Pfizer Oncology

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The Sixth Patient Expert Meeting on Metastatic Breast Cancer
20-21 June 2017, Berlin, Germany

Through the Patient Expert Meeting (PEM) series, patients are working together with Pfizer to improve conditions for women living with metastatic breast cancer (mBC) around the world, by creating new patient resources, inter-disciplinary events and developing patient advocates' communication skills.

Executive Summary

On 20th and 21th June 2017, Pfizer hosted the **sixth Metastatic Breast Cancer Patient Expert Meeting** in Berlin. More than 30 patients and patient advocates from 11 countries joined, together with their local Pfizer representatives. The group reviewed the implementation of patient-centric information tools across the region. They worked together as a think tank to further develop the cross-functional MBC Summit and address the shared goal of supporting the needs of women living with mBC.

1 ½ days of engaged discussions showed how much the group has already achieved but also how much more is possible. **Christina Claußen, Director Alliance Management & Patient Relations, Breast Cancer IDM Region, Pfizer**, announced how proud she was to be part of this special group: *"It makes us aware that we are doing something meaningful, that it is not just a patient expert meeting, and so we strive to achieve more progress."*

During the meeting, the group shared their best practices for implementing the co-created Me&MBC Handbook, Website and Doctor-Patient Communication Toolbox in their countries. Building on the input from previous meetings, two new Pfizer key initiatives were also presented for feedback: the EmotionSpace App and Website and the Patient Navigator. Both tools are ready to be shared with patients and patient advocates across the region and the group discussed how they could help get the materials into the hands of a wider audience. Through interactive workshops ranging from Social Media guidance to Storytelling tips, the members also received a lot of new input to voice their opinions with new messages to new audiences. Another focus was the role of nurse-patient consultation, allowing the group to learn more about the nurse perspective.

The meeting also provided an opportunity to review the outcomes of the MBC Summit last year, the MBC Summit Report and the MBC Summit Position Paper. The group had the chance to discuss the agenda for the 2nd MBC Summit together. The PEM members provided invaluable insights and ideas to further develop all these initiatives and provide the greatest possible benefit for women with mBC. In this way, the PEM aims to increase recognition and understanding of the disease among wider society.

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A Unique Co-Creation Approach Improves Support for Women with mBC

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Meeting Report

The Sixth Patient Expert Meeting once again brought together a special and intimate group of mBC and breast-cancer patients, patient advocates, nurses and Pfizer employees to discuss the needs of women with mBC. Over 1 ½ days, they shared their personal experiences and refined and developed initiatives that can help to support the needs of women with mBC around the world and bring them to the attention of wider society.

Christina Claußen welcomed back the group members: *"It is truly amazing what has been achieved in the last six months. Today we come together to celebrate as a group and to learn from each other. I can see all these different country flags - our friends from around the world."*

Some patient advocates and patients were unfortunately unable to attend, but were sent warm wishes. Condolences were spoken for the passing of Gabriele Herzog, a strong member of the PEM-group from the start who helped developing the Me&MBC Handbook. This year's PEM also welcomed Martina Krammer from Austria as a new member to the team.

Everyone was excited to hear the progress that has been made and what the next steps will be, the room was full of motivation and all attendees were ready to be part of this truly special meeting again.

Conceicao Ferreira, Commercial Portfolio Lead Breast Cancer, International Developed Markets (IDM), Pfizer Oncology, said: *"It is always such a pleasure and honour to be part of this meeting and I am always so amazed by how much energy is in the room. It inspires me to continue to do better and help women in need."*

Following the introductions, the group watched the video from the grand MBC Summit 2016 in Madrid, featuring many of the attendees sharing their thoughts and ideas on how to improve mBC patients' everyday lives.

Session 1: Me&MBC Initiatives

Martina Weiss, Brand Director, IDM, Pfizer Oncology summarised the achievements to date with the truly valuable patient resources from the Me&MBC Initiatives:

- Me&MBC Handbook has been launched in six countries and more to come
- Me&MBC Website has so far been launched in five countries
- Doctor-Patient Communication Toolbox is almost ready to be launched in four countries

These assets are of huge value to the mBC landscape and provide all-round support for patients' needs. Some best practice cases were presented from the respective countries to learn about the challenges and impacts achieved through local implementation and share advice on how to create the maximum benefit for everyone.

