

## Inside the Fight Against Celiac Disease

Celiac disease has long been misunderstood and is often reduced to a “lifestyle choice” rather than recognised as a serious autoimmune condition. But for Dr. Daniel Leffler, a leading expert in the field and representative of Chugai Pharmaceuticals, education, research, and collaboration are central to changing that narrative.

The ISSCD sat down with Dr. Leffler to discuss how awareness, innovation, and global partnerships are shaping the future of celiac care.

Abigail Britnell

To begin, what role does education and disease awareness play in your organisation’s approach to celiac disease?

**Dr Dan Leffler**

Despite the progress we’ve made, celiac disease is still widely misunderstood and underappreciated. This isn’t just among the public, it extends to non-specialist clinicians, government agencies, and even parts of the healthcare industry.

There’s still confusion about the scale of unmet needs, what patients are really experiencing, and what they’re looking for. The celiac population is growing and becoming more diverse, yet awareness hasn’t fully kept pace.

For us, improving education and awareness is foundational. It helps align everyone patients, clinicians, policymakers, and industry around why this work matters, where the gaps are, and how we can improve health outcomes. Data shows that celiac disease impacts far more than just diet. It affects long-term health and quality of life in significant ways.

Abigail Britnell

It does seem like the condition has been “hijacked” in some ways by lifestyle trends. From a global perspective, alignment on diagnosis and definitions feels crucial.

**Dr Dan Leffler**

Absolutely. And another challenge is that we don’t yet have clear severity classifications for celiac disease like we do for conditions such as inflammatory bowel disease.

Historically, everything has been grouped together because we only had one treatment, the gluten-free diet. When that’s all you have, there’s no real way to tailor care.

But we’re now recognising that celiac disease exists on a wide spectrum, biologically and in terms of patient experience. My hope, as a clinician, is that we’ll eventually have tailored therapies for different types of patients, just as we do for many other chronic diseases.

Abigail Britnell

How does Chugai, identify unmet needs in the celiac community, and how does that guide your strategy?

**Dr Dan Leffler**

We start with the growing body of international research, which has been incredibly valuable. Studies consistently show that many patients struggle despite strict adherence to a gluten-free diet, whether through ongoing symptoms, incomplete intestinal healing, or both.

Beyond that, we conduct one-on-one interviews, patient workshops, and surveys. We work closely with advocacy groups such as the Celiac Disease Foundation and Beyond Celiac to understand community perspectives.

Our clinical trials also play a key role. We collect additional data to better understand who responds well to treatment and who needs more support. It's a multifaceted approach, and while we've made major progress in the last 10 to 15 years, there's still more to do.

Abigail Britnell

Once those unmet needs are identified, how do you measure the impact of your initiatives?

**Dr Dan Leffler**

It comes down to strong, well-designed clinical trials. We focus on selecting the right patients and meaningful outcomes such as biopsies, symptoms, and emerging biomarkers.

We're currently planning and launching studies evaluating our treatment, DONQ52, across different patient populations. One major study, beginning soon in the US, Australia, and New Zealand, will focus on patients with ongoing symptoms and intestinal damage.

These are individuals who haven't achieved adequate control through diet alone. We've become more sophisticated in how we design these studies, which helps us better understand what treatments can realistically achieve.

Abigail Britnell

Beyond supporting organisations like the ISSCD, how do you engage with the wider celiac community?

**Dr Dan Leffler**

Much of that overlaps with how we learn from the community. We've held multi-stakeholder workshops bringing together patients, caregivers, advocacy groups, gastroenterologists, primary care physicians, and dietitians.

Having everyone in the same room is incredibly powerful. It highlights where current care falls short and where improvements are possible.

We also work closely with organisations such as Celiac Australia, the Celiac Disease Foundation, and Beyond Celiac. These partnerships help us understand patient needs and move research forward more efficiently. Ultimately, we all want the same thing: better treatment options for people for whom diet alone isn't enough.

Abigail Britnell

How do these partnerships strengthen education and support globally?

**Dr Dan Leffler**

Education remains a huge unmet need. One of our main strategies is working with organisations like the ISSCD to expand clinical expertise and knowledge.

One initiative I'm particularly proud of is the mentor-mentee programme. I helped fund whilst in a previous role at Takeda and now continue to support in my current role. It connects experienced clinicians with those new to the field, helping build a new generation of specialists.

This is one of the most effective ways to expand the pool of passionate, well-trained professionals, physicians, dietitians, and researchers who can support patients locally.

While we should strive for global consistency in areas like diagnosis, care must be adapted to local needs. Encouraging more clinicians to specialise in celiac disease, whether in research or patient care, is essential to achieving that.

Abigail Britnell

Finally, what gives you the most optimism about the future of celiac care?

**Dr Dan Leffler**

The growing collaboration across sectors from patients, clinicians, researchers and through to industry gives me real hope. We're learning more than ever before, and we're closer than we've ever been to offering meaningful alternatives to diet alone.

After decades of waiting, patients deserve real options. And I truly believe we're moving in that direction.

## **Acknowledgment**

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