

The Global Breast Cancer Impact Summit Report: What We Learned



Foreword

Every year, more than 2.1 million people around the world are diagnosed with breast cancer.¹

Living with breast cancer means experiencing a range of emotions — fear, pain, courage and strength. Just as each person living with breast cancer is different, there is no one way to tackle the complex challenges in breast cancer care. The community has seen many advances in the management of breast cancer, but we know that innovation in science does not ensure access to care, quality information and needed support.

That's why over the course of four days in October 2020, **more than 30 multidisciplinary breast cancer advocates from more than 20 countries** virtually convened for the first **Global Breast Cancer Impact Summit**. Together, we shared insights and ideas to continually strengthen and empower the breast cancer advocacy community to address challenges and create change to support patients.

We chose to focus on four areas where we felt we could make a significant impact: **Research, Policy Advocacy, Patient Support Programs and COVID-19**.

Our dialogue centered around the following: Incorporating patient voices in clinical study development; supporting patient involvement in policy decisions; improving communications and empowering patients in treatment decisions and management; providing information, inspiring dialogue and finding solutions, always with patients at the core; and identifying opportunities to support patients during the pandemic and in the future.

The Summit and its outputs would not have been possible without the indelible guidance, direction and support from the **Global BC Impact Summit Planning Committee** – Bertha Aguilar, Claudia Altmann-Pospischek, Conchi Biurrun, Renate Haidinger, Ranjit Kaur Pritam Singh, Stacy Lewis, Shirley Mertz and Catherine Ubaysi.

Together, we will make every effort to build on past experiences, learn from each other, innovate and adapt to meet the unique needs of people living with breast cancer all over the world.

Please refer to the last page to meet the Planning Committee.

We must innovate and adapt to meet the unique needs of every person living with breast cancer today.

1. World Health Organization. Breast Cancer Fact Sheet. <https://gco.iarc.fr/today/data/factsheets/cancers/20-Breast-fact-sheet.pdf>. Accessed March 22, 2021.

Executive Summary

The **Global Breast Cancer Impact Summit** virtually assembled breast cancer patient advocates from around the world for discussion and problem solving around key breast cancer priorities. Pfizer worked collaboratively with a Planning Committee of nine advocacy leaders from around the world who provided input on the Summit goals, agenda and content, and led various parts of the meeting.

This report details key challenges and solutions discussed during the Summit, spanning four prioritized areas:

Research

Policy
Advocacy

Patient
Support

COVID-19 &
Breast Cancer

The group proposed a list of nearly 150 potential solutions, which were combined to a final list of 81 ways to improve breast cancer care. It's our hope that these solutions will serve as thought starters for Pfizer to act on with global partners and for the global breast cancer community to further facilitate discussion.



Discussion Summary

Research

The global research community works every day to apply science to improve health and well-being for women and men living with breast cancer. For many cancer researchers, including those at Pfizer, cancer is personal. The work that goes into cancer research is inspired by the millions of people facing this disease. But patients shouldn't just inspire research advances, they should also drive them. Patients need to have a voice in decision-making and co-creating solutions that enhance their experience and outcomes.

In order to ensure that Pfizer takes real, impactful action when it comes to implementing patient-centric clinical trials, the participants of the Global Breast Cancer Impact Summit discussed several issues and actionable solutions.

Knowledge gaps and misperceptions: There is much room for improvement around how patients learn about clinical trials. For example, many patients do not know what clinical trials are and if they are an option for them. Some may be concerned about the uncertainty of how clinical trials may create extra stress for themselves and their family. Others may feel that clinical trials are perceived as a last resort for those who have exhausted all other viable treatment options. Further, those patients who are interested in clinical trials often face challenges in understanding the overly technical terms used in materials that are meant to inform them. **The group discussed several ideas for how to improve education and address these misperceptions:**

- Create materials in lay language to communicate about clinical trials, including adjusting informed consent documents to make them easier to understand;
- Utilize patient testimonials to educate on and combat misperceptions about clinical trials;
- Use digital platforms (e.g. social media, TV, radio) to educate and inform about clinical trials; and
- Train patient advocacy groups and healthcare providers on how to effectively communicate about clinical trials with patients, including explaining clinical trial enrollment process before and after a trial.

