A patiënt’s vision on Access Breastcancer patient organisation Netherlands

FIGON 9 oktober 2025

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(potential) conflict of interest

Potentially relevant company relationships in connection with event

Company names

- Sponsorship or research funding
- Fee or other (financial) payment — Lygature, day ticket access
- Shareholder
- Other relationship, i.e. …

A short introduction into breast cancer and our patient organisation

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A few figures

Breast cancer

- Every 1 out of 7 women are diagnosed, around 170 men and around 3.500 metastatic
- Around 3.000 patients die every year
- Average age is around 60 years.
- Treatment duration varies from 9 months to 2 years
- Risk factors are genetic, hormonal and lifestyle

Types of breast cancer

Receptor status:

Hormone receptor positive (HR+) 80%

- Luminal A (HR+, HER2-, Low grade 55%
- Luminal B (HR+, HER2- high grade OR HR+, HER2-) 25%

Her 2 positive 6%

Triple negative 12%

Who is Breastcancer Organisation NL?

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Belangenbehartiger

Annette Arps
Belangenbehartiger

Berrie Leijs
Administratief medewerker

Cristina Guerrero Paez
Directeur

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Controller

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Mariëlle Groenendijk
Administratief medewerker

Marjan van Beest
Financieel administratief medewerker

Mirjam Rinzema
Communicatieadviseur

Belangenbehartiger

Luna
Kantoorteckel

Mission and Vision

Mission

We are committed to ensuring that people affected by breast cancer and hereditary predisposition and their loved ones, receive the treatment, care and support that is tailored to them and suits them.

Vision

To achieve this, advocacy for good quality of care and life are essential. As are information provision and peer contact.

Quality of care focuses on diagnosis, treatment and aftercare.

Quality of life is about the physical, psychological and social functioning of (former) breast cancer patients and people with hereditary/familial predisposition.

They need good information that is reliable and up-to-date. This allows them to make informed choices about their treatment and how they want to deal with their disease or hereditary/familial predisposition. In this regard, BVN is a strong advocate of Sharde Decision Making. This is the process that leads to you deciding together with health care providers which care, in which form and in which way, is best for you. BVN puts issues on the agenda of hospitals, researchers, health insurers and other important stakeholders in order to improve the quality of care and life. We also respond to current developments, government decisions and health insurers.

Wat do we do?

Information

Patient advocay

Peer support

Our strategy 2026-2032
4 main goals

A. **Person-centred / Integrated care**
B. **More conscious choices**
C. **Accessibility**
D. **Enhanced Support**

Imagine you are a patient

“And you are ill and depending on medicines. Somewhere in the world there is a medicine that can help you

But it has no acces, there is no trial, is there hope?

Maybe only through a CUP or a NPP.

What do you do?

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A “translation” to acces

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Before access

Development of new medicines

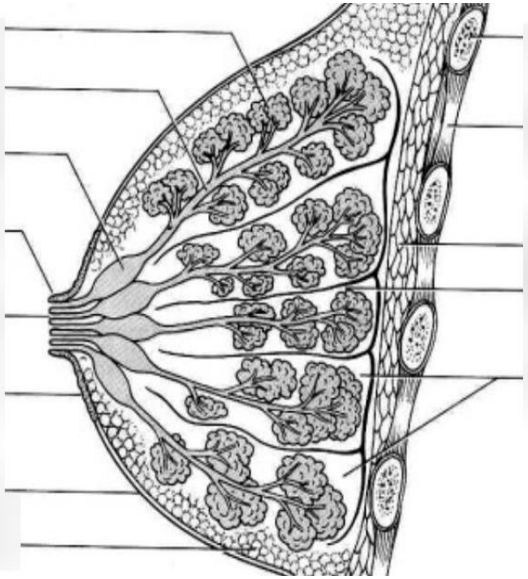
What patients need new medicines? Analyses of sub groups, p.e. triple negative -> a lot of companies are focused on MBC.

WHY?

Patients from the early start, p.e. patient driven research agenda for breast cancer

Important aspects are:

- OS and PFS
- Adversory effects short and long term
- Combination with other medicines
- Method of administration



We need access (after EMA)

- To be able to have **personalised treatment**
- To be able to implement **shared decision making** and have choices
- To be able to **gather data** to validate the effect, adversory effects, patients reported outcome data
- To set the **“landscape”** for patients that need new treatments most (subgroups, rare breast cancers)

Treatment options / patient journey Breast cancer curative

Six important choices

1 to start or stop (neo-)adjuvant therapy; hormonal treatment.

2 to start or stop (neo-)adjuvant therapy; chemotherapy or targeted therapy (i.c.w. chemotherapy).

3 yes or no radiotherapy of mammary/ thoracic wall (incl. partial breast irradiation)

4 yes or no boost radiotherapy.

