Global BC Advocacy Webinar Series

Research Session 3: Infusing the Patient Voice into Research

PATTI JEWELL, *Pfizer*: Welcome everyone and thank you so much for joining us today. My name is Patti Jewell. I am senior director of patient advocacy for Pfizer. On behalf of Pfizer colleagues around the world, thank you for taking the time to be with us.

We're recording this webinar to help us share the content and ideas with those in the advocacy community that were not able to listen live today. Please remain on mute to avoid background noise. And we encourage you to submit your questions and comments that you have through the chat function that you see on the lower right-hand side of the screen. You can submit them throughout today's session. We will integrate them into the conversation as we see them come up.

Next slide please. I'm also pleased to introduce you all to Isabella Grueso. Isa is our new global oncology public affairs lead for breast cancer and precision medicine. She lives in Bogota, Colombia, and has been working over the last seven years to advance public policy change to support better access to care for people with metastatic breast cancer. We're thrilled to have Isa on our team and you'll be hearing more from her in the future. Welcome Isa.

Next slide please. This webinar series was inspired by a meeting with breast cancer advocates from 24 countries. We developed together a list of 81 ways to improve breast cancer care, and a key topic of interest was to learn more from each other about how patient advocates can engage in clinical trials and other types of research. This webinar is the third in a series that Pfizer is hosting. And today we will focus on how to infuse the patient voice into research.

Next slide please. The recordings of the first two webinars from this series are available on breastcancervision.com under the section 81 Actionable Solutions to Help Improve Breast Cancer Care. It's so important to Pfizer and the advocacy leaders with whom we work that these webinars connect to the ideas and the actionable solutions list so that we can make

progress towards addressing unmet needs. Our first session focused on learning about the research process and how to educate about clinical trials, and the second session focused on real-world data, what it is, and why it's relevant to patients.

Next slide please. None of this work is possible without our planning committee of six advocacy leaders who work together in deciding what specific topics to focus on for these webinars. My heartfelt gratitude goes to Bertha Aguilar of Mexico, Conchi Biurrun of Spain, Renate Haidinger of Germany, Stacy Lewis of the U.S., Shirley Mertz of the U. S. and Ranjit Kaur of Malaysia for taking their time to share their ideas and insights that inform this and future sessions.

I'd now like to turn this over to Renate Haidinger. Renate has been a breast cancer survivor since 2000. She's a medical journalist and the founder and president of the German Breast Cancer Association. She specializes in educating the lay audience about breast cancer through doing interviews with experts. Renate serves as the chair of the patient advocate subcommittee of the international ABREAST registry. She's a member of the advisory board of the SUCCESS trial. And she's a member of the independent data monitoring committee of a large German study group. And she's also president of the general assembly of the ABC Global Alliance. Welcome, Renate. I'll turn it over to you to lead today's discussion.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you very much, Patti, for this lovely introduction and it's so exciting to have had already two webinars and today we have the third one. Thank you to you especially but also to Pfizer that you give us the chance to somehow give our knowledge to other participants of these webinars about research and everything that comes around it. Today we have very nice experts that will tell us how to infuse the patient's voice into research. I welcome Marzia Zambon, who is the executive director of EUROPA DONNA. EUROPA DONNA is the European Breast Cancer Coalition and has been advocating for evidence based, best practice breast cancer services, or breast services, for more than 25 years. EUROPA DONNA is a pan European umbrella nonprofit coalition of affiliated national groups covering 47 countries. And I welcome Ryan Hohman the vice president of public affairs from Friends of Cancer Research. Friends of Cancer Research drives collaboration among partners from every health care sector to power advances in science, policy and regulation and that speed life-saving treatments to patients. So, welcome very much, to both of you. Marzia, tell us a little bit about EUROPA DONNA, and what you are doing.

MARZIA ZAMBON, *EUROPA DONNA*: Hello to everybody and welcome. Thank you, Patti, for inviting us and for making this happen. Thank you, Renate, for the very kind introduction. As you see from the map, and as Renate already explained, we are an umbrella organization, a nonprofit and European organization of affiliated national groups. We currently have 47 member countries, all 27 European Union countries. And this, of course, means dealing with 47 different cultures, health systems, independent governments and policy makers and approximately 35 languages. We have 10 main goals that we carry out through our activities of education, information and advocacy. And for the purpose of our meeting today, one of our key goals is to promote the advancement of

breast cancer research, which we actively are involved in at a European and at an international level.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you very much, Marzia. And Ryan, please give us an overview of Friends of Cancer Research and what you are doing, Ryan?