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We need to reach more people just beyond those who are engaged with clinical trials and include advocacy and patients referred to by pharmaceutical companies and healthcare professionals.”

— Catherine Ubaysi
Patients en Réseau

“

It is important to ask how we can use technology to address misconceptions and misperceptions about clinical trials.”

— Stacy Lewis
Young Survival Coalition

Limited diversity: Increasing the inclusion of diverse populations in clinical studies can expand the knowledge on how medicines work in different populations. However, often clinical trials do not represent the populations they aim to serve. In many countries, access to clinical trials is only feasible to those who live near major cancer institutes or hospitals. Additionally, in some countries, certain ethnic groups and races are underrepresented in clinical trials. **In order to close these gaps, the group brainstormed several solutions:**

- Support use of mobile care units and virtual visits to help reduce geographic barriers to clinical trial participation;
- Host educational meetings for patient support organizations to learn more about clinical trials happening in their regions; and
- Adjust clinical trial eligibility criteria to support diverse patient participation.

Trial design: Giving patients a voice in cancer research can lead to improvements in clinical trial design. Patients are the most important part of cancer research and they deserve a seat at the table; however, they are rarely involved in the development of clinical trial protocols, which are often designed with regulatory authorities in mind. While many companies, like Pfizer, have made improvements in soliciting patient and advocacy input when designing clinical trials, more can be done. **Some ideas the group brainstormed include:**

- Train patient advocates on clinical research design and processes to give them the tools they need to serve in an advisory capacity during the creation of future trials; and
- Consider increased use of patient reported outcomes as important clinical trial endpoints.

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People who are members of minority groups that have experienced distrust in the medical system in the past often ask, as patients, “Will I be treated fairly?” “Will I be respected?” and “Will I have a safe experience?”

— Shirley Mertz
Metastatic Breast Cancer Alliance

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It’s important that clinical trials be patient centric, it’s a good start.

There should also be more consolidation and comprehensive strategy across the board and collaboration with patients and all stakeholders.”

— Jamil Rivers
METAvivor



The Summit participants brainstormed the following actionable solutions for Research:

Research

- > Create materials in **lay language** to communicate around clinical trials.
- > Use **digital platforms** (e.g. social media, TV, radio) to **educate and inform** about clinical trials.
- > Use **patient testimonials** to educate on and **combat misperceptions** about clinical trials.
- > Support use of **mobile care units** and **virtual visits** to help **reduce geographic barriers** to clinical trial participation.
- > Train **patients and advocates** on clinical research design and processes to **support clinical trial advisory roles**.
- > Adjust clinical trial **eligibility criteria** to support **diverse patient participation**.
- > **Advocate** for increased use of **patient-reported outcomes** as important clinical trial **endpoints**.
- > **Educate patients** that clinical trials exist for **all stages of disease**, not just for metastatic disease.
- > **Educate** on how to **access information** on **existing** clinical trial registries.
- > **Create virtual** clinical trial study protocols to **support participation** when patients are not close to the trial site.
- > **Host educational meetings** for advocacy groups to **learn about clinical trials** happening in their regions.
- > **Provide two-way trainings** for doctors and patients to better **understand each other's treatment goals**.
- > **Train** patient advocacy groups and healthcare providers on how to **effectively communicate** about clinical trials.
- > **Solicit input** from patients in clinical research **design and process**.
- > Form **multidisciplinary group** to **educate patients and the public** about clinical trials.

Discussion Summary

Policy Advocacy

Policy advocacy is challenging work. Though patient advocates work tirelessly to have their voices heard, most report it is often difficult to break through the noise among competing interests in the public policy arena.

The Summit participants identified several challenges patient advocates face with regard to policy advocacy, and discussed solutions aimed at ensuring decision-makers hear and address the needs of people living with breast cancer from a systemic perspective.

