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Cancer is a very difficult disease. It's a traumatising disease for you and your family. And you want to forget as soon as possible everything. However, some of us believe that our experience can be useful for others, and that's how most cancer patient organisations have started - on the kitchen table or in the yard.

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Eleanor - Welcome to this episode of the BBMRI-ERIC Podcast. My name is Eleanor Shember, Head of Outreach, Education and Communications here at BBMRI. You just heard from Kathi, Apostolidis who is a patient advocate and has been a member of the BBMRI Stakeholder Forum Patient Pillar since BBMRI's inception ten years ago. We'll return to her story in a moment.

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This is a two part episode which will share different perspectives on why the patient pillar is so important. The research and development of medical treatments is widely seen as a separate process, with patients only appearing at the very end when treatment is delivered rather than a one-way process. What if it was iterative? Where patients and patient groups are part of the innovations in health long before they may need treatment?

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This is the intention, at a meta level, of the stakeholder forum Patient pillar. The patient pillar covers most European countries by bringing together 19 organisations from 13 member states and six EU wide organisations. It's BBMRI's wish to foster a strong community of patient organisations working across a range of topics and no other research infrastructure engages patient organisations like this.

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It's through this unique cooperation that patient organisations can also jointly access policymakers and shape European wide policy. Within BBMRI, the patient pillar guides the direction of the organisation over key issues such as paediatric biobanking, cancer research and the European Health Data Space Initiative. These themes also support wider pan-European projects. In this two part episode, you'll hear about the work of pillar members Kathi Apostolidis and Dr. Stephanie Houwaart.

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In part two, you'll meet the new chair of the Stakeholder Forum, Eric Vermeulen. Since this episode is partly about Kathi, let's return to her. She's past president and chair of the Scientific Committee of the European Cancer Patient Coalition - ECPC. This is the voice of cancer patients in Europe with over 450 members, making it Europe's largest umbrella cancer patients association.

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Kathi is a founding member and president of the Hellenic Cancer Coalition. ELLOK - ellok.org - and steers other Greek cancer patient

associations. She survived breast cancer twice and has been involved in breast cancer survivorship and cancer patient rights advocacy for the last 25 years on the national and international level. She discovered a lump in her breast whilst on holiday in August 1990.

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Faced with little information, stonewalled by health officials, and dealing with the silence that surrounded cancer at the time, she decided to take action. One of the a few people in the early 1990s with an Internet connection and a business computer, Kathi discovered a wealth of information on breast cancer that she used to inform herself and set up a patient advocacy organisation in Athens.

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It's still going strong 30 years later. Early on, she understood the power of working at an EU policy level and connected ten Greek cancer organisations with ECPC. I wanted to know from her experience of cancer why biobanking plays a key role for patients like her. Kathi had a lot of foresight about the importance of her sample and how to connect that through to the rest of her family.

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Kathi - It's very, very important, and I'll tell you why, because this was very apparent and practical when I got the second breast cancer, because then you need to check the first sample with the second one to see are they the same? Are they different? But of course, it was already 2001 and 11 years had passed.

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I had learned a lot, so I was able to do that. So, you understand that for me, understanding what my cancer was, what exactly it was, what they were aware of, the implications of the pathology for my future. Because by that time I had realised that something strange was happening in the family because from the side of my father, my father died, his sister died, and my uncle died.

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His son died and daughter died of breast cancer, of pancreatic cancer. So, this is strange. And myself now I find myself with a, I would say, benign cancer this year, but it's a cancer.

Eleanor - Kathi undertook advocacy training in the US with an aim to positively influence policy in the European Parliament as part of ECPC. Over time, Kathi, along with other patient advocacy groups, were able to access the labs to get an insight into how Biobanks worked.

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They prepared information from a patient perspective and it also advantage to her work when Greece joined BBMRI. I asked Kathi how being involved in the BBMRI Patient Pillar has influenced her work in Greece and across ECPC.

Kathi - What the patient is interested in is to know what will happen to his sample. Is it going to be thrown? Is it going to be kept?

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Who is keeping it? What kind of research is done on it, how the patient will know? What kind of research is done on it? Can research be done on his own cancer? Lots of things that you and I are interested to know. And with this little booklet that we have given to patients across Europe, the possibility to learn a few things which are now useful because then afterwards we had GDPR

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and then this links very nicely together because it's your right to request information. It has also been translated by ECPC members in other languages, and we have also, of course, translated into Greek for my colleagues here. So, I believe now coming to BBMRI, when I heard that Kurt was organising this forum in 2000, then I said, I must go.

