Melanie Croce-Galis – Director, US Patient Engagement, Oncology, Novartis

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Melanie Croce-Galis, RN, MPH explains the specificities of her work as patient engagement lead for Novartis Oncology in the US market, where significant disparities in patient access to information and to care throw up several challenges. Croce-Galis also outlines the work being done around CAR-T therapies and why integrating and amplifying the patient voice throughout the drug development process will benefit all stakeholders.

What are the fundamentals of your role as patient engagement lead for Novartis Oncology in the US market?

It's simple, really: my job as patient engagement lead is to make sure that the patient voice and perspective is imbued throughout everything that we do, from early development to clinical trials all the way through to product launch and beyond.

In practice, it's a bit more challenging, however. The patient is ultimately the reason why we work in this industry, but historically the patient experience has tended to be sidelined. However, thanks to patient advocacy that is changing rapidly – which is extremely exciting. There is a growing recognition that patients are experts in their own illnesses, that they are increasingly well educated about treatments, and want a say in what is being studied and what kind of treatments are available. It's incredibly important that we acknowledge this. And really when you think about it, it is a win-win situation: if we are better at meeting the needs of patients, then more patients will benefit from our therapies. Therefore, it also makes a lot of sense from a business standpoint.

Having been involved in patient advocacy for several years, what made you decide to work with a corporate sponsor and what kind of impact are you looking to achieve that perhaps was not possible from the other side?

I previously worked in HIV policy to ensure policies and programs met the needs of patients living with the disease. Oftentimes, countries would say that they were trying to be more inclusive in their policy-making, for example of women, but would then put in place policies or practices that made the patient experience more difficult. For example, trying to increase HIV testing by requiring pregnant women to bring their partners to prenatal appointments.

Frequently, these policies looked good on paper but did not work in practice. In this example, women struggled with getting their partner to agree to come to an appointment, and if they came alone, they were made to wait until the end of the queue. It was very stigmatizing and discouraged women from coming in for care at all. I worked on dialling down into the actual experience of a patient to understand how policies helped or hindered them and then translated that in a way that helped policymakers and program managers change those approaches.

My years focused on understanding patients’ needs and making sure that their views are used in generating solutions give me a valuable perspective within Novartis today. I bring that advocacy focus to cross-functional areas within the company to make sure that we are centering the patient experience throughout.

What are the most serious challenges that cancer patients face in the US today?

The US is a big country with robust patient advocacy groups. However, because of this size, there are still many pockets without the necessary information and resources. Our large and diverse population is very divided in terms of education and economic levels, and unfortunately, our own healthcare system drives some of that inequity. There are also significant divides – geographic, racial, economic, etc. – that lead to great disparities in health care across the country and that is one of our major challenges. I’m committed to addressing these disparities to ensure all Americans have access to the information and resources to improve their health and possibly save their life. When patients better understand their treatment options, they can be advocates for themselves and take back a measure of control over their lives that a cancer diagnosis can take away.

There is an added level of financial stress in the US for people with cancer as well. On top of the trauma of finding out that they have cancer, many have to worry about whether or not they will be able to make the necessary copayments, or if treatment will be approved by their insurance company. It is a big job for both caregivers and patients, especially for patients who do not have much in the way of caregiver support. This is something that I am very attuned to and we work hard at Novartis to make sure our patient support services address as many needs as we can so that patients can focus on the most important thing – beating cancer.

CAR-T therapies have been dubbed potential one-time ‘cures’ for cancer. How challenging is correctly communicating the expectations that patients should hold for CAR-T and generating awareness of a previously unknown field?

The whole idea of CAR-T therapy sounds futuristic. Taking a person’s T Cells, modifying them to target cancer cells and putting them back in the body to eliminate that cancer on their own sounds like science-fiction. It’s important to realize that this kind of precision medicine is the future of cancer treatment. And it’s now! The challenge is making people aware of this rapidly changing treatment paradigm in oncology, especially in some areas of haematology. While some CAR-T-eligible patients have heard about these therapies’ potential as a treatment option, many others have no idea of its existence or understand how it works.