Create policy spotlight on breast cancer: Breast cancer is one of many key issues raised to policymakers who are balancing the disparate needs among their constituents. The Summit participants agreed that policymakers need to be briefed on the pervasiveness of and opportunities to improve the outlook for people with breast cancer in order to work towards solutions. **They shared their varied experiences in policy advocacy, and aligned on ideas to get policymakers to pay attention to breast cancer:**

- Build coalitions of advocates and healthcare providers to join many voices with a shared interest to show unity and breadth of advocates to policymakers;
- Develop educational initiatives, including the sharing of patient stories, to help policymakers understand their needs;
- Collect data to identify needs for policy change;
- Advocate for government funding support for breast cancer research; and
- Learn from experiences of fellow patient support organizations from other disease states or geographies.

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The common thread we all have, despite differences in cultures, health systems and resources, is our work to speak up and be heard by decision makers so that the needs of breast cancer patients are addressed.”

— Stacy Lewis
Young Survival Coalition

“

So then we understood the importance of generating data to have some impact in our laws, so our work could truly transcend and make a difference in our country.”

— Bertha Aguilar
Médicos e Investigadores en la Lucha contra el Cáncer de Mama (MILC)



Targeted training in policy advocacy: A breast cancer advocate's job is far from simple. From educating patients and supporting people impacted by breast cancer to raising funds for and supporting research, to engaging in effective policy advocacy, advocates need to have many skills. This makes training a key priority identified by the Summit participants. **Ideas for policy advocacy training included:**

- Communicating effectively with policymakers, the media and grassroots organizations on the need for change and recommended solutions;
- Learning how to conduct surveys or otherwise generate evidence relevant to policy making and communicate that data effectively;
- Sharing specific policy ideas such as improving affordable access to care or increasing use of telemedicine; and
- Sharing experiences from fellow patient support organizations from other disease states or geographies.

“

Being at the table is all about persistence, persistence, persistence. I was always seeking a seat in places where decisions were going to be made.”

— Ranjit Kaur Pritam Singh
*Breast Cancer Welfare Association
of Malaysia*



The Summit participants brainstormed the following actionable solutions for Policy Advocacy:

Policy Advocacy

- > Advocate for **government support** for **breast cancer research**.
- > **Strengthen collaboration** with government to ensure **patients are included** in policy decision-making.
- > **Collaborate** with advocacy organizations and independent entities to **advocate to government** to improve breast cancer care.
- > Support **advocacy training** on utilizing **social media** for policy advocacy.
- > **Invest in data infrastructure**, such as cancer registries, to **improve data collection and analysis**.
- > Use **patient stories** to advocate for **policy changes**.
- > **Train** patients and patient advocates **to communicate with policy makers**.
- > **Communicate** around policy issues that **impact access** to needed care.
- > Seek **grant support** for policy advocacy activities.
- > **Work with HCPs** to support policy advocacy that can **improve breast cancer care**.
- > **Integrate** patients and advocates into the **government grant awarding process** for breast cancer research.
- > Provide an **accessible platform** for advocacy organizations to **learn** from each other and **share best practices** (e.g. cultural adaptation) around policy advocacy.
- > **Advocate** for policies that **enable patients to share their experiences** living with breast cancer with **regulatory authorities**.
- > **Advocate** for stronger **public health systems** because this is where marginalized and financially vulnerable patients often go for help.
- > **Advocate** for better **equity in national cancer plans**.
- > **Encourage healthcare providers** (e.g. doctors, nurses, etc.) to **advocate on behalf of patients**, especially in countries where patients **may not have a voice** within the community.

Discussion Summary

Patient Support

Today, breast cancer patients are more empowered than ever before. Many seek out information and support, and are taking active roles in their treatment planning, and that is in large part due to the resources provided by the advocacy community. But there is more work to be done to ensure breast cancer patients in communities around the world receive the support and care they need and feel empowered to speak up for their health. The Summit participants discussed the topic of patient support programs, focusing on how they can continue to evolve to make an even bigger impact for patients.

