

Interview with Mia Bajramagic, Type 1 Diabetes Advocate and IDF Europe Coordinator of the Trials@Home Patient Expert Panel

IDF Europe is a consortium member of the EU Innovative Medicines Initiative research project, <u>Trials@Home</u>, which aims to reshape clinical trial design, conduct and operations, by developing and piloting standards, recommendations and tools for the definition and operationalization of decentralized clinical trials (DCTs) in Europe.



Within the project, IDF Europe has established a Patient Expert Panel (PEP) to facilitate the engagement of people living with diabetes (PwD) and to ensure that their experiences, needs and preferences are heard. The PEP has, for example, contributed to the development of an inclusive informed consent process and of a communication and messaging framework; has reviewed training materials for people in the trial; and has participated in various outreach activities.

Mia Bajramagic, type 1 diabetes (T1D) advocate and IDF Europe Project Coordinator answered some questions about the role of IDF Europe and the PEP in the project.

Can you tell us something about your background?

I am a fourth-year medical student, in Split, Croatia. I have been living with T1D for almost nine years now. I am a volunteer at the local hospital. In this role, I shadow my professors and mentors and get to learn hands on, while also being of assistance, giving back to the community. Last year, I joined the International Diabetes Federation (IDF) Europe, as a part-time staff member.

What is your role in IDF Europe?

Because of my medical background, I am involved in several EU-funded projects. Besides Trials@Home, I also participate in <u>ISLET</u>, a project looking at developing stem cells for transplantation. An interesting initiative in this project is to connect young scientists to young persons with T1D, which brings valuable insights for both.

Another area of IDF Europe's work in which I am engaged is a working group on digital health platforms and some advocacy initiatives. A major area of work for IDF Europe in 2023 will be to leverage the new diabetes Resolution adopted in November 2022 by the EU parliament: "Prevention, management and better care of diabetes in the EU" (ref). This will be done through the communities for all PwD, in collaboration with our member associations – both PwD and healthcare professionals (HCPs).

We will also advocate for the rights of PwD by publishing scientific articles, meta-analyses (e.g., the IDF <u>Diabetes Atlas</u>) and testimonials. We work with different partners on EU-funded projects in ensuring that the voice of PwD is truly represented and they are engaged as equal partners.

Tell us about a PEP accomplishment that you feel has impacted the progress of Trials@Home

In Trials@Home, the PEP is bringing the patient perspective into the development of the RADIAL study. One example is the messages and alerts in the RADIAL participant app. Also understanding the glucose management of people living with type 2 brought some new insights to the team. It had not been expected that some people living with T2D would only measure their blood glucose a few times a month. The PEP also tested the pen and the pen cap, which proved very valuable.



What do you expect of Trials@Home?

What we are trying to achieve is going to open a lot of doors for future patient care and for much more patient-oriented clinical trials in general. Access to trials, I believe, will be greatly improved.

What excites you the most, considering an upcoming RADIAL or Trials@Home activity?

To see the project come to life and show the world that decentralized clinical trials will work. Let's use all the communication tools we have at our disposal to do just that.

What is the awareness of clinical trials among the population? Who will we reach?

People will need to get used to the idea of decentralized clinical trials. But I am hopeful that we will reach other people, maybe from new locations, jobs and/or people who are not able to travel. There are definitely people who are interested in improving their health but are not near a trial site.

We regularly communicate on the project in our monthly IDF Europe newsletter. We invite people to connect to the Twitter feed and to the website. I plan to continue doing this when we have the study running in the various countries.

What do you dream about?

We have this philosophy in the Trials@home project – and generally at IDF Europe – that the voice of PwD is equal to that of the other partners. I would like to continue working on this after this project. The combination of the different viewpoints and experiences holds much potential to get fabulous outcomes.

As a matter of course, I think that every clinical trial should have a patient expert panel, which gets involved in all aspects of the project – from inception through to the communication of final results.

On a personal note, I dream of a research year, that will allow me to focus on one topic and maybe publish about it. And after that, due to the different perspectives that I have gained through my volunteering activities, my work and my life as a PwD, I hope to become a pediatrician.

What is your hobby, or activity to do on your own or with your family or friends?

I am committed to maintaining a healthy balance in my life between my private life, my work and my studies. I find joy in the things I do in my work and study. I have two dogs, with lots of energy and they will get me outside of the house. In the hours that are left, I paint with acrylic or oil paint.



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