RYAN HOHMAN, *Friends of Cancer Research:* Can you go to the next slide then? So good morning from Washington D. C here and good afternoon and evening to those around the world. I also want to reiterate my thanks for Patti and the partnership with Pfizer over the years. Friends of Cancer Research is an advocacy organization based here in Washington. D.C. We focus on the regulatory policy side of things understanding there's incredible other partners out there working in all sectors of cancer oncology, and other rare diseases that we partner with. We focus on the U.S. Food and Drug Administration and work to unite both companies, individual researchers, patients, and caregivers to work on policy solutions to some of the most pressing problems, both here in the United States, and around the world. We use cancer as a case study here with Friends of Cancer Research to extrapolate to other disease settings and we also use the U. S. FDA and U. S. clinical trial system to partner overseas as well. So, I'm excited to be here this morning to talk about our education outreach and patient engagement program that you'll hear more about shortly. But thank you.

RENATE HAIDINGER, ***German Breast Cancer Association:*** Thank you very much Ryan. I think we now need to know what your two organizations are doing to support patients to participate in research. So, Marzia, what does your organization do?

MARZIA ZAMBON, *EUROPA DONNA*: EUROPA DONNA engages in research both directly and with educational programs and publications to educate our national patient advocates, which I will cover in the next slide. As for our direct cooperation, we cooperate with BIG, which is Breast International Group, it's a network of more than 50 international research groups and data centers that are dedicated to breast cancer. EUROPA DONNA president and CEO participate in the scientific committee meetings, and this allows us to interact with major international institutions, researchers and medical experts in order to be constantly updated on breast cancer research advancements, and the status of clinical trials run by BIG members.

We are actively involved on the steering committees of research projects, such as MINDACT trial, the AURORA and the POSITIVE studies and the OlympiA trial.

Patient involvement in research has also been helped by the European Commission with the European Cancer Plan. There's this major funding program for research and innovation in Europe, which is the Horizon Project program. And we are involved in research projects that are funded by the Horizon 2020 add Horizon Europe, giving the patient advocate's perspective in these studies and finally EUROPA DONNA participates in the breast cancer working group of the OECD Paris study on patient reported indicators for breast cancer

care. So, this is what we do directly, then our educational projects, programs that are in the next slide.

Okay. We have conferences and every year we have training programs for our national advocates. But mainly, I'd like to speak today of our three publications. They are open source available on our website under the research section. But you have the hyperlink here. And the first one I'd like to speak to is a guide to clinical trials. It's aimed at explaining who conducts these trials, how requirements for participation work, where the risks and potential benefits are, and how to find out about them, at least in Europe now that we just had a new regulation. So, everything is sort of changing and there'll be a European protocol. Let's see how it works.

In this booklet, the last pages hold questions to be asked and facts to be known before deciding on participating in a clinical trial. For example, what is the aim of the trial? Where will I undergo treatment? What information will be collected and how often? What type of longer follow up does it involve? et cetera.

The second publication, the Advocate Guide to Understand Breast Cancer Research, aims at giving an overview of the technical medical terms and health literacy an advocate needs to have and be familiar with if they want to relate to researchers' clinicians, and all the players that are involved. So, understanding the basic medical terminology, some degree of the logical expertise, and the overall research and strategy. There's also a glossary included in order not to be lost when you interact with professionals, when you are not a professional, you are a patient representative.

And then the third booklet is exploring the role of advocates and breast cancer research. And, that's what we can do. How we can get involved and make the difference. So, this is a booklet that I would recommend to read. It explains what a steering committee is., what its role is. What an ethics committee is and what it does. What questions you need to ask, and what procedures you need to ensure are in place and transparent in order to have a positive and useful impact that truly benefits the patient's involvement in research and in a clinical trial.

RENATE HAIDINGER, ***German Breast Cancer Association:*** Thank you very much Marzia. These wonderful booklets and all the participating you do in clinical trials so far, and probably in the future as well. So, um, Ryan. What about your organization?

