Stefanie Houwaart on the GBN podcast – transcript

German Biobank Node (GBN): What are patients' views on biobanking? What about their participation in the whole research process and what are the benefits? Today, I will discuss these and other questions with Dr. Stefanie Houwaart from the BRCA Network, who is also a member of the Scientific Advisory Board of the German Biobank Node. My name is Verena Huth and I am responsible for communication and public relations at the GBN. Dear Steffy, thank you very much for being a guest on the GBN podcast today.

Dr. Stefanie Houwaart (SH): Thank you very much, Verena. I am very pleased to be here.

GBN: As a member of the GBN Scientific Advisory Board and especially as a patient representative, what is your view on the academic biobank landscape and its development in Germany in recent years? What progress do you see in terms of harmonisation and networking and how do you assess its position in the research landscape?

SH: I can still remember when I joined the Scientific Advisory Board of the German Biobank Alliance and the German Biobank Node in 2017, and the topics we discussed at that time. Everything was just getting started, there was a lot of talk about networking, of course, how to include new biobanks and then also about big themes like quality assurance. When I think about it today and remember the last meeting of the Scientific Advisory Board – so much has been realised, implemented and is now being used. Especially the training programmes and how many biobanks have joined. Also in the context of quality assurance: everything that has been implemented and has actually been evaluated, where it has been demonstrated that things are really going well, that the quality is assured and that the samples can be used well. That you can really see exactly where the samples are located all over Germany. That I, as a researcher, can submit applications. When I think back, the leap from 2017 to 2023 is really, really big.

GBN: Under what conditions can patients provide their biospecimens and associated data for research 'with a clear conscience'? What is important for biobanking from the patient's point of view?

SH: I come from the BRCA Network, this patient community of people with familial cancers. And for us, from the very beginning, it was absolutely relevant that research and healthcare go hand in hand. Biobank research or research with biobank samples with clinical data that is not necessarily associated with this sample in the first context, but subsequently because we know what happened to this patient and we can then link this data. And we know from our healthcare context, because it is very relevant to us: what does the biospecimen say, in particular, what does the genetics say about the clinical development of our personal disease? That is why we are so keen to support academic, clinical, preclinical, basic research biobanks. And a second point is that when it comes to academic biobanks, we have a high level of quality assurance. For us as patients – and I think this is clear to everyone – we want to receive a therapy and, ideally, get well. And these therapies must – and these are two words that are always very important to us – they must be *effective*, they must really have a good effect. And they should be *safe,* and the word safe refers to the side effects. I want the spectrum of side effects to be as small as possible. The basis for this is, of course, robust

and good research results. And for that I need good, quality-assured samples. They have to be stored in a quality-assured way, they have to be issued in a quality-assured way and, above all, these samples have to be used for research questions that are relevant from the patients' point of view. Those are really the three big reasons: Linking the samples to the clinical data, quality assurance of the samples for ultimately effective, safe therapies, and that we give out these valuable biosamples for patient-relevant, really good research questions.

GBN: Where do you think there is room for improvement?

SH: I am speaking from the patients' perspective and from that point of view, that there is awareness in the patient community about biobanking, that you can give your samples there. And we have already done a lot of work in this area, including public relations. We have a lot of very good information material. Possible improvement in this area, or another effort that could be made would be to offer workshops on specific topics. To bring together researchers in the biobank context, but perhaps also the German Biobank Node, that we have joint events, that we go to the patient organisations, that we network even more – I think that's a very important point. And what could be improved in the context of biobanking? As a member of the Scientific Advisory Board, I can say that we are dealing with very big topics there, with a really big diversification. And I think the challenge now is to maintain the momentum. The path we have taken so far has been very successful – there has been a very successful start-up phase. And now it should be followed by a very successful and strong utilisation phase.

GBN: Representatives of GBN, GBA biobanks and patient representatives have published a joint position paper on strengthening academic biobanks and patient participation in biomedical research. What was your specific motivation for participating in this initiative?

SH: My motivation is multifaceted. First of all, of course, because I've been a member of the Scientific Advisory Board for the patient perspective since 2017, so I've known the German Biobank Alliance and the German Biobank Node for many years. And then coming from the motivation of the patient community, knowing how important academic biobanks are to us, also really in contrast to – I have to emphasise this – commercial biobanks, where we don't know what happens to the samples, what research questions are being addressed based on them and also how they can be linked to clinical progession samples. There is this hard cut between the clinic and industry, and that is why our efforts come from the patient community, because we know how important the interface between research and care is for us. That's why we were so motivated to work on the position paper. And the third motivation is that we also see that many calls for funding do not explicitly state that this infrastructure should be used. And that's where the motivation to contribute to the paper comes from.

GBN: What does patient involvement actually mean and what are its benefits?

SH: Patient participation means that patients are involved as collaborators in either research projects or healthcare projects. This means that they are involved in certain work packages and help to shape them. They can also be involved in committees. But this participation means that they have influence and that in joint discussions, depending on the topic, sometimes you follow what the researchers say and sometimes, if it makes sense, you follow what the patient representatives say.

In other words, you really have a right to participate and have a say. I think this is also important in contrast to taking part in research or enrollment. For example, if we give out questionnaires and people answer them, that is qualitative research on the one hand, but it is also a form of taking part. Of course, that's absolutely important, that's what we're all about at the end of the day, that people are enrolled, but – and you asked about the benefits of participation – participation is there to develop healthcare products or certain interventions that are tailored to the patient community. This means that for example in a biobank project I can sharpen the research question, the relevance, I can even add more research questions because I talk to the representatives. I can decide together and really look together at what other data are relevant, how I can collect the data, when I can approach the patients. When does it make sense, also in the context of the disease management cascade, but also in the therapy cascade – when are patients accessible at all? What information do they need to give their consent? This brings us to the point where patient representatives have a say, they participate, which in turn makes it easier for other patients to take part in the project. That's why I made the distinction earlier between participation and enrollment. Patient participation also has a long history, a long tradition. There is a lot of scientific work on this. There is a lot of evidence that patient participation and the participation of people in general for whom research is done is useful. And I can understand that it is not absolutely necessary for researchers to have all this theoretical background. But that's what all these interface positions do, and I think it's really great and important that they exist now. There is a lot of momentum around patient participation in basic research. And now we have to bring it all to life.

GBN: And what opportunities do you see for biobanks in particular to involve patient representatives in their work, or what would you recommend?

SH: The very positive answer is that patient participation can be implemented in many different ways. If we look at the ladder of participation, there are so-called pre-stages before participation takes place. For example, there are hearings – in practice this means that patient representatives sit on advisory boards. The points and comments that the patient representatives bring to the advisory boards are then implemented or not, depending on whether they are relevant and useful for the biobanks. That would be the first point. And then, of course, it makes a lot of sense for the individual research projects – and I would advise all researchers to do this right from the start – if they have research ideas and know which disease area they are researching, that they simply look for the patient organisations in their research area and start networking with them. And then when they have a specific research question want to apply for a call for proposals, they can build on that relationship. And in this way, I can implement patient participation at very different levels and in very different ways. Of course, it would be wrong to instrumentalise it in the sense of: „I've got somebody involved pro forma on paper, but what this person says will never have any influence, we won't implement it. But we keep telling the outside world that we have a person here.“ I think that's almost the only wrong thing you can do. So this ‘fake participation’. But apart from that, patient participation – that's the great thing – offers a lot of opportunities to get on well together, and that's what it's all about.

GBN: Thank you so much for this interview, Steffy!

SH: Thank you very much for giving me the opportunity to present the patient perspective in such detail. Thank you very much.