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Definitely learn what is going on in Europe, what are they going to do? And I was pleased to see that the BBMRI was growing, was getting members. And when the Greek biobank by the Greek Academy of Sciences became a member of BBMRI, I invited the researcher to tell us about his work. What is he doing, how long it takes to find the result and why?

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I mean, he can work for years if he does not find something that has resolved. Because, okay, you are outside. You cannot understand that research is not something that you start now, and you finish in 3 hours, 5 hours.

Eleanor - In our conversation, Kathi outlined the high dropout rates of patient advocates once they move past treatment. Yet she has, despite retirement, made a new career out of advocacy.

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Kathi told me what keeps her interested in being at the heart of patient representation.

Kathi - Because you see, also results. They might be a little or few, but you do see results. And for us at ECPC, we have seen results in cancer policy. We have seen the amendments we have proposed for the balance between work life and family life.

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We had ten amendments, but two were approved. Also, we have seen our amendments accepted or accepted there in the change of the EMA policy in 2017. Also, again, our amendment was accepted. So, you see a few wins but if you expect that every day a win in cancer policy, then you are totally wrong. It does not come;

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It comes only by perseverance, by knowledge and I would say, I would say also by resistance You cannot expect the results to fall from the sky. They don't. They don't. So I believe that what BBMRI is doing with this stakeholder forum is very valuable.

Eleanor - You heard from Kathi the direct relationship between a patient undertaking treatment for cancer, the vital need for representation at country and European policy level and the value of biobanking in developing new treatments.

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In just a moment, we'll meet another member of the patient pillar.

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I'm speaking with Dr. Stephanie Houwaart, who is a biologist and has a master's in public health. She's a member of the Scientific Advisory Board for the BRCA Network in Germany and is also a member of the scientific Advisory board for the German Biobank node. Stephanie is a newer member of the BBMRI Stakeholder Forum's Patient Pillar and brings with her a background in patient engagement and biobanking.

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The BRCA Network focuses on genetic or familial high risk cancers breast, ovarian, colorectal and it supports people through early detection, family considerations and the associated legal and insurance issues. Stephanie, thank you for making some time today. The first thing I want to ask you is how did you get involved in patient engagement and then decided to become a member of the patient pillar here at BBMRI?

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Stefanie - That's been quite a journey, I have to say, about a couple of years, actually. I started as a member of the BRCA Network in 2012, and then I was, was locally invested engaged in my home town at the moment. And then from there I started to work more and more with the board of the BRCA Network.

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And then we have, and BRCA network in general is a patient organisation that's very scientifically active, political, active. And so we really had from the beginning, very close ties to clinicians to other sciences. And with that we got questions and to participate in research projects and this actually was my first step into patient engagement at the BRCA Network and we specifically have been asked to participate.

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And then it just got really fast from there that we got into several political committees, scientific committees, and then 2017, I was asked to be member of the advisory board of the German Biobank alliance which I really happily took on. And because from my scientific background I had some connections to biobanking and I understood as a patient

representative the scientific perspective, especially the lab perspective.

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So, from there then they asked me whether I would like to go on the European level and be a member of BBMRI-ERIC Patient Pillar from the Stakeholder Forum, and this is how I'm here today.

Eleanor - In all of that, you've developed quite a sensitivity to patient needs and an understanding that patients are not a homogenous group.

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How do you ensure that you're bringing that broad and representative set of perspectives to the pillar?

Stefanie - That's a very important question, and that's a very important thing to keep in mind for us as patients representatives. I really heavily lean on the word representative. So, what's important for me is that when I'm on those different paths or engaged in different projects that I'm specifically not bringing in my personal opinion.

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I mean, of course that influences what I say. It influences my what I'm weighing and what I think, of course. But really the task of patient representation is to be really rooted into the patient community, not only in my patient organisation that I'm coming from, so the BRCA network, but really being rooted in the community of patients with breast and ovarian cancer, with hereditary cancers, generally with cancers.

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But I'm also - since the patient's organisations are connected with other patients organisations and then being a member of one of the big umbrella patient organisations in Germany. So, and there you talk to lots of different people. Of course, you are a member of the support groups and this is really that you get what are the concerns really on the roots of the community, of the people.

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So, their everyday thoughts and challenges, their everyday thoughts and challenges regarding care, also regarding research, and then to bring all of those different views together, like being a channel for those different positions. Because as I said, it's really the case that the patient community is very heterogeneous. So, we do have patients. As for myself, for example, I'm a risk patient.

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If you want, because I do have a predisposition for several cancer types. But then there are other cancer patients who maybe have their disease, which is already very advanced. And of course, they do have other points of use, they do have other priorities already. So we really differ regarding the topic of data and data use. So but it's really my task to

transport this differentness and this heterogeneity and to be honest about this.