Patients understand how chemotherapy works because it’s been around longer and almost everyone knows someone who has gone through it and what the potential side effects are. They also know that it takes several weeks and rounds of treatment.

CAR-T, on the other hand, is relatively new and people do not know much about it, including the fact that compared to chemotherapy it is a relatively straightforward experience and a one-time treatment with curative potential. It can be hard to believe. So helping to educate people about how it works and helping patients share their stories about their experience with it has been a focus of ours. After all, most patients would rather hear from someone who’s gone through it.

Even though CAR-T seems very promising, it needs to be made clear that it might not be 100 percent effective for everybody. As a sponsor, how do you explain this to patients?

Patients obviously must talk to their treating physician about what's appropriate for them in their individual cases. There's nothing that's 100% effective for everyone – yet. Overall, though, it's important to us, as we engage with patients and patient groups, that we make clear that CAR-T is another really powerful weapon in the oncologist's arsenal, but it's not the only one. The science is exciting though! As science and medicine progress, we will most likely see these types of treatment come in earlier and earlier lines and additional indications.

How is Novartis championing relationships with advocacy groups and how it is engaging in these relationships earlier in the drug development process?

There has to be more conversations between advocacy groups and pharma, and between patients and pharma. Novartis is recognizing this in our new strategy towards patient engagement. Patient engagement is a two-way street. I spend a lot of time trying to learn about what patients want to know and what kind of gaps there are with patient needs. We are listening to patients, answering questions, and soliciting feedback that we can internalize to help make their journey better.

Advocacy groups are critical partners in this journey. I have the utmost respect for our US. advocacy partners. They take on a huge role in patient and provider education, as well as patient support. We work very closely with our partners to understand and support their priorities, as they talk to patients every day and know best how to help.

At the same time, we can't forget that there are many, many patients who aren't connected to advocacy groups. The aforementioned inequity in the US plays into this question. As the COVID-19 lockdowns showed, many people are isolated and without sufficient internet access, bandwidth or other resources to take advantage of webinars or other telehealth opportunities. From an equity perspective, it is very important for us to be diverse in who we work with and make sure we are reaching all patients and helping our advocacy partners do the same.

Most patient groups and physicians feel that there is a necessity to learn more about CAR-T outcomes on patients via real world data collection. What is your take on that?

I think that is true. Patients might share their personal experience with other patients in support groups or even social media groups, but there is still a disconnect between patients wanting to share their information and a formal way to collect that data in a meaningful way that also allows scientific analysis of these data. One approach is using formal registry data (cibmtr.org) as the post-approval commitment we made to the FDA.

There are also a lot of patient advocacy groups that collect data from patients to help drive their programming. However, running large registries that can also be opened up to academic or private sector researchers for real-world-evidence data use is a highly complex and resource-intense undertaking and can thus be prohibitive for patient advocacy groups. Another important point to consider is the long-term nature of such a registry – data curation may come at risk once an organization runs into financial problems as we have seen during the COVID pandemic.

What do you think is the key issue to consider around CAR-T from a patient advocacy standpoint?

I am very excited about CAR-T and as a health science nerd, I have been even before I began working at Novartis. So much of the medical research going on today is so incredibly advanced with seemingly endless possibilities. However, the key issue is making sure that access to these therapies is as wide and as equitable as possible. Innovations need to reach everybody everywhere and at the time that it’s truly needed to really have life-altering effects on our society. In addition to addressing these inequities, we must make sure the patient voice is not only heard but elevated into all areas of medicine development. There’s a quote I like that goes “if you want to go fast, go alone; if you want to go far, go together.” From a patient advocacy standpoint, I know that if we partner together with those affected by cancer, there’s no limit to how far we can go.

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