Me&MBC Handbook & Me&MBC Website

Martina Weiss expressed her delight that the *"green book"* is everywhere and already available in a lot of countries because it is the key asset of the PEM group. She also noted that the Me&MBC website is a fantastic opportunity to further expand our audience. She pointed out that the digital trend is growing, making it more important than ever to be active on digital platforms and provide local websites with local information.

Tali Rosin, Public Affairs & Policy Manager, Pfizer Oncology Israel, guided attendees through the Israeli implementation of the Me&MBC Handbook and unveiled her tips to overcome certain challenges, like finding the right words in Hebrew to translate the powerful text. The translator must not only have medical experience but also be able to capture the story in an empathetic way: *"The tone makes the music."* She said she was truly amazed that the content is now available in a lot of countries: *"Imagine there is a woman now in Ireland or in Paris or in Moscow and she is holding the Me&MBC Handbook. She is looking at the very same text and graphics, I think that's amazing and we can be proud of that."*

Nicole Zernik, patient advocate from France, Myriam Jabri, Pfizer France, Maria Marfisa, Patients & Citizens Advocacy, Pfizer Italy and **Elena Mukhacheva, Pfizer Russia**, each introduced their implementation paths. They were able to involve various patients and PAGs to make sure the Me&MBC Handbook mirrored the needs of patients in their country.

They pointed out that the adaptation to local laws is very important and the medical information should be handled through a breast cancer specialist.

Doris C. Schmitt, patient expert and communication trainer and Anja Schmidt, Alliance Manager, Breast Cancer IDM Region, Pfizer, presented the German implementation process for the Doctor-Patient Communication Toolbox. Doris pointed out that, *"The Doctor-Patient Communication Toolbox is a valuable tool which should be used. It is not easy but needs to be broken down for everyone to start their own journey with the materials."*

The communication between HCPs and patients needs to be improved and it is important that this tool achieves a broader uptake across the region allowing patients to get educated and prepare for their doctor's appointments.

The German Me&MBC Handbook has also been distributed with over 6000 copies so far which is not only a great success but motivated everyone in the room to continue to spread the word about the materials.

Session 2: EmotionSpace and Patient Navigator

This session was all in the name of introducing two very special Pfizer initiatives that support women with mBC in two different ways: by 1) providing emotional support and 2) guiding patients through their healthcare systems.

The EmotionSpace App helps patients and their families to deal with the emotional strain of mBC. The app is a digital solution and it doesn't replace the actual family members and friends to talk to but it helps patients to get clarity and to communicate more easily. Martina Weiss called out to the PAGs to actively use the community functions and share their upcoming events to be listed in the app.

The attendees had the chance to try out the app on phones provided. They were highly engaged, discussing and sharing insights on how patients would receive it in their respective countries and detailed needs for local adaptation. Feedback about the app was very positive.

The **Patient Navigator** launched in May 2017 in Germany and is a website which guides patients through the care landscape. Doris C. Schmitt and Anja Schmidt explained how the website allows patients to track their pathway, log appointments and navigate through the healthcare system. All this information can be saved as part of a timeline which can be taken to take to appointments with doctors and nurses as a digital version.

Doris C. Schmitt: *"Our aim was to provide each patient with a personal coach. This is not realistic. However, our creation of a digital patient navigator fulfilled our dream of coaching patients to help them manage and redefine their life with cancer."*

The user-friendly design offers patients and HCPs access to useful information and provides answers to wide-ranging questions, all summarised in a Q&A. The content has been verified by HCPs and KOLs who also offer expert guidance and local support services. The group loved the new tool and were already very keen to know when it will be available in their countries where it will change the lives of mBC patients tremendously.

Naomi Fitzgibbon, oncology nurse from Ireland: *"This truly fills a gap in the healthcare system. Patients need information and especially support to chart their course through the healthcare system – so the navigator is a much-needed tool. This lifts mBC care to a different level."*

Session 3: Lecture: Social Media & Patient Advocacy // Going Practical I: Social Media Training

Stefanie Bockwinkel, communication trainer, introduced **Eva Schumacher-Wulf, patient advocate and chief editor for "Mamma Mia" breast cancer magazine,** jokingly describing her as the *"Queen of Social Media"*.

Digital solutions have been progressively becoming part of everyday life and are becoming true helpers along the cancer journey. Social Media provides a huge advantage when communicating with different audiences.

Then, the group learned how to use social media to raise awareness for mBC and how social platforms can be used for different audiences and messages.

Eva Schumacher-Wulf explained the various channels and their appeal to different audiences.