RYAN HOHMAN, *Friends of Cancer Research*: Yeah, so Friends Cancer Research is the primary organization, and we do work a lot on regulatory policy and legislative work. Today, I'm going to be focusing on our program, which is progressforpatients.org. It's our online education program. The goal of this program spun out of Friends of Cancer Research holding of a very specific space within working on regulatory policy and clinical trial access and equity. We were doing more and more one offs and helping to educate our partner organizations across the country here that ran from extremely large other nonprofits to some small, and individual advocates. We are constantly kind of educating these

individuals, and we realized that there was an extreme need and interest in learning more about clinical trials and how to get involved. So, we started progressforpatients.org to understand and be able to educate our partners. And what we created is an online learning platform, self-guided, that takes patients and their advocates to get to an understanding of drug development, the regulatory process requirements and guidelines associated with drug approvals, but also a very comprehensive understanding of the terminology. We spoke about this, Marzia spoke about this, about the understanding when you're at the table and not feeling like, you're not able to participate in the conversation because some of the terminology that's being used. We spent a lot of time developing a very extensive glossary because more and more we were getting feedback from patients that participated in panels and trials and protocol development that they there was jargon that's being used and acronyms being used. That was a key place on that. And then the baseline understanding of the clinical trial design. We focus on the clinical trial system here in the U.S. in this program, but we do touch on some of the partnerships with the EMA and other organizations.

And go to the next slide. So as part of this, once the individual goes through our online learning platform, and it's totally self-guided you can come back and go, each individual patient or their advocate then participates in a matchmaking service that they select. So, what we've done here in the U.S. is, and Pfizer has been an excellent partner in this as well, but really pushing the companies, other nonprofits, research institutions to provide the opportunities to us here, at Friends, of Cancer Research so we can match up directly with some of these advocates. What you see on the screen here are examples of the many 100s of matchmaking types of programs that we've set them up with. With pharmaceutical companies for instance, we've had individual patients embedded within the early protocol development and the research teams at companies, all across the country, and across the world really. And that has looked at clinical trial design, the resources, some of the informed consent forms and barriers to participation in those clinical trials. And then you'll see below here some other examples, which range from academic institutions to the U. S. Food and Drug Administration who has drug advisory committees that has an individual, has a patient, seat on those and they help guide individual drug choice decisions by the agency. And a huge part of what we do, I'm here in Washington D.C., so we do involve patients in the legislative writing process too. When those pieces of legislation touch on clinical trials, access equity and other groups, as you see here, as well, as Friends of Cancer Research, use these individual patients, and informed advocates to inform some of our science and policy work here at the organization as well.

RENATE HAIDINGER, ***German Breast Cancer Association:*** Thank you very much. I think it's just marvelous what both of your organizations are doing, but how did it start? What made the two organizations to start programs for research? Marzia?

MARZIA ZAMBON, *EUROPA DONNA:* Yes, I think it is a bit of a mission, because you are guiding people in invading an area where, up to very recently research, was on patients, and not with patients. Now, with all this holistic view and patient centricity from prevention to early detection to treatment all the way to follow up and the survivorship

and palliative care. The first step toward the innovation is research, and I think patients should be involved in that. And have their say, and make sure that the endpoints of the research and or the clinical trial of the project are actually matched with the expectations of patients. So, basically patients' perspective is necessary to make sure that the design of the project is properly targeted, really aimed at either improving or saving the lives of the patients. This is what we very strongly think and, we'd like to see implemented always.

In this phase it's quite important that experts recruit representative of patient interests to be involved in order to make sure that patients' relevant endpoints and benefits are central to the study. And we hear, how does it work? You need to build up credibility and the relationships with the researchers, and the experts that are involved, because you are not an expert. So what are your main objectives in interacting with them? You have to make sure that the research protocol is designed according to the applicable good clinical practice guidelines, and any regulations, and with ethical principles, for example, stand by the declaration of health. To make sure that the patient's perspective is considered and respected. To make sure that the envisioned outcomes and endpoints are patient relevant and from the start providing input in the draft protocol.

And then review them afterwards and ask for updates. And then progress, status and results. We have to be prepared to give input and allocate time and efforts to learn and to be present and to actually participate in an active way. So that it is, in fact, the true opportunity to be there as patient representatives, and not just there to tick a box for the research. And finally, we have to make sure that the patient documents are drafted in a clear lay language and in a comprehensive way, so that the patients involved are properly and completely informed and protected.

RENATE HAIDINGER, ***German Breast Cancer Association:*** Thank you. Yeah, yes. I think that's very important. You just, you didn't say something about the independent data monitoring. Maybe you could just briefly explain what that is.