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So not to use my position and to only bring in my view or the special view of the BRCA network, but to really do the work and channel the different views. Patient representation is a little bit comparable, I think, to the work that politicians are doing because normally they should represent and this is what we try to do and we are not perfect yet, I have to say.

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But we try to really bring in the broad perspective, yes.

Eleanor - We haven't really talked about the Biobanks and course that's our bread and butter at BBMRI. Why is high quality biobanking so important for patients?

Stefanie - So what we want is of course when we are in this vulnerable position that we are suffering from an acute illness. And so what we want is of course survive and what we want is in order to do this, we need research.

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So this clear, what we also want is we want good care and we want therapies that are safe for us, that are therapies that really have an impact and that really help us to survive, but not only to survive, but also having in the end, a good quality of life. And for this, we really need a high quality and robust research.

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The backbone of those research is quality assurance in biobanking, because I know as being a member of the scientific Advisory Board of the German Biobank alliance, I have quite an insight on this and I know how much work is behind those academic quality assured biobanking. So I know all the work that goes in there, how they assure the quality, how they assure then that they have certain criteria that when people and research groups have an idea to use the sample.

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And I think those samples are extremely valuable. So that I really think, okay, we have all the quality criteria not only in storing those bio samples but also in giving them out. So that we think, is this really a good research idea? Has this maybe already answered yet or not? So are those ideas or is this project, if I can say it's worth it, to give this valuable bio samples?

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And I think this is really important for patients so that when we give those bio samples, whatever that is, and I really know that I know even more about biobanking, I can really appreciate all the work behind this and also having the bio samples and specifically also academic biobanks.

So that this is really we have a sharing infrastructure and also that all the research groups I think should know about those quality assured Biobanks because I think from the beginning on when some research groups start the research project, they sort of think about those already and set up Biobank infrastructure and not start a little biobank on their own for each and every project because we

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need those bio samples to be connected. We need basically we need big data banks where you can look up where is which sample located, what's the quality behind the sample? What can I do with a sample? So we really need yet to get all of this together, tie this together, because this in the end leads to robust research results and this in the end is the basis for effective but also safe therapies.

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So this is why we as patients really support and we want quality assured biobanking that it has such a big impact then in the end on our therapies and our lives.

Eleanor - You've kind of connected through the humanness, the ethical, the sociological, right down to the sample that's held in the biobanker's or the researcher's hands. And that's a really interesting way to put it, because at the patient pillar level, you know, it's really operating as a meta level.

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And you've talked about this in a very different way. But at that meta level, which is where you're sitting, how does the Patient pillar's function, along with BBMRI and the national biobanking networks, how does that strengthen patient awareness and participation in donating samples and increasing trust?

Stefanie - That's also very good question, because I think this is also a two way situation that we are having here.

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And I described in the beginning that how important it is and to bring all together or channel all the ideas and priorities of the patient community into the Biobank community, to the clinicians and scientists. And then on the other hand, this channel goes back for the BRCA network and our boards, I tell them what I learned. I tell them the newest developments.

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I tell them how everything is interconnected. And we raise an awareness then that for the people itself, and their very individual situations of care. When they are asked whether they donate some samples really to be alerted and ask, is there a being alerted, I have to say it's a little bit difficult for the individual person in this vulnerable position of, "Oh, I'm in the hospital, I'm at the point of care, and now I have to decide that."

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Then having in mind, okay, biobanking is a good thing, first thing, but then, oh, quality assured biobanking. So maybe to ask will this go over the say only in this little project that you have maybe locally or will my sample be contributed to the greater quality assured Biobank? So it's a two way street and what you have what we basically have here now the podcast is a very important medium to transport this information and to get this across.

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But what we also have locally in Germany, we are working closely together with the German Biobank nodes and several other patient representatives to talk about how can the Biobank address specifically the patients and their concerns and to take into account what they need so that everybody fits comfortable, so it's really we work closer and closer together, I have to say, and it's a two way street.

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So the information goes up and forth, up and forth, Yeah. Mmm.

Eleanor - You've described, I think really effectively how as patient representatives working with patient engagement, but as members of the patient pillar that you act as a hinge between the two and it's so critical. Stefanie, thank you so much for your time today. In this episode, you've heard about the passionate contribution that two patient advocates make for better treatments and the possibilities to shape policy.

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They do this through their work in Germany and Greece, but also as members of the Stakeholder Forum Patient Pillar here at BBMRI. Listen to part two of this podcast to meet Eric Vermeulen who'll explain how his background as a paediatric nurse and sociologist have coincided in his new role as chair of the Stakeholder Forum Patient Pillar.

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