Family Education Day

Two-way communication between the patient and the doctor is important for both 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 on the topic.



Research Fund

The fund will be established in connection with DaSPGHaN's General Assembly on September 26, 2022. A minimum of EUR 130.000 is required to kickstart the National Research Fund - the first of its kind. Approximately EUR 100,000 is expected as a surplus from DASPGHAN.

STEP 6 Impact

Family Education Day

ESPGHAN will integrate the concept as a part of future congresses, which will likely affect even more families on a global scale. Copenhagen Legacy Lab will follow the development.

Talent Workshop

Copenhagen Legacy Lab will be able to track this if it converts into a talent in the future in close dialogue with PREDICT.



Research Fund

Gastrointestinal and liver diseases are common in children and nutrition is of foremost importance in healthy infants and children as well. However, there is too little research in this area. This is why the local organisers wanted to set up a Danish research fund to support young PhD researchers to mitigate research and talent gaps for the benefit of patients, relatives and (future) professionals.



Potential legacy

All activities support the strategic objective of closing a research and talent gap. The Family Education Day was a success but will need to be developed further, taking into account the participants' feedback. 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 surplus money from the conference is expected, and the fund is about to be legalised.