MARZIA ZAMBON, *EUROPA DONNA:* Yeah, it's basically a panel that's made out of independent experts and it's always good to have a patient on there and they're not directly related or let's say it's the panel of people, or persons, that are not directly involved with the research or the funding, and they actually monitor and check. And I think you are on one from what Patti says, I mean it's extremely important that, before we decide to be involved in research projects, we make sure that they include, or they are open to interaction and to be monitored.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you we go further on in a minute. I just wanted to add because as I'm in an independent data monitoring committee of a big study group in Germany, it's really so important to have a patient on that, because we look differently to side effects to everything concerning the patient and, or even the management of side effects within the trial. So, I think there's a lot from the patient perspective or advocate perspective. We could get into the trial and the running trial, so I completely agree. So, keep on. Show your next slide. Thank you.

MARZIA ZAMBON, *EUROPA DONNA:* Yes, actually the patient's voice and the patient's perspective enriches, and in some way, makes the projects, and this has been actually studied and confirmed, that it makes the trials and research more effective because there are more linked to the true, real effect that they're trying to reach, which is, in fact, aimed to the patient and for the patient perspective. So, what is our role in clinical trials and research? How do we do this?

Here's a list of tasks and roles that patient advocates can cover in order to try to make a difference. Make sure that the research addresses a question of interest to the patients that it's not just to write an academic article. That it really addresses the need that has a gap and needs to be addressed. Have a say from the beginning and the design in drafting protocols and drafting patient information documents and this is why first, you have to learn and self-educate and then help educate others and it's a pioneer's work. You have to… It's a trial by error. You don't start that, you have to gather the information that's provided and then you have to just go and swim and see if you actually relate to other parties involved in research.

You have to ensure clarity of language. It has to be understandable and clear lay language that everybody can understand, yourself and the patients enrolled. You have to encourage communication of all parties and transparency. Encourage communication also between the researchers and the patients. That's where we should try as patient advocates in order to make sure that they communicate that they understand each other and that the patients feel involved and that their needs are heard. Make sure that the quality of life issues are incorporated to assess the real cost and benefit of the project, or of the clinical trial. And make sure that the informed consent forms are truly informative and cover all the issues that participants should know. We have a checklist for that. And finally make sure that the follow up and post study is covered, and that long-term side effects are considered and addressed in the overall design of the study from the start.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you Marzia. One question, if someone who hasn't done anything with research before, what do you suggest they need to know first, before they could start participating somehow.

MARZIA ZAMBON, *EUROPA DONNA:* Okay, the booklets that I think first of all one should read and then we have educational events. For instance, this next September, we have our advocacy leader conference is one every two years and all of our national delegates and national representatives are invited and we actually invite them to Milan. And one of the items on the agenda this year is clinical research. How to get engaged as a patient. What does the patient advocate need to know? Now of course, we invite experts to speak about this. And the expert that we have invited this September is Dr. Olivia Pagani, she is a medical expert. She's very, very, she's a very good speaker. She's very involved in research, I think you have to educate yourself, you have to provide education and then from the basic you have to engage and just go and try.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you very much. Ryan back to you. Why did your organization start in the beginning and what we're the special needs you, not you, but your organization, thought has to be addressed? Yeah, thank you.

RYAN HOHMAN, *Friends of Cancer Research*: My next slide please. So what you see on the screen is Project Teach, but I'll talk about or dive into progressforpatients.org. So, yeah, I agree with everything that Marzia has said, and the goals of her program are very aligned with ours here at Friends of Cancer Research and Progress for Patients. What was happening here in the U.S. was what is probably happening all across Europe, and I know with partner organizations was, patients were having a seat at the table, but it was a box to check. And so, those patients were getting frustrated as all would, that they were just there and as a kind of side part of the conversation, and so when the need was there and the interest was there, we wanted to make sure that patients were armed with all of the knowledge they needed, were able to access that knowledge quickly and educate themselves. Patients wanted to just dive into this information. So we wanted to provide it to them in the easiest and best most adaptive way possible.

