

EFCCA PROJECTS DIGEST

AUGUST, 2023

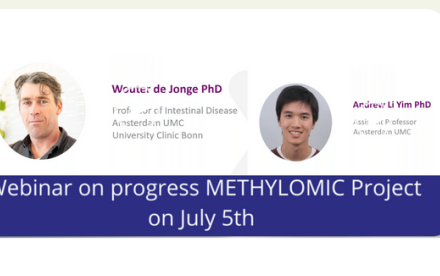
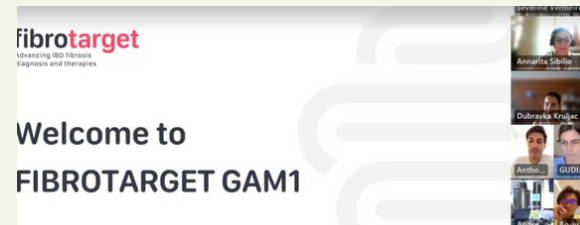
#1 ISSUE

SUMMARY

PROJECT UPDATES

FIBROTARGET: 2ND ONLINE GA

During FIBROTARGET's General Assembly, attendees shared the latest updates on this project shaping the future of intestinal fibrosis research in IBD. We've summarized the topics covered at the event.



METHYLOMIC'S PROGRESS WEBINAR

On 5 July, METHYLOMIC, in partnership with GenDx, hosted a webinar where Prof. Dr. Wouter de Jonge provided insights on the project's progress.

IDEA-FAST WEBINAR

The IDEA-FAST webinar held on 7 June centred on innovative approaches to measure fatigue and sleep disturbances in chronic diseases, showcasing expert insights and patient testimonials.





NEW GLYCANTRIGGER NEWSLETTER

GlycanTrigger has just released its first newsletter, a project that will soon be followed by a new podcast series. Learn more details about it all.

UP CLOSE: UNVEILING HORIZON EUROPE PROJECTS



AN INTERVIEW WITH EFCCA'S CEO LUISA AVEDANO

Our CEO talks about various aspects of the Horizon Europe Projects and the role of our associations in these projects. An interesting interview to know more about how EFCCA is involved in these projects, their significance, and the benefits they can provide to the IBD community.

PATIENTS STORIES

OONA LIIKANEN: STUDYING ABROAD WITH IBD

Meet Oona, a Crohn's disease patient and IBD advocate, as she shares her inspiring story of studying abroad and embracing new experiences despite the challenges, in the new blog series of the GENEGUT's Patient Stories.



PROJECTS' UPDATES

FIBROTARGET ONLINE GENERAL ASSEMBLY

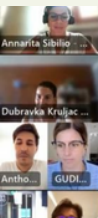
During its 2nd General Assembly, celebrated on-line on 10 July, Fibrotarget gathered experts to discuss cutting-edge fibrosis research and therapeutic approaches, with a focus on collaboration for innovative treatments.

New recruits from partners, including EFCCA, were warmly welcomed by Fibrotarget Project Coordinator Dr. Séverine Vermeire from KU Leuven. Management and communications were emphasised as pillars for Fibrotarget's success, highlighting seamless collaboration with partners and ensuring compliance with EU data protection regulations in scientific publication and data management.

KU Leuven research colleagues presented the initial Fibrotarget Training Academy draft, a webinar series with top researchers from different research institutions. The goal is to enhance partners' understanding of fibrosis under the microscope, with plans to make them available on the project's website in the future.



Welcome to
FIBROTARGET GAM1



At the event, different partners also had the chance to talk about their progress in essential project areas, such as research on biomarker signatures for fibrosis in IBD, inhibitors in human IBD cells and colitis mouse models, and monitoring intestinal fibrosis in people with Crohn's disease using imaging techniques.

Read the summary of the assembly's content on [Fibrotarget's website](#).



This project has received funding from the European Union's Horizon Europe programme under grant agreement No 101080523.

METHYLOMIC'S WEBINAR

Wouter De Jonge and Andrew Li Yim talked about the progresses on the Methylomic project in a webinar organised by GenDx. The webinar was held on 5 July, on the subject "An epigenetic biomarker that predicts treatment success and allows personalised management in Crohn's Disease". You can watch it [here](#).



This project has received funding from the European Union's Horizon Europe programme under grant agreement No 101095449

IDEA-FAST WEBINAR



The webinar, held on 7 June, focused on exploring novel ways of measuring fatigue and sleep disturbances in chronic diseases, featuring expert insights and patient testimonials.

