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*Christian Conrad outlines his role as patient engagement lead for Novartis Oncology in Germany, how individual patient interactions differ from those with advocacy groups, and the current situation for cancer patients eligible to receive Novartis' CAR-T therapy in Germany.*

**Could begin by telling us about your position at Novartis?**

It is always challenging to explain my role, but in essence patient engagement and patient advocacy is about talking and listening to the patients and getting their insights. These insights are not limited to the collection of data but are more about trying to understand the patient's perspective. This is really important for Novartis and our commitment to patients and caregivers; the company tries to include the patient community's perspective in all of its work and be very transparent. In my role, I talk to patient organizations and patient advocacy groups to get their perspectives, learn what moves them, and figure out what could help them in their journey.

**Given that patient engagement is a relatively new function within pharma companies, what do you see as the key skills that are needed for this role?**

You are absolutely right, the idea to have a department for patient engagement and patient advocacy is quite new. It comes from the need of having someone who is really dedicated to it because every department has a different interest and a different perspective. The skills that you need might vary, for example, the marketing and the medical perspectives are very important, but they cannot be taken alone, leaving the patients' needs out of the equation. It is important to integrate all of these perspectives and interests and do it with empathy.

There has been a big change in the last few years within Novartis, where patient engagement is now very present across all our cross-functional teams. We try to understand the patient journey and help in any way possible. Early involvement of patients in clinical trials is key, and so is getting their input on patient safety and other issues related to the patient experience. On some occasions, we even co-create initiatives in online and offline information platforms and digital solutions together with patient organizations.

**Not all patients are part of patient advocacy groups; do you see a difference in what patients demand when they are organized and when they speak with you directly?**

It does vary. Every individual is different and has different needs. When I talk to individual patients that are not a part of any patient organization, they are always happy to receive information and have a guide during the process they are going through. On the other hand, patient organizations generally have a stronger awareness of the political landscape, so they bring initiatives and have physicians or medical experts on their side, as community consultants. It does change how they interact with me.

For example, a patient with a haematological disease like lymphoma or leukaemia has an acute need and is supported by their caregivers or relatives, which is something we must always take into consideration. Therefore, we make sure to include the caregivers and the relatives in the discussion, and not only the patients or physicians. However, when we talk about the same subject with a patient organization the focus is more on strategy and the overarching goal.

**Germany is one of the richest economies in the world, how would you describe the situation there in terms of access to healthcare?**

It is true that Germany is very developed in terms of medical knowledge, science, and health insurance. Almost everybody has some form of health insurance, either public or private. As soon

as a therapy is approved here it should be reimbursed.

Although there are many advantages, the issue is that they are not always distributed evenly. Regional problems are common, as the healthcare system is decentralized, therefore a lot of bureaucracy is involved. CAR-T centres are a perfect example; with the many referrals and costly treatments that are needed the process does not flow as smoothly as it should and that is something that we still need to work on. This relates not only to CAR-T but to all innovative therapies.

**When was CAR-T approved in the country? Does the approval process work in a similar way to that of the FDA in the US?**

It was approved in 2018, but it obviously took some time and was a very complicated process. The simplified version is that there is a joint federal committee of physicians and health insurances and guidance that must be followed and a form of HTA body doing a therapeutic assessment. Only when all this is finished a final decision on pricing can be made. All these processes can be delayed, especially if we are talking about getting real-world evidence, then those decisions might not be so quick. Patients or patient organizations are sometimes included within the HTA bodies and it would be ideal to always consider patient-reported outcomes, but it is not always the case.

**When it comes to CAR-T there is a lot of expectation and excitement, but how do you manage patient's expectations versus the actual scientific panorama?**

From my experience, the patients and patient organizations are the ones welcoming new innovative therapies, like CAR-T. They really try to get all the relevant information to their communities. Some eligible patients are able to profit from a treatment, usually very early on but we still need to make sure that early referrals are done and that way patients are aware of all the options they can have at every stage of their treatment journey.

**As a patient advocate how are you working to improve the referral process and have all the experts on board?**

This is not entirely under my scope, but more in the hands of our medical department. We have highly qualified medical colleagues and they try to bring all the experts together. But we do talk to

patient panels, discussions, advisory boards, and also physicians in order to have the patient perspective present and create connections with patients and with patient organizations.

**How is the company championing advocacy relations internally and how is it engaging in these relationships earlier in the clinical development process?**

As I mentioned earlier, we try to include the patient's perspective as early as possible, when we create the concepts and protocols of clinical trials. This is not easy as there are many regulations and rules in play. It is also very complex as it is a global decision and different approvals are required to make it happen. We also try to bring together different members of several patient advocacy groups from many fields like haematology and oncology to get their impressions and insights on patient-reported outcomes among other topics. When it comes to data, there are also certain restrictions, because many of the findings are from an early phase of the process, hence they are not allowed to be shared with just anyone as it is a very regulated environment.

**What makes Germany a great environment for CAR-T type therapies?**

I think the awareness of these types of therapies, which we try to improve with campaigns for physicians and patients is key. It is not the first line of therapy, but it often comes up as an option later in the process. Creating that awareness among patients, caregivers and physicians is fundamental. We are actively working on different campaigns to ensure the information is available to people, and for patients to know and understand that there are other options, and they might be eligible for those options.

**Is it challenging to present eligibility in plain terms?**

It is definitely very complicated, as it is a very sensitive issue. It is also important that the patient, relative and other caregivers, as well as patient organizations, are on board, aware, and informed. Consequently, it is much easier to make an informed decision with your physician. We strive to be as transparent as possible and give all the important information available to the interested parties. Eligibility is not black and white issue and information is needed.

**Do you think price is an issue when it comes to innovative treatments like CAR-T?**

I think when it comes to this treatment, price is not the main concern, at least not in Germany. Our environment allows us to focus on the results and not deviate from that goal. I think the issue is more related to following the sequence of approved drugs and CAR-T being presented too late in the process.

I think getting the therapy at the top of the minds of physicians and patients is something that needs to be addressed. Patient organizations are key in that process as they are always willing to help because it is in their interest to get the optimal treatment to the patients as soon as possible.

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