So, by creating this, we are able to really create an army of educated advocates and partners within the program, within clinical trials. We were telling companies, time and time again, patients are the most scarce and most important resource in clinical trials. There's very few clinical trials that actually reflect patient needs, though. Any company can create any clinical trial they want, but if a patient doesn't see the value in it and want to participate, that trial won't progress. So you have to ask yourself, does the clinical trial match patients' needs? And by embedding patients early on, and I think all of us here will reiterate this many, many times, if you're asking a patient to give input on a clinical trial, but it's already done, or it's so far along that they can't actually impact what that trial looks like, you're kind of wasting that precious patient resource by asking them to participate just in the end game there. And so what we were able to do, and able to see over the years now that that Progress for Patients has been around is, it's really changed. Not only an individual clinical trial, but whole teams inside companies that now have a different perspective because the patient is guiding early on and answering early questions to those individuals. We've seen incredible success turning around perspectives of individuals that have been in the field for decades and by engaging with these patients that can speak on their level it has formed clinical trials and practices that really reflect the patient's needs. And we've seen, and we'll talk about this a little bit later, some incredible numbers of patients and match making services that have really changed culture and practice.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you very much. First of all, Patti, just wrote into the chat to all to the audience. Please if you have any questions or comments write into the chat, which is at least on my computer on the right bottom edge where it says chat. If you click on that, you can write as questions and comments. If you want to know something. Okay back to you, Ryan. So, what are you? Are you doing something special now about diversity? I mean, everybody is talking about it now and we know that certain ethnicities are not really part of clinical trials. Probably the same they won't have a voice into clinical trials. So what are you doing about that?

RYAN HOHMAN, *Friends of Cancer Research*: Yeah, so you're exactly right. These have always been issues within not only clinical trials, but just total equity and access for health. A little over two years ago we had developed a partnership. And this was before the social justice movement in June of 2020 really bubbled up in equity and access across not only health, but every walk of life here in the U.S. and the center of that was here in Washington DC, with those movements.

This was a PCORI, which is a Patient Centered Outcomes Research Institute, so a large organization that was formed out of the Affordable Care Act. And they helped fund this collaboration between us at Friends, the Black Women's Health Imperative, and Stand Up To Cancer. And what this did, this built progressforpatients.org to expand our advocacy education work in this collaboration. And this created a new online learning education platform because what we were hearing and what we all know is, all patients are not the same and black women provide a pivotal role in their communities, not only for support, but education, and looking to those advocates and patients to see if they should participate in a clinical trial because there's some issues there. We've now trained within this separate program 100 what we call EPPs, Empowered Patient Partners, to pair them to actively engage in this community. And with everything that happened during COVID, what this program has now also done is educate individuals on the clinical trial process and how a therapy, or in this case a vaccine, is viewed, clinical trial and approved. Through this education we've been able to make people more comfortable in understanding where those therapies and vaccines that have come through during this process. So, it is focused on cancer and focused on oncology, but the knowledge base of the clinical trial system, from the perspective of a black woman has changed people's perspective on the science community.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you. Marzia, you already said that you have all different well, advocates from different countries that are within EUROPA DONNA. how do you somehow get along with the diversity within them?

MARZIA ZAMBON, *EUROPA DONNA:* It's complicated and we really, we try to do networking, roundtable meetings. We had one this morning and, we started this with COVID and what we do is, we try to have our, we call it Meet/Catch(?) Up. Our national organizations, share a project or show an example, or say what they're doing. For instance, this morning we were speaking about genomics and genetics and how the that evolves in each country. So, what we try is we facilitate communication. Now what we have found is that in Europe, inequalities to access, to research and clinical trials is majorly a social economical factor – t's geographical – and many women, because we deal with breast cancer, many patients, find out about possibilities with research and being involved, or enrolled in clinical trials through their doctor.

So, there is a lot of talk about educating the doctor as well because there's also that in equal access, because if your doctor is involved in research, perhaps you will be involved, or if you are particularly educated as a person, and you go and find out yourself as many. That's

why the inequality of people who are actually enrolled in clinical trials are usually at a higher education level, because they found it themselves.

RENATE HAIDINGER, ***German Breast Cancer Association***: Okay, thank you. Now, we have a question for Ryan. When you match patient advocates to pharma clinical trials as consumer reviewers or EPPs, do the companies pay the patients for that time and input?

RYAN HOHMAN, *Friends of Cancer Research:* Yeah, that's a great question and something that has been a focus as of late about patient value. We do encourage the companies or other organizations to not only pay, but also just we use the term support, which includes having someone that can guide them through the process. But a focus here in the U.S. with advocacy organizations and companies has been on the fair market value of really the value of those individual patients. So we understand their time is precious. So yes, we encourage them, but it does vary by company. It does vary by opportunity, and I'll turn it over Patti, because it does vary by country as well.

