

Spotlight on the Mentor in Mentee programme

What drew you to celiac disease research?

I've been working as a clinical dietitian in the paediatric department at a university hospital in southern Sweden for more than ten years. During that time, I've worked closely with many children with celiac disease and their families. I completed my PhD in the epidemiology of celiac disease, focusing on early-life diet and the risks of developing the condition. My supervisor was Professor Daniel Agardh, who is well known in celiac research. While that work was more epidemiological, my personal interest has also been clinically oriented, particularly around nutrition management.

One area that really caught my attention was the gluten-free diet itself, especially advice around gluten cross-contact. When you look closely, there's surprisingly little solid evidence guiding how strict recommendations should be and the advice given by dietitians seems to vary widely.

It made me question why patients might receive different guidance depending on who they see, or even which country they live in. Some national celiac societies give very strict advice around cross contact, while others are more relaxed and we wanted to understand, why is that?

This matters enormously for patients. These recommendations shape their everyday lives and have a major impact on quality of life. Patients need to trust that the advice they're given is both safe and evidence based.

How did you first become aware of the Takeda sponsored ISSCD MinM Programme?

I'd been a member of the ISSCD for a few years and saw the opportunity through the newsletter. At that point, I had just finished my PhD and was working as a postdoc, so it felt like the right time in my career to start building new collaborations and developing my own research ideas.

The timing was perfect. I was actively looking to connect with other research groups internationally, particularly those with a strong clinical focus.

How would you describe what you've gained from the MinM programme?

The programme has been incredibly important for me. My main mentor through the MinM has been Professor Edwin Liu. We had collaborated before, but not specifically on the clinical aspects of celiac disease. Years earlier, when I was still a PhD student, we had talked about shared interests in these questions, so the programme gave me a natural opportunity to reconnect.

Within my previous research environments, my focus had not really been on the clinical aspects of celiac disease. Being part of the M&M programme made it possible to establish such connections and start building projects in this area.

I visited Professor Liu's group twice, once in November 2024 and again in March 2025. During my first visit, they were also hosting the inaugural symposium on general population screening for celiac disease, which was a fantastic opportunity. I was invited to give a talk and connect with US-based researchers working in the field.

Beyond that, I spent time in the clinic, shadowing Professor Edwin Liu, dietitian Sadie Nagle, and psychologist Dr Monique Germone, who is also one of my mentors. These visits allowed us to really dig into clinical questions, exchange perspectives, and discuss future collaborative projects in depth.

Are any of those discussions now developing into active research projects?

Yes, absolutely. One key outcome is the international survey project we're currently running aimed at dietitians. It grew directly out of conversations between Sadie Nagle and myself during my visits. We both work in paediatric celiac disease clinics where dietitians play a central role with strong involvement of dietitians who follow patients closely over time.

While we shared similar clinical experiences, we realised that the advice we gave, particularly around gluten cross-contact, sometimes differed quite a lot. We began asking each other: What would you advise in this situation? What about this food, or this ingredient? When we saw how much variation existed between just the two of us, we realised this was likely a much broader issue.

That's what led us to develop the survey to explore how dietitians around the world think about and advise on gluten cross-contact and the gluten-free diet.

Survey Participation- Still Open

We launched the survey in November and have received just under 200 responses so far. Some regions are well represented particularly the Nordic countries, partly the UK and the US.

However, many countries are still not represented at all. To truly understand the global variability in advice, we need broader international participation. That diversity is essential if we want to clearly demonstrate how practices differ and why.

Anyone who would like to take part in this survey can contact me directly by email and I can share the survey invitation and link - elin.malmberg_hard_af_segerstad@med.lu.se

We would welcome further input from celiac disease professionals around the world.

Looking back, what does the M&M programme mean to you personally?

I'm incredibly grateful for the programme. Without it, I honestly don't know if I would have had the opportunity to visit the group twice and build these collaborations. In many parts of the world, funding for celiac disease research, especially clinically focused research is limited.

Having a programme that is specifically dedicated to supporting celiac disease researchers, particularly those early in their careers, is so valuable.

It opens doors that otherwise might remain closed.

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