5 on type of breast surgery; breast-conserving or mastectomy (ablatio).

6 on reconstruction in case of ablatio; immediate/deferred, prosthesis/own tissue.

But not by all means

For curative BC:

- New medicines need to be more efficate than SOC
- The adversory effects need to be manageable
- And the late adversory effects minimal
- The pricing needs to be competitive

For MBC:

- the same level of efficacy is minimal
- OS and PFS are equally important
- Differentation between possible sub groups for best result
- The pricing needs to be competitve

Adversory effects

- Short term effect, during treatment;
  - Fatigue
  - Hair loss
  - Skin problems
  - Neuropathie
  - Nausea
  - Diarrhoea or congestion

There are treatments for the effects, but an effect can lead to change in treatment plan. This has a mayor impact.

- Long term (even after 10 year and 88% of (ex) patients)
  - Fatigue,
  - reduced physical fitness,
  - memory or concentration problems
  - neuropathy.
  - transitional/hormonal symptoms

Impact of illness and treatment

- Fysical effect
- Mental effects
- Work and financial
- Socially

88% >
10 years

“I became a 2.0 version that I didn’t know existed”

https://youtu.be/3oH6ZBHn_rY?si=sffB90hL8VxyTGm0

CUP and NPP

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CUP What do we know as a patient organisation?

- *Patients in general do not know about these programs*
- *If the oncologist doesn't mention it*
- *It can provide early treatment for a patient, but what if it does not get access?*
- *How long can a patient count on the CUP?*

It can make the difference between being at the wedding of my daughter or not.

NPP What do we know as a patient organisation?

- *Patients in general do not know about these programs*
- *If the oncologist doesn't mention it*
- *Again it can be life saving! From stepping stone to stepping stone.*
- *We depend on the "kindness" of the manufacturers*
- *Adminstrative work unclear*

The company can use it as a leverage

For patients it can be life saving

- There needs to be more information about the programs and how to access them on a comprehensive and accessible level
- There is need for more freedom in applying CUP and NPP
- It needs to be disconnected from the access process

"A patient with metastatic breast cancer said: 'I was given extra years as a gift. A time when I could not be a patient, but a mother again.'"

What do patients need?

- **Transparency**: Be honest from the start. What can a patient expect? What conditions apply? What are the risks?
- **Involvement**: Patients and their organizations should be involved in the design of CUP programs.
- **Continuity**: When it comes to CUP policy, also think about the 'exit strategy'. How do you prevent someone from losing access in the event of a positive response?
- **Guidelines and ethics**: Make clear rules of the game and agree on who bears responsibility. Where are the borders, and who guards them?

What about new complex developments?

1. Patients can help by adressing their general needs to policy makers, to society
2. Patients can help by translating their needs to potential new medicines and developments
3. Patients can help by joining in early developments, fase 1 trials, etc
4. Patients can help by translating the outcomes to what access is necessary (if included in an early stage)

After access

- A long road ahead to have a national standarised process
- There are different paths to inform HCP
  - In Netherlands for breastcancer the HCP united in the NABON and the NVMO
  - The guideline mammacarcinoom in NL has more than 130 modules and each year they update about 6/8 modules
  - There are expert meetings to help inform and provide a uniform policy

But in our opinion it still depends to much on the active role the HCP takes in keeping up with the latest developments

Take home messages

- Access is needed
- But within certain conditions
- Strategy should not be conducted at the cost of the patient
- CUP and NPP are tools to to gather real world data and bridge the time gap

Questions?

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Additional slides

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Patiënt participation and research Breastcancer patient organization Netherlands

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Patient driven research agenda

- Focusing treatments on tumour and patient characteristics.
- Long-term effects of different treatments (e.g. fatigue, (nerve) pain, effects on other organs.
- Insufficient communication about effects of treatments, side effects and late consequences.
- The best sequence, length and intensity of treatments in patients with metastatic breast cancer (aiming at longer life).
- The best sequence, length and intensity of treatments for survival in the initial treatment of breast cancer (aimed at cure).
- Effectiveness of follow-up checks and self-monitoring in early detection and recurrence of breast cancer.
- Psychological consequences of living with hereditary predisposition, including for children and family

A small organization

We depend upon members, donations and funding for our team of 6,5 formation

Our base funding is Pink and KWF and our donors. For our projects we are dependent of funding.

- We organise and attend more than 100 meetings a year
- We have all kind of information and support on every step of the treatment a
  and late adversory effects and end of life

EVERY SUPPORT IS WELCOME

Sort of tumor

- 3 or 4 main types; triple negative, HER2 positive, Inflammatory
- Around 10 other rare types
- Auxiliary
- Metastatic

“How am I supposed to remember all the medical info?”