PATTI JEWELL, *Pfizer*: Yeah, exactly. I would just say, from my perspective for Pfizer, that is our approach is to want to recognize the value that the patient and or advocate contributes to the work. But the rules do vary by country. So you may see some differences there, as well as by companies.

RENATE HAIDINGER, ***German Breast Cancer Association***: But I think it's the recognition of the work and everything, the patient or patient advocate puts into it, right? Exactly. Marzia, how about you?

MARZIA ZAMBON, *EUROPA DONNA*: Well, yeah, I think for us, we are a coalition. And we are Europeans, so we're stuck in the middle. What we have tried to organize is, we basically convey and cascade information to national organizations. So what we do is we stay steer clear from national activity. We facilitate it. We encourage it. We try to make a one sole voice and educate each of them in the same way. And then it's up to them. I see in the chat that there was a question regarding translators present at our meetings. Actually, in order to be a national representative or a national delegate of the coalition, you need to be fluent in English. Because then your role is to find this out and then do that same program and translate it into your language with your people, with the patients, because patients and patient organizations on a national level territorially are much more comfortable in their own language. That's the problem. You can't expect somebody to speak about emotions, quality of life, or to actually be a patient advocate in a language that they're not comfortable. Now in Europe especially a lot of people have become much more fluent in English. But that is the language that we speak at our meetings and by the way, Google translator has become extremely good if you just put it in there it usually translates quite reasonably what is said in English.

RENATE HAIDINGER, ***German Breast Cancer Association***: Even though, I think if somebody starts to work with EUROPA DONNA within any country, I mean, probably not everybody at that time is so fluent. So, but you don't use translators for that.

MARZIA ZAMBON, *EUROPA DONNA*: Well, we did. What we do is we translate the material and the documents we had. For instance, in our metastatic breast cancer program, we had a short guide to the EDIC guidelines, and that was translated in a number of languages in order to actually give the material to the national advocates, in order to share them with the women and the patients and to educate at a national level. But, theoretically, the translation is something that the national organization the national EUROPA DONNA would be doing.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you. Now we have the situation that we all patient advocates from all over the world, ask for being somehow implemented into the course of clinical trials and having a voice into it or even patients. And, what can we do to really educate them and how can we monitor what is happening there? Ryan, what are you doing?

RYAN HOHMAN, *Friends of Cancer Research:* Yeah, Yeah. So here's the key for Progress for Patients. So it's five years over 500 patients. More than 50% have gone on to participate in drug development, clinical trial, regulatory and 70% have been indicated with other existing partnerships and advocacy organizations. But this kind of almost goes back to the do you pay a patient, but the second question is, do you support the patient during that process?

So there's two success metrics here. It's the outcome of what that specific program was that they were embedded in, whether it was about a specific therapy or a specific research program. But was that patient perspective respected, taken into account, and did that patient perspective change that outcome of that trial for the positive, or did that patient change the process? And that sometimes is almost more important than the specific question that they were asked, if they were able to change minds and change the process. So, we're constantly supporting our patient advocates and checking in with them to make sure that they're being respected in the program and then we're also checking in with the company and seeing if the culture or specific individual questions were being answered and changed and it's important then to reflect as these programs go on. We've had an advocate that was one of our first embedded with the company's clinical trial and research team that when they were originally placed, they had a terrible experience. They came back to us and said, those individuals treated me with disrespect. It was not a good experience. But that patient was almost even more motivated to change that team. So, with our support, we went back in and now six years later that individual patient is still embedded with that same research team that she said treated her with disrespect. And these people are all very close friends and respected colleagues of each other now. And their researchers say time and time again, this individual patient totally changed their perspective and what and their understanding of what they really needed to do in their job. So that's just an example of how powerful patients can be when they are given the opportunity to help change minds.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you. I completely agree. When I first showed up in this independent data monitoring committee 17 years ago, everybody, it's a small group, and everybody looked at me and the others are all physicians. And so they looked at me and said, well, don't interfere with what we are doing. And I told them I don't want to interfere, I want to add something to what you are doing. And so I think that changes with time now. I mean the advocate community is much bigger now and many advocates work together. For example, thanks to Patti and Pfizer that we all can do from the Summit and what we worked out from the Summit now to realize really what we found out were the key points we have to work on. Marzia?

