

Listen, learn, understand:

The voices of patients driving innovation

Warnyta Minnaard – Warnyta Minnaard is co-founder of Missie Tumor Onbekend, a patient advocacy organization based in the Netherlands. She is also the co-founder of the global umbrella patient advocacy organization (World CUP Alliance) for people with a cancer of unknown primary. Brian Woolhouse – Brian Woolhouse is Managing Director at MSD Netherlands since December 2024, representing approximately 5,000 employees in the Netherlands. He grew up in Canada and has held various international roles in pharma in Canada and the United States. Over the course of his career, he has focused on various therapeutic areas, from infectious diseases to respiratory illnesses and from cardiovascular to rare diseases.

Being diagnosed with a serious disease profoundly impacts how people experience life, work, and relationships. While new treatments are being developed globally, many diseases still remain untreated or undiagnosed. In the Netherlands alone, over one million people live with rare diseases, with approximately 95% of these conditions lacking approved treatments. However, change is underway—thanks to patient advocates like Warnyta Minnaard and the collaboration of key players in healthcare, including pharmaceutical companies like MSD. We had an informative discussion with Warnyta Minnaard from Missie Tumor Onbekend and Brian Woolhouse from MSD on their efforts to drive innovation in the fight against diseases.

A journey of uncertainty

For many patients the road to a diagnosis is long and filled with uncertainty. When symptoms are vague and common patients are frequently misdiagnosed or dismissed. “In these cases, it

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Warnyta Minnaard, Co-founder, Missie Tumor Onbekend

takes a long time to achieve a correct diagnosis. Personal stories that we hear from patients bring this to life. What is especially touching is to hear patients explain the emotional impact a misdiagnosis can have, explains Brian Woolhouse. “In the meantime, patients are advised to lose weight or exercise more, for example. Or they are told that nothing is wrong, while their underlying disease remains undetected.”

For Warnyta, this reality became painfully personal in 2018 when her partner fell ill. His symptoms didn’t fit the typical cancer patient profile, and without a clear primary tumor, doctors were hesitant to initiate treatment. “If you don’t have a label, even getting into the right hospital clinic can be quite challenging,” she recalls. After months of uncertainty, her partner finally received a diagnosis—a cancer of unknown primary (CUP). Unfortunately, when the general chemotherapy treatment finally started, it was too late. He passed away the next day. In her grief, Warnyta found a purpose. She realized that her partner’s case was far from unique. “I thought he must be the only patient, as this cannot be normal,” she reflects. However, upon reviewing cancer registry data, she found that at the time approximately 1,500 similar cases were recorded annually in the Netherlands Cancer Registry. “These are patients that don’t

“We must listen, learn, and understand – so that we can amplify the voices of patients”
– Brian Woolhouse

have a voice themselves, as most of them die before being able to make a case. I felt that I could be the voice of these patients.”

The power of data

Determined to prevent others from experiencing the same struggle, Warnyta co-founded the patient advocacy organization Missie Tumor Onbekend. From the start, she and her team had a clear goal: to help patients with unknown primary tumors gain access to treatments and ultimately getting rid of this disease. Rather than focusing solely on individual patients, they wanted to change how entire groups of patients receive better diagnostics and treatments. “Having data strengthens our case,” she explains. “We weren’t just sharing one or two patient stories; we could speak about an entire group, because of data compiled by IKNL and statistics available via the Netherlands Cancer Registry.” This data driven approach proved crucial when advocating for policy change. Warnyta and her team reached out to health insurance companies, hospitals, researchers, pharmaceutical companies, and politicians. Initially, many stakeholders underestimated the prevalence of rare cancers like CUP. But, armed with data, the organization - together with several clinical experts - successfully lobbied for the reimbursement of crucial molecular diagnostic tests. The strategy worked. A critical paragraph was added to a government motion, and within two months, the Netherlands Healthcare Authority approved the reimbursement policy—a process that can take over a decade.

Listening to patients to improve treatments

One of the key elements in enhancing care for patients is ensuring their voices are heard. “We must listen, learn, and understand,” says Brian. He recalls how input from patient representatives directly influenced a new treatment program at MSD. “For example: if patients can’t walk upstairs, how can they visit a hospital every three weeks for an injection?” This insight led to the creation of a home-administration option, which greatly increased access to care for those in



Brian Woolhouse, Managing Director MSD Netherlands

need and ensured these patients really received the treatment. Warnyta echoes this sentiment. “Knowing which patients to treat when can prevent unnecessary tests and hospitalizations.” In her vision for the future, Warnyta aspires to bring about fundamental change. “I dream of a healthcare system where we don’t wait for treatments to fail before finding the best options. We need to implement more personalized treatments and better diagnostic strategies earlier.” Brian agrees, adding, “Understanding which patients will benefit the most can lead to better treatments, shorter hospital stays, and fewer adverse events. This not only benefits patients, but also the healthcare system.”

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Brian emphasizes that delivering the right treatment to patients is at the core of MSD’s mission. “We have been present in the Netherlands

for 70 years now. Our work underscores our mission to save and improve lives around the world. We do everything in our power to deliver medicines to patients and enhance patient access, to clinical studies, medicines and vaccines. And we use the power of leading-edge science to bring innovative medicines to underserved patients.” One of MSD’s landmark contributions is in the field of cancer treatment, particularly through the development and production of immuno-oncology therapies. “Our most significant innovation is Dutch, and we are proud of that. We’re not just discovering new medicines; we’re ensuring they reach the patients who need them most,” Brian emphasizes.

Collaboration is the key to change

Both Brian and Warnyta stress that meaningful progress in treating diseases can only be achieved through collaboration. “Missie Tumor Onbekend is leading by example in empowering patients by giving them a voice and helping us identify gaps and needs. We need these kinds of coalitions of industry and societal partners to realize systemic change,” Brian states, while emphasizing the importance of breaking down silos in the healthcare system.

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“At times, we are quite fragmented in the ecosystem. We need to bring all voices to the table and ensure that everyone is included.” From patient organizations to pharmaceutical companies, hospitals, policymakers, health care professionals and insurers—every stakeholder has a crucial role to play. “Everyone has their own interests, and we need everyone involved,” Warnyta agrees. The Netherlands offers a unique ecosystem in that regard. “I think I underestimated the unique environment in which we operate in the Netherlands. We really have world-class R&D capabilities and some of the best doctors and scientists, all in close proximity,” Brian reflects. Warnyta agrees, adding, “The Netherlands has a strong framework where patient advocacy is valued. It’s a very democratic system in many ways.”

Looking ahead: a future with faster diagnoses and better treatments

There is still much work to be done. Delays in diagnosis continue to be a widespread issue, and many treatments remain inaccessible due to financial and regulatory hurdles. However, the successes of organizations like Missie Tumor Onbekend demonstrate that progress is possible when patient voices are amplified and supported by robust data, while pharmaceutical companies like MSD continue their innovation efforts to ensure new medicines reach patients with unmet medical needs. As Brian and Warnyta continue their respective missions, one message is clear: no single entity can address these challenges alone. Brian ends the interview hopeful, “It’s clear that our healthcare system is facing challenges. But we are optimistic: together we can make it happen!”

“We use the power of science to bring innovative medicines to the people who need it”
– Brian Woolhouse