Whole person care: While there have been efforts to advance the management of breast cancer, including the growing body of knowledge about breast cancer biology and improvements in surgical and medical treatments, considerable room for improvement in complete patient care outside of the clinic remains. The importance of advancing patient care and support along the care continuum was discussed – especially how to have holistic and detailed conversations that empower patients to participate fully over the course of their care. **Proposed solutions include:**

- Create or promote existing disease education materials focused on diagnosis, treatment options, side effects management and palliative care;
- Expand the role of breast cancer nurses or navigators to provide information to patients, such as explaining medical terms, providing financial information and offering emotional support;
- Create tools to help patients manage other issues in their lives, including balancing work and family, comorbidities or mental health needs;
- Provide education to patients who are not knowledgeable about technology so they can better access online educational and telemedicine resources;
- Educate patients on potential impact of cancer therapies on their daily life (e.g. food to avoid); and
- Create or promote existing campaigns for family and friends that help educate on what to say and what not to say to someone with breast cancer.

“

We all work on patient empowerment, raising awareness and want to improve the lives of patients – this is our mission.”

— Claudia Altmann-Pospishek
*Europa Donna Claudia's
Cancer Challenge*

“

A breast cancer diagnosis can be a whirlwind, and it can be hard for those hearing they have the disease to process all of the information they're receiving. It can be hugely helpful to have a partner, friend or family member with you during appointments.”

— Libby Burgess
The Breast Cancer Aotearoa Coalition

Tailored support: The breast cancer community knows there is no one-size-fits-all approach for breast cancer care. Communication between patients and their care team needs to reflect each patient's specific needs, including their unique attitudes, experiences and goals about breast cancer. **Recommendations discussed include:**

- Provide personalized patient support tools that address what, when and how they want to receive information;
- Create new materials or promote existing materials, including use of pictorials (e.g. pictures, videos) in patient support materials to help people with lower-literacy levels;
- Create materials targeted toward patients and their care team at different ages (including adult children who act as caregivers), ethnicities and cultures;
- Provide educational materials regarding country-specific rights and laws and how to navigate the local health system;
- Host workshops facilitated by subject matter experts on how to support patients experiencing poverty and/or food insecurity;
- Expand access to translation services for patients who speak a different language than their doctor;
- Create a set of guidelines/standardize language for early breast cancer detection campaigns; and
- Create native language support groups for patients locally.

“

We need to meet patients where they are and determine their comfort level with technology, language and disease knowledge.”

— Renate Haidinger
German Breast Cancer Association



Communicating with the healthcare team: Healthcare teams (including doctors and nurses) are critical partners in truly driving changes in patient care. There is a need for more open and proactive communication between healthcare teams, especially nurses and patients about treatment options and necessary support. **Specifically, Summit participants identified a need to:**

- Form multidisciplinary group(s) of patients, patient support organizations and healthcare professionals to educate patients and the public about clinical trials;
- Offer training to doctors and nurses on how to share both good and bad news to patients in a hopeful yet honest and clear tone, while also being sensitive to cultural and ethnic differences;
- Train healthcare professionals, especially nurses, on how to discuss medical terminology in lay language with patients;
- Create communication channels with hospitals and community cancer centers to distribute existing materials to doctors and nurses;
- Provide resources (e.g. phone apps, discussion guides, etc.) to help patients identify questions to ask their healthcare teams, take notes during appointments and encourage tracking of follow-up questions after appointments;
- Encourage patients to bring someone with them to doctor's appointments;
- Conduct focus groups and surveys with patients to inform best practices for communication;
- Encourage healthcare providers (e.g. doctors, nurses, etc.) to advocate on behalf of patients, especially in countries where patients may not have a voice within the community; and
- Develop programs to empower patients to be their own advocates, and speak up to have their wishes known to doctors and nurses.

“
HCPs should have conversations with their patients to find out where they are in their life, what they want to do and what they were doing when breast cancer actually dropped in their lap.”