MARZIA ZAMBON, *EUROPA DONNA*: Can I pitch into this? Because yeah, I really think that it's a matter, of gaining respect. And I think that women like you, and like our CEO, Susan Knox, and just wanting to be involved in gaining experience, and then writing booklets on the basis of their experience. Patients weren't included or considered in research at the beginning. But the role of patient advocates, you elbowed your way in, and now it's actually something that is required and is considered an important input or addition to their job. Also, because we, I think it's a matter of creating good networks with the experts and the medical and the researchers that are there that they understand that you're not there to interfere. You're there to give something more. And so I think it's a matter of mutual respect and it starts from our respect to their position, good communication skills and assertiveness without being aggressive. Just trying asking the right questions. And if you don't get an answer asking the right question again. And that's how you do it.

RENATE HAIDINGER, ***German Breast Cancer Association***: Yeah, that's very helpful. I think if you start Ryan.

RYAN HOHMAN, *Friends of Cancer Research:* Yeah, I just think it's so important that advocates push, and organizations like all of ours push these companies to really provide the opportunities to step in outside of their comfort zone or whether they really would think because it's incredible. Like, when you talk to someone like I mentioned before, this research team, but you talked to someone that has never thought that a patient might even want to be involved so early in the clinical trial process.

RENATE HAIDINGER, ***German Breast Cancer Association***: Ryan, about the diversity, and you've said that you are now working with black women and their organizations, but what about women with Latin background? Latinas.

RYAN HOHMAN, *Friends of Cancer Research:* So using Progress for Patients, and then Project Teach, the next evolution that we are going towards, we'll be looking to Spanish language and it's been an incredible opportunity with Project Teach to learn and be educated on how different, we spoke about does Marzia use translation? Well, does the education program we have speak the language of that particular culture? I mean, take that into account is so important. It was such an incredible lesson to learn.

RENATE HAIDINGER, ***German Breast Cancer Association***: Now, I have a question for Patti. Patti do you think that all these different cultures and ethnicities will in future be more taken into account for clinical trials?

PATTI JEWELL, *Pfjzer:* I think so. I mean, I look at how Pfizer has changed and the last five years, and how it's ever evolving. I look at what we've done, we've added staff people to specifically learn about the interest and insights of patients from all around the world from different communities, from different cultures. And then we take that in, and we try, we think about how do we need to adjust the trial or adapt our communication in order to really reach people and connect with patients that we're trying to reach. So it's definitely an evolving situation. We continue to learn. But we do learn so much from patients and advocates on all different angles of the process. One other comment I would make just thinking back about the conversation is that we do, we hear the feedback and then we also try to give the advocates that participate feedback on what we included and why we included it. Sometimes we're not able to incorporate every idea that comes up and so we try to explain why we didn't. So we want people to know, we heard them, but if we couldn't accommodate it, why couldn't we accommodate it. So that's another part of the feedback loop. That's hopefully helpful to participants.

RYAN HOHMAN, *Friends of Cancer Research:* Yeah, I think that the feedback loop is so important and it's a show respect to the patient that participated and even a patient that has been in a clinical trial, we've talked to companies about that patient if they were on a therapy that was successful for them, they want to know what happens with that clinical trial. Was it successful? Did they really contribute to the betterment of, of all patients by participating?

PATTI JEWELL, *Pfizer*: Yeah, and that's another area where we're trying to do better, trying to communicate with all participants both during, and after the trial as we can. Yeah.

RENATE HAIDINGER, ***German Breast Cancer Association***: Yes, I know it's a big problem because usually you have it in a medical paper what came out, and patients don't have access to these papers. So we need to have a solution how the patients get to know what came out of, what was the result of the clinical trials, right? In a lay language. Certainly. We still have less participants of clinical trials patients and clinical trials from certain countries like South America, and probably it's the same in many other countries, but it's also probably the same that the advocates there maybe also in Africa, in African countries, that the patient advocates are not trained, educated for that. So what kind of advice could you two give to advocates who are thinking about developing some kind of program in their country? Ryan. you first.