The [webinar](#) "New Ways of Measuring Fatigue and Sleep Disturbances in Chronic Diseases" saw active participation from various

stakeholders. It focused on advancements in research and the potential benefits of digital endpoints for treatment. Experts discussed challenges faced by patients with chronic diseases related to fatigue and sleep disturbances, while patient testimonials provided valuable perspectives.

The Q&A session covered topics like digital biomarkers for improved patient care, managing sleep disturbances, and measuring fatigue in individuals with chronic diseases.

Participants expressed interest in supporting the research project globally and stressed the need for awareness and education on digital endpoints. Overall, the webinar served as an informative platform, emphasising innovative solutions to enhance patients' lives.

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU). More info: ideafast.eu



GLYCANTRIGGER NEWSLETTER

The first edition of [GlycanTrigger's newsletter](#) provides an overview of their Kick-off Meeting held in Portugal, where project partners convened for collaboration and scientific exchange.

The newsletter highlights achievements of project members, and their participation in international events, and it also features two scientific publications exploring glycans' impact on T-cell development.

The newsletter also serves to announce the upcoming GlycanTrigger Podcast Series, which aims to share project progress and advancements through engaging



discussions between experts, and facilitate knowledge-sharing among medical professionals, scientists, patients, and patient associations.



This project has received funding from the European Union's Horizon Europe programme

UP CLOSE: UNVEILING HORIZON EUROPE PROJECTS

BRIDGING RESEARCH AND PATIENTS: AN INTERVIEW WITH CEO LUISA AVEDANO



Luisa Avedano kindly participated in this interview to discuss EFCCA's involvement in several Horizon Europe projects. Luisa emphasises the importance of patient representation in these research initiatives and highlights the benefits they can bring to the IBD community. She sheds light on EFCCA's efforts to bridge communication between research institutions and patients, while also providing educational resources.

Last year EFCCA, in partnership with research institutions, successfully applied for five Horizon Europe Projects. This is quite a significant number. What led EFCCA to participate in so many projects?

In fact, there are two other projects related to the Horizon Europe initiative in which we are involved in: Idea-Fast and Immuniverse, both currently in the middle of their implementation. We began with a small participation in these two Horizon projects in 2020, and now we are on our way to better understand the role patient associations can play within these huge research projects.

Patient representation is now a key requirement for these projects, signifying the European Commission's recognition of involving patients in initiatives. That's why we were approached by Idea-Fast

and Immuniverse projects in the first round, and we gladly joined.

At that time, our general assembly believed that these projects could offer an opportunity to diversify our sources of funding. Historically, EFCCA has relied primarily on its membership fees, which account for around 20% of our budget, while the remaining funds mainly came from grants and sponsorships. This means that a significant portion of our funding was connected to stakeholders like the pharmaceutical industry. Thus, the idea was to seek alternative sources of funding allowing us to focus on our priorities regarding unmet needs and patient preferences.

During the current round of Horizon projects, we received many requests for consortium inclusion with patient

associations. After multiple meetings in early 2021, we decided to participate in five projects—a significant accomplishment for our patient community.

"The idea was to seek funding that allows us the flexibility to focus on our priorities regarding unmet needs and patient preferences. "

How long will these projects run for?

Some of them are scheduled to last four years, while a couple of others are projected to continue for six years. Of course, the actual duration will depend on how well the projects are implemented. However, it is crucial for us to have sufficient time to fully comprehend the teams involved and ensure that the patient perspective is given equal importance alongside the viewpoints of the researchers and the academic community.

These projects are conducted by large consortia comprising major research institutions, along with patient organisations such as EFCCA.

Although our role within these projects may be relatively small, why do you believe our involvement, both as an organisation and as patients, remains significant?

Drawing from our experience with projects in 2020, we realized that our role was not only small but even smaller than expected. However, in current projects, we're actively involved from the start. Some are highly research-focused, making it challenging to delve into technical content. Still, we closely collaborate with all consortium members to ensure the patient perspective is incorporated at every stage, including research and clinical study protocols.

We are also engaged in all communication-related aspects of the projects. Our role is to translate the scientific language into patient-friendly terms. Moreover, it is crucial to translate the project results and outcomes into a language that is accessible to a broader audience, not just limited to patients but also to the general public. The extent of this work depends on the nature of each project; some are focused on scientific and research elements, while others address social issues like diet or preventive measures for the disease.