- **Facebook** reaches out to patients, family and public and is useful for longer messages
- **Twitter is** for politics and media, messages must be kept very short with the option to link to other websites, typically professional audience
- **YouTube** is a platform for video stories and allows a mix of emotions and facts in an entertaining way
- **Instagram** is very good for campaigns using stunning pictures with little text
- **Snapchat** is used for a younger audience with short videos and could raise awareness for mBC in public

The group revealed that they most commonly use Facebook and Twitter, followed by Instagram and Snapchat. Eva recommended using links, pictures and creative tools to make the social outreach more successful.

Additionally, social platforms create an engaging community through online groups where staying in contact and sharing latest facts and figures is now possible and easy to manage for everyone.

Eva Schumacher-Wulf: *"Social media is a real chance to give all our patients a voice because it doesn't cost any money. Previously we had to go to journalists and hope that they would write a story for us. Now we don't have this wall anymore and we can publish directly with what we think is important."*

Main tips to remember:

- Develop an editorial calendar to post messages at preferred times for different channels
- Post continuously with popular hashtags
- Check regularly for feedback and answer questions
- Use pictures to build an emotional connection and attract attention
- End posts with a question to start discussion
- Post links to other websites
- Share creative activities like petitions with a wider community

Esraa Elsayed, patient advocate from Egypt, held an energetic short talk about the importance of interesting social content to spread the word.

"Content is most important and can change cultures and opinions."

Session 4: Going Practical II: Storytelling

The next step was to learn how to tell a good story about mBC. **Stacy Wiedenmann, Senior Manager Communications Oncology Europe IDM, Pfizer** opened her session by expressing her joy: *"It is always so inspirational no matter who I sit next to and makes me so proud to be here -it is my favourite meeting."*

She explained that stories are a powerful form of communication to connect with people and open people up.

"You can hear statistics but you feel stories, you never forget how people's stories made you feel." The session's aim was to share tips on how to create an impactful story:

- **Start with a message**: Know the audience and repeat the message
- **Connect messages with experience**: Show vulnerability, personal struggles and experience
- **Hero but not the focus**: Introduce all people involved in the story and make the audience part of the story
- **Highlight struggle**: Create a plot to bring the story to life
- **Keep it simple**: Streamline the way you're thinking about it and don't get bogged down in details

The group was animated to put their heads together and find stories they would like to tell using this 5-step plan. The result was some truly powerful personal stories. **Martina Krammer, mBC patient from Austria,** explained her emotional journey and how she got back on her feet: *"I was shocked after the diagnosis with mBC and I will never forget the doctor's face but I also want to motivate other women to create the world the way that provides the support they need to improve their everyday lives."*

Doris C. Schmitt spoke about the initial diagnosis and how she became a patient advocate.

Session 5: Best practice sharing among PEM members

The group often asks to hear what other patients and patient advocates are doing and learn from their best practice examples.

Lize de Jonge, patient advocate from UAE, presented her initiatives "Seven years for seven emirates" and "Pink Caravan". She specified that they are working on a continuous social media presence across the year to accompany the 12-month campaign. They came up with 25 different videos showing health tips from fitness to nutrition to attract not only cancer patients but also the general public.

Figen AR, patient advocate from Turkey, revealed several activities from her PAG "Dance with Cancer" including a Facebook-Page and a new mBC-app which will support mBC patients in Turkey.

Ewa Grabiec-Raczak, patient advocate from Poland, filled the group in about a very successful mBC conference with more than 300 attendees as well as a workshop for 40 volunteers to support women with mBC. She also highlighted a Polish guide with patients' stories and tips for better doctor-patient communication, called "Let's talk".

Nicole Zernik commented that it was *"such an inspiring and emotional afternoon."* She added that the need for mBC information is immense but that it also has to be combined with a true story. They created a mBC brochure about issues and daily life with patients and HCPs for patients.

Day 2:

Session 1: Insights from nurse's perspective

Oncology nurses already play a huge role in the lives of women with mBC so this PEM offered the opportunity to get first-hand insights from the nurse point of view and how nurses prepare for a patient consultation. They are the ones who hold important conversations with the patient and often accompany the patients for years.

Naomi Fitzgibbon gave insights into the nurse perspective and how to best include patients into the decision-making process: *"What's important is not just the information you think you need to get across as their nurse, but also to understand what is important to the patients and families you are talking to – what are their greatest fears and concerns?"*, she explained. Oncology nurses need to understand mBC patient needs to be able to prepare for conversations with patients.