— Ranjit Kaur Pritam Singh
*Breast Cancer Welfare Association
of Malaysia*



The Summit participants brainstormed the following actionable solutions for Patient Support:

Patient Support

- > **Expand the role** of breast cancer nurses or navigators to provide **information** to patients, explain **medical terms** and offer **emotional support**.
- > **Encourage** the hiring of **breast cancer navigators or nurses** in places where this support is not already being provided.
- > Provide **personalized patient support tools** that address what, when and how they want to receive information.
- > **Create tools** for patients to **track follow-up questions** they may have after they leave their appointment.
- > **Create tools** to help patients **manage other issues** in their lives, including **comorbidities and mental health conditions**.
- > Offer **HCP training** on how to share both **good and bad news** to patients in a **hopeful yet honest and clear** tone.
- > Offer **HCP training** on how to discuss **medical terminology** in **lay language** with patients.
- > **Provide resources** that encourage patients to **write down questions** in advance of appointments and **take notes** during appointments.
- > **Tailor** resources for each **stage and type** of breast cancer.
- > **Improve telemedicine** so that patients are able to **easily access and benefit from it**.
- > Encourage use of **mobile phone or apps** to enhance communication between **HCPs, patients and caregivers**.
- > Establish **peer-to-peer support groups** for patients in **similar circumstances**, including by age, disease stage or culture.
- > **Translate** patient educational tools into **multiple languages**.
- > Create **educational resources** regarding **palliative care**.
- > **Create materials** targeted towards adult children who act as **caregivers for their parent** with breast cancer.

- > Provide **educational materials** regarding **country-specific rights** and laws, and how to **navigate the local health system**.
- > Assign **breast cancer nurses or navigators** to patients based on commonalities, including **culture, language or diagnosis**.
- > Host a **workshop** on how to **support patients** experiencing **poverty and/or food insecurity**.
- > Expand **access to translation services** for patients who speak a different language than their HCPs.
- > **Encourage patients** to take someone with them to doctor appointments.
- > Use **pictorials in patient support materials** to help people with **lower-literacy levels**.
- > **Create new materials** or update and promote existing materials that **educate on health equity** for underserved populations.
- > Offer **HCP training** on how **cultural differences** may impact care and support.
- > **Offer training** on the differences between **communicating with patients** with different stages of breast cancer.
- > **Create videos** of real patients speaking to physicians and vice-versa to **illustrate effective doctor/patient communication**.
- > **Provide resources** beyond treatment that **address daily life** following a breast cancer diagnosis.
- > **Conduct focus groups** and surveys with patients to **inform best practices** for communication.
- > Create **communication channels** with hospitals and community cancer centers to **distribute educational materials**.
- > Provide **educational materials** and support to locations where **diverse communities** commonly gather to **reach patients** outside of the clinic.
- > Provide patients **technology “how-tos”** so they can better **utilize educational and telemedicine resources**.

- > Support **ongoing two-way communication** between oncologists and other HCPs.
- > **Empower patients** to be their **own advocates**, speak up and have their wishes known to HCPs.
- > Provide **easy-to-understand** information on potential **side effects** of treatment to aid in **decision-making**.
- > Create a set of **guidelines/standardized language** for early breast cancer **detection campaigns**.
- > **Disseminate resources for family and friends** that help educate on what **not to say and what to say** to someone with breast cancer.
- > Educate those who are **diagnosed with eBC** that they should continue to see their doctors and **be proactive** about their health **following treatment**.
- > Provide patients with **financial support information and resources**.
- > Provide treatment by a **multidisciplinary team** in more community clinics and hospitals to enable patients to **stay closer to home**.
- > **Provide transportation** to those who have difficulty accessing treatment centers.
- > Create **native language support groups** for patients on the local level.
- > **Collect data on patient needs** to create targeted programs.
- > **Educate patients on potential impact** of cancer therapies on their **daily life** (e.g. food to avoid).



COVID-19 & Breast Cancer

In 2020, the world was significantly impacted by the global COVID-19 pandemic. Summit participants discussed how disruptive COVID-19 has been to the breast cancer community meaningful solutions resulting from the disruptions to address the needs of people with breast cancer.

