

**Aktivity krajín** zdieľané počas podujatia resp. po ňom pomocou vytvorenej uzavretej fb skupiny po ukončení pre účastníkov *Europa Donna MBC Patient Advocates - Milan – 2018* (bol aj návrh vytvoriť na stránke ED priestor pre zdieľanie best practices medzi krajinami; ED zväži & neskôr pošle aj zápis zo stretnutia):

ED: 13. október – medzinárodný deň metastatickej rakoviny prsníka

CR aktivity: Café Donna – pacientky v kaviarni sria osvetu (program, v ktorej kaviarni kedy bude ktorá pacientka); ostro sledovane prsia (krajin V4 – odliatky, info ďalej); plavanie – video:

<https://www.youtube.com/watch?v=9xbkcTSfgyA&feature=youtu.be>

<https://www.facebook.com/BellisYoungAndCancer/>

<https://www.facebook.com/AlianceZenSRakovinouPrsuOps/>

<https://www.facebook.com/narodnionkologickyprogramcr/>

FR – rozhovor v rádiu MBC pacientka; <https://www.facebook.com/Collectif-1310-319645125509524/>

Holandsko – (statom dotovaná) infografika k mamografickému vyšetreniu

[https://www.rivm.nl/Onderwerpen/B/Bevolkingsonderzoek\\_borstkanker](https://www.rivm.nl/Onderwerpen/B/Bevolkingsonderzoek_borstkanker) + schema ku komunikácii

pacient-lekár: [https://www.b-bewust.nl/uitgezaaide\\_borstkanker/vragenlijst](https://www.b-bewust.nl/uitgezaaide_borstkanker/vragenlijst)

Pozn. & vysvetlenie k letáku (uitgezaaide borstkanker – MBC):

CONFIRMATION: I shared some shared decision making posters with you all and you asked whether you could use them. I just got the confirmation that is okay to use and to share them with others.

B-bewust, is a part of the website of the Dutch breast cancer association. It is all about how to talk with your doctor. Online you can find all sorts of question lists. You can - online - fill in your own personal question list, and keep it going on during all your treatments. I'll give you a few links, but of course it is all in Dutch.

for every part is a separate question list. Diagnose- treatment possibilities and consequences of each treatment - alternative therapy (for instance diet, or homeopathie etc. - scientific research - palliative care - etc.

Time-out means that you should have some time to consider all possible treatments with your doctor: he or she tells you what the next step could be, and the advantages and disadvantages of the different treatments, and it would be wise to think about those choices before you make a decision.

Rakúsko: blog: Claudia's Cancer Challenge: [www.facebook.com/claudiascancerchallenge](http://www.facebook.com/claudiascancerchallenge); výtvarné aktivity: <https://www.stark-mit-brustkrebs.at/kunstklasse/>

Luxemburg: video/blog: [https://www.youtube.com/watch?v=T\\_tSHbg0u0s&feature=youtu.be](https://www.youtube.com/watch?v=T_tSHbg0u0s&feature=youtu.be)

čo nehovoriť MBC pacientovi: [https://www.verywellhealth.com/what-not-to-say-to-someone-with-metastatic-breast-cancer-4115517?utm\\_source=facebook&utm\\_medium=social&utm\\_campaign=mobilesharebutton2](https://www.verywellhealth.com/what-not-to-say-to-someone-with-metastatic-breast-cancer-4115517?utm_source=facebook&utm_medium=social&utm_campaign=mobilesharebutton2)

A US based data gathering project but you can also count yourself in no matter where you live in the world. <https://www.mbcproject.org/>

This is the page that one of my friend created to give informations to metastatic italian women. Hope you can appreciate. METAvivor Research and Support Inc.: <https://www.facebook.com/metavivor.it/>

An app for finding research: 'MTB-app' (Molecular Tumorboard app). Meant for doctors but available for all. Voor iOS: <https://itunes.apple.com/us/app/mtb-app/id1339669552...>

Voor Android: <https://play.google.com/store/apps/details...>

Here's the link to my book: [amzn.to/2NQsDI1](https://amzn.to/2NQsDI1) & and my blog:  
<https://www.facebook.com/KateCanDoThis/>

Look at Instagram # Ospriddsanning.  
where I am one of the participants who writes about my breast cancer.

Mamografia – vekové rozpätie skríningu per krajina (z fb diskusie):

In the UK it is currently every 3 years over the age of 50.

In the Netherlands it starts at the age of 50 and stops at 75. Every two year. There are regularly discussions about the usefulness of the screening, because there can be also damage by the screening.

It starts with 40 in Austria and you're invited every 2 years.

because of this early check up starting from of 40. What can you tell about statistics? Do less woman die of breast cancer in Austria? Is it out of 4, 1 out of 5, or less?

here is the data: <https://www.europadonna.org/breast-cancer-facs/> (see table)

interesting reading, knew the causal factors but not the 20% under 50 etc.

Some parts of the UK now 47!

In france, if no particular risk, from 50 to 74, every 2 years. Every women receives an invitation from the social security to have a mammogram and it's free of charge

In Sweden, from 40, and stops at 75.

In Slovakia from 40 to 69, every two years if everything ok. In case of BC family history, once a year, as well as in case of hormone contraception, hormone & substitution therapy. No systematic screening yet (though planned to be launched since next year after patients organizations have made pressure); only 21% women go for mammography. That's also why OZ Amazonky recently launched the I've already been awareness campaign, supporting prevention, demything this examination & awarding mammography centers here.

really???? only 21%? that is shocking.

In the Netherlands there is a special website about this check-up. Woman who have this check up, do have 50% less change to die from breast cancer. [https://www.rivm.nl/.../Bevolkingsond.../Wel\\_of\\_niet\\_meedoen](https://www.rivm.nl/.../Bevolkingsond.../Wel_of_niet_meedoen). explanation on that website in english : [https://www.rivm.nl/Ond.../B/Bevolkingsonderzoek\\_borstkanker](https://www.rivm.nl/Ond.../B/Bevolkingsonderzoek_borstkanker). this is a presentation of the Dutch government

Such a shame the uptake is so low. Hopefully better information and understanding that the disease is treatable especially when caught early will influence people's decision in time x

It starts in Iceland at the age of 40 and ends 70. You are invited every 2 years. It will maybe change in the near future and start 47 and end 75. I am in committee which are looking into the screening programs by the ministry of health. And the plan is different if you are BRCA 1 or 2 positive.

In Estonia, women aged 50-69 years are invited to breast cancer screening at two-year intervals. In 2017 56,3% of womans who got invitation went to the mammo.