Keren Arfi, oncology nurse and Michal Melamed-Cohen, mBC patient, from Israel shared their emotional joint journey through Michal's disease. Keren Arfi gave an overview of the nurse-patient relationship and its importance in real life. For many patients, the biggest question is: *"Who is going to take my hand and walk with me all the way? Will it be the oncologist? No. It will be the palliative nurse."*

Michal shared her personal story, from diagnosis, to tamoxifen, to chemotherapy, to telling her family and children: *"I made a decision – I was not going to hide. I didn't do anything to make myself sick, so I have no reason to be shy about who I am."*

The members were part of a truly passionate and honest dialogue when Keren and Michal discussed living with mBC and how they handle their day to day life together. They offered very personal insights from how to cope with the decision on changing treatments to how to manage energy levels even on good days and when even nurses have to step in sometimes. *"For nurses, there are points when if the decision that a patient is going to make is a life-threatening decision, then we as nurses have a hard time. I can say, this is her life, she has the decision on what happens. But if I know there is a risk, and I have the power to stop it, it isn't easy."*

"At the end of yesterday, I was exhausted, but I lay in bed and said to Keren – I can tell you in one word what I am feeling right now: happiness. We are here. We are like a family and the energy here is so different. So, thank you for the energy. You are making us feel healthier", said Michal happy at the end of their session.

The PEM members were overwhelmed by so much honesty and clarity about how their relationship works and how it helps both to make the best decisions and focus on quality of life.

Carolina Welin Ohlsson, patient advocate from Sweden, summarised the interaction: *"There is a such a beauty in your relationship, you can be safe that she will be there and stand the tears and she won't disappear."*

This session highlighted the importance of interdisciplinary collaboration of patients, nurses and physicians and underlined the importance of the cross-functional approach of the MBC Summit.

Session 2: 1st MBC Summit revisit

The group was then delighted to think back and remember the 1st MBC Summit last November that brought together patients, advocates, oncologists and nurses to address the needs of women with mBC for the first time in that setting. **Clara von Matthiessen, Senior Brand Manager Breast Cancer Oncology, Pfizer** introduced the session by saying what a powerful event it was with nearly 50 attendees from 20 different countries with one truly common goal: improving the lives of mBC patients in an incredible team effort. She looked back and refreshed the memory of the group to have a closer look at the outcomes from the MBC Summit last year.

Clara von Matthiessen is so delighted that the interdisciplinary group at the MBC Summit developed ideas and positions together and the PEM members had time to discover the freshly printed **MBC Summit Position Paper** and **MBC Summit Report** and give their reactions. Jointly, next steps were identified how to implement the materials across the countries and turn the positions into action.

"I really like the Report and can't put it out of my hands, it is so glossy and colourful. It is a great report on what happened in Madrid and gives a comprehensive overview about what was achieved and what will happen from now on," Clara von Matthiessen said about the MBC Summit Report.

The MBC Position Paper was received with excitement considering how many possibilities it provided for raising awareness and putting mBC on the political agenda. The session closed with a highly-motivated discussion about the international call for action on mBC and how to best use it, e.g. creating small social media images of the positions or opening an online petition to raise awareness around the world.

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Session 3: 2nd MBC Summit 2017 in October

From talking about the great outcomes of the 1st MBC Summit, the group was looking forward to hear about the plans for the 2nd MBC Summit **from 16-17 October in Vienna**.

The main point gathered from the 1st MBC Summit was that a more efficient doctor-patient communication is what helps to improve the lives of women with mBC. As a result, the next Summit will be focussed on developing communication guidelines for patients with the help of HCPs and nurses.

Tali Rosin: *"It's really fantastic, I like the thought of guidelines. It is revolutionary-take what's there and develop it further as patient guidelines."*

Closing Remarks

After these genuinely inspiring 1 ½ days of being together and discussing how to create a brighter future and better mBC information for patients, the group is looking forward to see each other again at the MBC Summit in October. **Martina Weiss** then closed the 6th PEM in recognition of the important contribution made by the Every Day is Precious Group as friends and family:

"What a couple of days it has been. It was a truly fantastic and all contributions and stories will stay in my heart and my memory forever. We will all see us again at the 2nd Summit to continue our energetic journey to share and inspire one another and make lives better every day."

Christina Claußen echoed her words and simply said: *"You know I don't say goodbye - see you at the MBC Summit in Vienna."*