Fear of being exposed to the virus led to missed cancer treatments and drastic declines in cancer screenings, potentially allowing cancers to go undertreated and/or undiagnosed. In addition, people living with breast cancer reported increased feelings of loneliness and isolation brought about by quarantine.

To say this is a challenging time for people living with breast cancer is an understatement. At the same time, it revealed the resilience of the breast cancer community as it found ways to adapt to continue to care for and support patients. Summit participants discussed the solutions and opportunities brought about by the pandemic, with the goal of bracing the community to weather the remainder of this pandemic and improve breast cancer care well into the future.

Increase communication: COVID-19 has not only created barriers for breast cancer patients to access treatment, but it also has separated them from their healthcare providers and their loved ones. Effective and timely communications are needed more than ever, regardless of where patients are located. **Summit participants discussed the following ways to encourage communication:**

- Communicate with patients on proactive measures they can take to prevent the spread of COVID-19;
- Host recurring virtual support groups for patients with trained therapists and other healthcare providers;
- Leverage technology to connect patients with their loved ones when they can't be together during the pandemic; and
- Improve telemedicine by supporting a more accessible digital interface for patients.

“
Cancer patients should not be left out, and we need to make sure patients are getting the treatment they need despite the pandemic.”

— Ranjit Kaur Pritam Singh
Breast Cancer Welfare Association of Malaysia

“
One takeaway we've learned from COVID-19 is we can use telemedicine to improve communication between patients and physicians.”

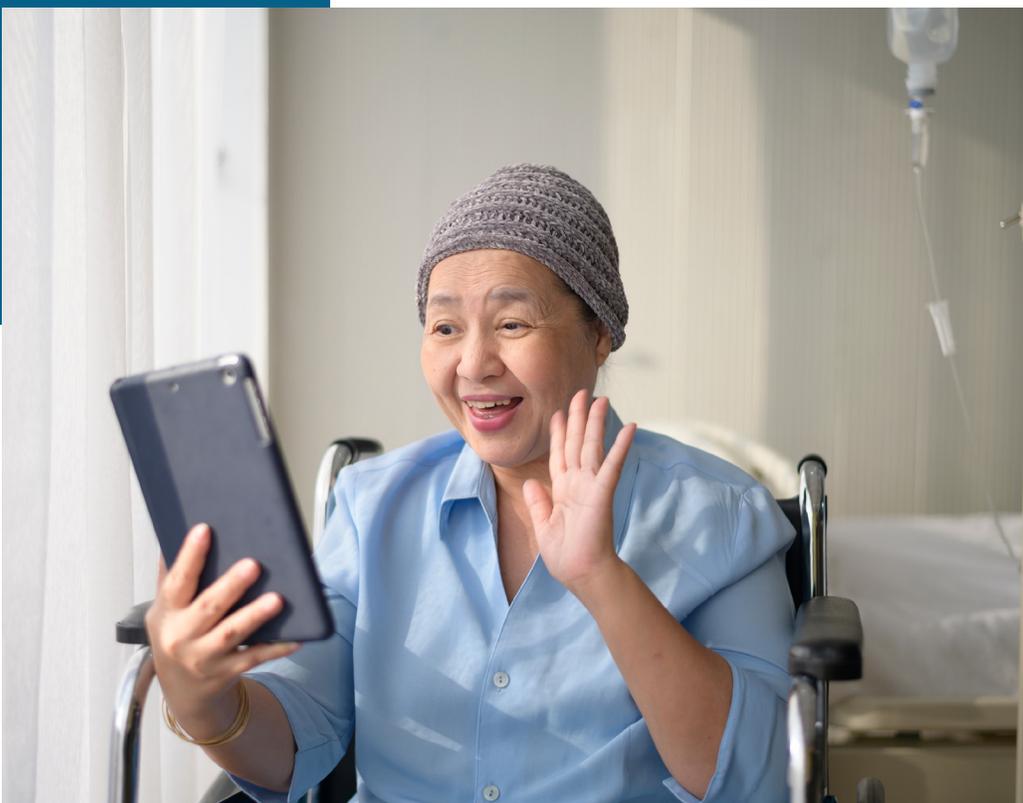
— Conchi Biurrun
Federación Española de Cáncer de Mama (FECMA)



