

## **Raising Awareness and Advancing Care in Celiac Disease**

### **A Conversation with Dr. Nelson Cheinquer**

#### **Global Medical Affairs Lead, Takeda**

Celiac disease affects around 1% of the global population, yet it remains widely misunderstood and underdiagnosed. We spoke with Dr. Nelson Cheinquer, a physician by training and Global Medical Affairs Lead at Takeda, about education, partnerships, and the future of disease management in this evolving field.

**ISSCD:** What role does education and disease awareness play in your company's approach to coeliac disease?

**Dr Nelson Cheinquer:** Education and awareness are absolutely central to what we do. Celiac disease is often perceived as a lifestyle disorder rather than a serious medical condition—but in reality, it's a chronic immune-mediated disease that can cause significant gut damage and long-term complications.

Although around 1% of the population is affected, only a fraction of patients are properly diagnosed and managed. One possible reason is that treatment currently relies on a strict, lifelong gluten-free diet. While that can be effective, it sometimes leads people to underestimate the seriousness of the condition.

Raising awareness helps elevate celiac disease and its true impact on patients. It also helps patients access proper care and participate in clinical trials, which are essential for the advancement of treatment options.



**ISSCD:** How do partnerships like these strengthen education and support for people with coeliac disease?

**Dr Nelson Cheinquer:** Collaboration is essential. I've been working in celiac disease for four years now, and one of the most positive surprises has been how passionate and engaged the community is.

My role in medical affairs involves working closely with patients, healthcare providers, and medical societies. But Takeda can't and shouldn't try to solve everything on its own. We need to collaborate with patient groups, key opinion leaders, and professional organizations.

Our relationship with the ISSCD has been particularly valuable. We've seen the society grow into a major global voice, running ambitious projects and campaigns.

One initiative I'm especially proud of is the Mentee in Mentor (M-in-M) programme that Takeda has supported from the beginning. It connects emerging clinicians with established centres of excellence. There simply aren't enough specialized celiac centres worldwide, and this program helps bridge that gap.

We've seen mentees go on to become clinical trial investigators and leaders in their regions. The program is also expanding beyond Europe and North America into Asia and Latin America, which is incredibly important. It shows what meaningful collaboration can achieve.

**ISSCD:** Beyond supporting independent organisations like the ISSCD, how does Takeda engage with the wider celiac disease community?

**Dr Nelson Cheinquer:** The community is made up of many different stakeholders, and they all play vital roles.

Patient advocacy groups are among the most important. We work closely with organizations such as Beyond Celiac, the Celiac Disease Foundation, Celiac UK and AOECS in Europe. These groups are invaluable in educating patients and healthcare providers and in helping us reach underserved regions.

For example, as we expand clinical trials into areas like Latin America, there may be few established centres of excellence. Advocacy groups help us identify local clinicians and connect with patients.

We also work extensively with key opinion leaders, physicians, dietitians, and multidisciplinary teams who specialize in celiac disease. We collaborate with them through advisory boards, research support, and continuing medical education programs. Together, medical societies, advocacy groups, and academic leaders form the foundation of our efforts in education, awareness, and research.

**ISSCD:** How does Takeda assess the impact of its initiatives, and how do those insights shape future strategies?

**Dr Nelson Cheinquer:** Everything we do is centred on the patient. That's our guiding principle.

Our ultimate goal is to bring new therapies to people who need them. While a gluten-free diet can work for many, some patients continue to experience symptoms and intestinal damage.

That's why we continue to focus on translational research and clinical development with the goal of addressing the significant unmet medical needs that remain.

We look at impact in several ways. One is how our initiatives raise awareness of clinical trials. Participation in clinical research—undertaken as part of a discussion between individuals and their health care professional—plays an important role in furthering understanding of a condition and potentially making treatments available to a broader range of patients. Another is how they improve medical and patient education, so people can receive better care even before new treatment options are available.

We don't rely on a single metric, but we see tangible signs of progress. For example, at recent major conferences like European Gastroenterology Week, there's been a surge in celiac-related sessions, abstracts, and presentations. That shows growing scientific interest and investment in the field.

We also see increased engagement with patient organizations and strong attendance at educational programs and conferences, such as the International Celiac Disease Symposium.

***“All of this tells us that awareness is growing. But what matters most is that patients are receiving more attention, better information, and stronger support.***

***That's the real measure of success”.***

## **Acknowledgment**

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