What do you think are the project's benefits for the IBD community?

I believe there are significant benefits. First, IBD has gained priority status not only within the scientific community but also within the European Commission due to the focus of the projects that we are involved in. This is a remarkable achievement given IBD's neglect and lack of awareness just a decade ago.

The substantial investment made by the European Commission in these projects is unexpected but highly beneficial. The collaboration of various research universities and institutes within these large consortia holds the promise of achieving positive results in treating and approaching IBD and developing new drugs.

Our main goal is to find elements that offer patients scientifically grounded tips, improving their quality of life.

"In current projects, we're actively involved from the start."

While nutrition is essential, we also investigate other scientific aspects to enhance our understanding of the disease. Some projects may not yield immediate products but will advance the scientific community's knowledge of IBD, potentially leading to new drugs in the future.

Research and development entail envisioning and investing in the final product, fostering learning and growth. It's a significant learning experience as we aim to move beyond addressing unmet needs and patient preferences to actively finding solutions. These projects aim to offer innovative solutions for managing and coping with IBD, improving patients' lives meaningfully.

#PATIENTSTORIES

OONA LIIKANEN: STUDYING ABROAD WITH IBD

Living with Crohn's disease can be challenging, but Oona defied the setbacks. Her inspiring journey showcases the resilience of those living with Crohn's disease.

I got my diagnosis back in 2018, when I had to go to the Emergency Room due to sudden, intense stomach ache, fever and vomiting. I ended up undergoing surgery and got left with a Crohn's disease diagnosis and a temporary stoma all in just one week. I started azathioprine and since then I hadn't had any major problems.

In 2022, I had been studying my bachelor's degree for a little over two years. I didn't always know in what area I wanted to specialise, or what would be my main languages, but one thing I always was sure about was that I wanted to go on an exchange semester.

The summer was starting, exams were done, I was about to start a new summer job in just a week... I had a lot of plans with my friends for that summer because after that I was finally going to go on my exchange in Belgium and leave Finland for half a year. But guess what?

After four good and steady years my Crohn's popped back up again. It was the end of May 2022 when I got a high fever, intense stomach pain and everything I put inside of me came right out.

Within a few days it went so bad that I had to go to the hospital. I ended up being there over a week because my whole large intestine was inflamed. I started biological treatment that started helping, and finally, the summer was gone and it was time to go to Belgium.

The decision to leave after such hard summer wasn't easy for me or my doctors. In fact, we actually had many phone calls during summer regarding me leaving Finland. At that time, I still had to go get the medication at the hospital, causing me intense headaches during summer.

All of these uncertainties were on my mind and my doctor was hesitant to



let me leave at first as well. But by the end of summer, roughly only two weeks before my flight, we came to the conclusion that it was okay for me to go.

I got instructions what to do if I got a new flare while being abroad, they prescribed me cortisone tablets just in case and told me that it's always possible to come back to Finland if I ever feel like it. After all the back and forth, I finally felt comfortable and 100 percent sure that this was my dream and that I want to go.

My biological medication was working excellently on the inflammation but with it came other side effects that did, and still do affect my life. One of the worst is fatigue.

I have energy to study and work, to see people and do activities but that requires a lot of sleep and rest. And I think for a lot of young people it isn't the case.

"That feeling of tiredness is really hard to explain to others. It's one of those things that if you know, you know. "

While other students managed on four hours of sleep, juggling study, partying, and travel, I need at least twice as much rest to balance a night out with my studies and activities. Fatigue often led me to turn down numerous plans.

Looking back at that time, after going through all the emotions, fears, and

questions about not knowing what and who was out there, I couldn't be happier that I experienced it. I had bad days, tired days, days when I didn't have an appetite, days when I wanted to give up and leave.

Those days are nothing in comparison with the ones I spent with people from all around the world, learning about new cultures and languages. The days I spent with friends, visiting places, travelling, eating, drinking and laughing.

How did I build up the courage to leave and change my whole life for six months after all the uncertainties I had during the summer? I have to be honest, I was scared. But keeping an open mind, listening to your own body and feelings and being open about IBD was what really made my time there.

Only if you're honest with yourself and let yourself open up to others, they are able to understand that even if it's not visible, it's still possible to be in pain or feeling sick.

The interview "Studying abroad with IBD" is reproduced from Genegut's ["Patient stories"](#) blog. We would like to extend our heartfelt gratitude to Genegut and to Oona Liikanen for granting us permission to use the text and pictures.