RYAN HOHMAN, *Friends of Cancer Research:* I would say as much as you can, , we all talk about finding these education components, whether it's something through ours, or Marzia's, and they're all over, but also asking for partnership. If asked, most people in the, I want to go outside of patients, most people in the health space, the drug development space, sciences and life science are willing and able and wanting to help and mentor other

individuals. So if you can educate yourself, but find a mentor, find someone that your perspective matches with theirs and they can help guide you. It unfortunately takes a lot of effort sometimes for a patient to find that. And so I think the more and more organizations like ours and companies like Pfizer can think about the partnership aspect of this and making the access very easy for these patients to get involved, the better.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you. Marzia?

MARZIA ZAMBON, *EUROPA DONNA*: I agree. I think I would encourage to learn with no pressure, nobody is becoming a medical expert. You just have to give your input and understand what you can do and what you can't. And I think in this international, and this kind of networking thanks to companies or networking like ABC Global Alliance. I mean, I participated in a webinar two weeks ago, and there were people from Africa, from Asia, from Australia, and we were talking about cancer and work and law. And I think this, and thanks to digital evolution, and in some way, thanks to COVID, unfortunately, because all of these it became more normal to have webinars. So easier to access and easier to be there without having to travel. And listen and see what others have done and see what others are doing and actually go by example, and be inspired to follow that example, and absolutely entitled to reach out and ask for help in setting up their program.

RYAN HOHMAN, *Friends of Cancer Research*: Yeah, I agree. You have to find silver linings of this pandemic. I think that has it has forced people to participate in this way, but also probably access. And it also a silver lining has been it changed how clinical trials are looked at in many ways by giving patients access to it at home. You know, things that they weren't able to travel, it really changed companies' perspectives, just out of pure need. But now where we have a lot of lessons learned from that. And I think all of our communities really need to lean into making sure those benefits to patients and access that were overcome during this pandemic, stay in place.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you, another question to both of you. If our audience, if the participants today would like to learn more, could they address you and or email you and ask questions if they are insecure how to do it?

RYAN HOHMAN, *Friends of Cancer Research*: Absolutely. That is, Patti is free to share my information with everyone, or you're welcome to go to progressforpatients.org as well.

MARZIA ZAMBON, *EUROPA DONNA*: Yeah, yeah, definitely. Definitely. I mean, we, welcome anybody who is willing and wants to learn. We have, as I say, we have our contacts, our website, we have all the open source information, but there's also the email and please feel free to reach out and will be more than glad to do whatever we can to point everybody in the right direction.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you very much. So what I would like to ask you now, while we can see the slide with your contact information,

which is not in. Yes. Now, if each of you in one or two sentences can somehow say something positive about getting involved. So, let's start with Marzia.

MARZIA ZAMBON, *EUROPA DONNA*: Okay, It's the uphill way, but it's very elating when you reach it from entitlement because everybody knows we are entitled to empowerment, and I think it's not easy. It requires interest. It requires drive and application. But it is something that really can make the difference. And if that interest is there, I think it really needs to be nurtured.

RENATE HAIDINGER, ***German Breast Cancer Association***: Thank you. Ryan?

RYAN HOHMAN, *Friends of Cancer Research*: Just say you can change the betterment of science for the next patient down the line. If you, by putting in your voice, you're not only describing what you went through, but you're making it easier for the next person.

RENATE HAIDINGER, ***German Breast Cancer Association***: And before I give the last word to Patti. I just wanted to mention, I think it's necessary and compulsory that not everybody in the science and regulatory community is talking about us, but that they are talking with us, right? So, Patti.

PATTI JEWELL, *Pfizer*: What beautiful words to end on. I can't say it any better. So what I would love to do is just to thank you so very much Renate, Marzia and Ryan for the conversation. Your ideas and insights and expertise are just so very helpful and informative. So really appreciate you taking the time to share with us today. So you can see their contact information here. As always, we welcome feedback. You can email me. If you want to go to the next slide. You can email me. I will send an email with a survey link. If you wouldn't mind taking it. It's five very brief questions. We do use your feedback to plan for future sessions. We take it seriously, so we welcome your ideas. And lastly, I'd like to close with a plug for you to visit breastcancervision.com. This is where you'll find the 81 Actionable Solutions in 9 languages, and then we have the recordings and transcripts from the first and second webinars in English. And we will post this third webinar in the next few weeks. So, we hope these you find these resources useful to you as you work to improve the life of people impacted by breast cancer, and we just really appreciate you joining us and being with us today and wish you all a great day. Thanks again, bye everyone. Thank you.

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