The Summit participants brainstormed the following actionable solutions for COVID-19:

COVID-19 & Breast Cancer

- > **Advocate for prioritized COVID-19 rapid testing for cancer patients and their caregivers.**
- > **Improve telemedicine** by supporting a **more accessible** digital interface for patients.
- > Hospitals to **communicate** with patients on **proactive measures** they should take to **prevent the spread** of COVID-19.
- > **Emphasize** the importance of **access** to symptom control and alleviation **treatments.**
- > **Collaborate** with patient organizations to **host recurring virtual support groups** for patients with trained therapists and other healthcare providers.
- > **Leverage technology** partnerships to connect patients with their **loved ones when they can't be together** throughout their care.
- > Make a list of **policy opportunities surfaced by the pandemic**, such as making **permanent telemedicine policy changes**, and advocate for these.



A Global Call-to-Action

If one thing is clear from the Global Breast Cancer Impact Summit, it's that making a true impact for people living with breast cancer will require a multitude of stakeholders, including patient support organizations, HCPs and policymakers, working together toward a shared vision.

While much work has been done to date to improve care for people living with breast cancer, we recognize that disparities and unique challenges continue to exist

at a global level and more can be done to address these critical needs. It is the responsibility of all of us together – patient advocates, the biopharmaceutical industry, academia and HCPs – to continue to push the boundaries, problem solve, improve and innovate for those who need them most.

The important conversations that took place at the Global Breast Cancer Impact Summit must not end there. It's our hope that the various needs of patients discussed will continue to stimulate future conversations and actions to improve breast cancer care globally. Pfizer will initiate and support programs based on the ideas generated during the Summit, and we hope these ideas will act as a catalyst for change in the global breast cancer community.

Now is the time to own the responsibility to improve policies driving care, create a better dialogue between physicians and people with cancer and advance inclusive scientific programs that improve treatments benefitting all affected by breast cancer.

It is the responsibility of all of us together to continue to push the boundaries, problem solve, improve and innovate for those who need it most.



Thank You

Pfizer would like to thank the patient advocacy experts on the planning committee who shaped the agenda and worked tirelessly to make the Global Breast Cancer Impact Summit a meaningful discussion with advocates from around the world. Working across different time zones, in multiple languages and in a virtual setting, the committee brought their creativity, leadership and expertise to the engagement.

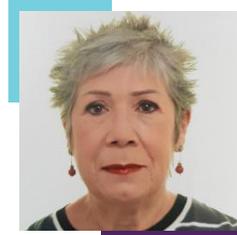
We are grateful for their perspectives and partnership. **Without their guidance, direction, review and support, the Summit would not have been possible:**



Bertha Aguilar
Médicos e Investigadores
en la Lucha contra el
Cáncer de Mama (MILC)



Claudia Altmann-Pospishek
Europa Donna
Claudia's Cancer Challenge



Conchi Biurrun
Federación Española de
Cáncer de Mama (FECMA)



Renate Haidinger
German Breast Cancer
Association



Ranjit Kaur Pritam Singh
Breast Cancer Welfare
Association of Malaysia



Stacy Lewis
Young Survival Coalition



Shirley Mertz
Metastatic Breast Cancer
Alliance



Catherine Ubaysi
Patients en Réseau

We would also like to offer our sincere thanks to the **34 global advocacy leaders from 24 countries** who participated in the Summit. It is their ideas and insights that inspire us to continue to improve lives for breast cancer patients globally. Together as a global community we can work in solidarity to make a profound impact to change the lives of people affected by breast cancer around the world.

Didem Aydin

Global Medical Director,
Pfizer

Carolin Guenzel

Global Medical Director,
Pfizer

Patti Jewell

Senior Director,
Patient Advocacy, Pfizer

Marissa Fehl

Director, Oncology
Communications, Pfizer

Lucy Ma

Director, Oncology
Public Affairs, Pfizer

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