

# Mamazone

mamazone  
Frauen und Forschung gegen Brustkrebs e.V.

# My very personal way to boost the immune system and survive breast cancer

**By Ursula Goldmann-Posch**

*Chair-woman and co-founder of mamazone –  
Women and Genomics Against Breast Cancer*

Mamazone is an organisation for women with breast cancer who want to know — women who want to get to grips with the science behind their disease, to understand the various treatment options, and to play a role in pushing forward the frontiers of research. Here, Ursula Goldmann-Posch, chairwoman and founding member, tells the story behind her own role in setting up this unique organisation – the story of how she decided to confront her own tumour face to face - literally – and how this forced her into another confrontation. This time with the attitudes of her own doctors.



© DR

**P**atients who, like myself, must live with life-threatening cancer have two choices: They can either practise the art of denial and entrust their fate to their doctors. Or they can educate themselves about the subject matter and become experts in their own disease. I chose the second path. Specialty: Breast cancer.

Whether a person opts to remain passive or become proactive during the course of their illness is a very personal matter.

Nobody has to be knowledgeable. Nobody has to study oncology on the fast track. Nobody forces us to do that.

But if we, the patients, want to do that, nobody should prevent us. If we want to be equal partners with our doctors, no physician should utter comments like: “But why, don’t you trust me?” or: “You take care of yourself, I take care of medical matters.”

To get deeply involved in one's own cancer is a voluntary decision depending on many factors and potentially changing one's entire life.

The cruelty of what has happened to us and what might still happen is not always easy to cope with. It makes us insecure, it frightens us, and often it leaves us at a loss for words.

But this lack of words is not limited to patients with life-threatening illnesses. In its own way, it applies equally to those on the other side of the physician's desk.

Most physicians do not have the right words for the emotional turmoil their cancer patients go through, and they often assume a defensive attitude towards them.

They feel obliged to quickly reign in their patients' boiling emotions. Physicians almost seem to be condemned to rationality.

It is rare that behind the protective shield of broken-off feelings the physician shows the caring human within, the one who feels responsible not only for the patient's body but also for her mind and soul.

In the book *The Lump Above My Heart. Breast Cancer Must Not Be A Death Sentence*, I wrote:

*Except for the leaden tiredness, radiation is an inconspicuous treatment. The invisibility of the treatment sometimes confuses me, makes me inse-*



**Ursula Goldmann-Posch, 54, breastcancer survivor, chair-woman and co-founder of mamazone**



**From left to right: Elizabeth Globber, Elizabeth Hantke, Prof. Ingo Diel from Mannheim, Prof Michael Untch from Munich and Ursula Goldmann-Posch receiving the mamazone mobile in November 2002, in front of the Klinikum Augsburg**

cure. I do not lose my hair and do not vomit. "You look like a corporate executive," the oncologist says when I enter his office carrying my black bag that contains some results. "And I dare bet that your blood results are better than mine," he adds. The fanfares blaring from the computer announce that the machine is booting up. The oncologist types something into the keyboard, enters my name and instantly has the confirmation: "Everything is in perfect order." "I help my body as well as I can," I say and tell him about my (additional) complementary therapies.

"This only helps the manufacturers' wallets," he says shaking his head at so much ignorance. "Rather than injecting mistletoe you could just as well scrape the plaster from the wall and eat it."

I remain silent, do not dare to object. What should I tell him with my half-knowledge?

"And what about psychotherapy," I ask shyly, "could psychotherapy be helpful during convalescence?"

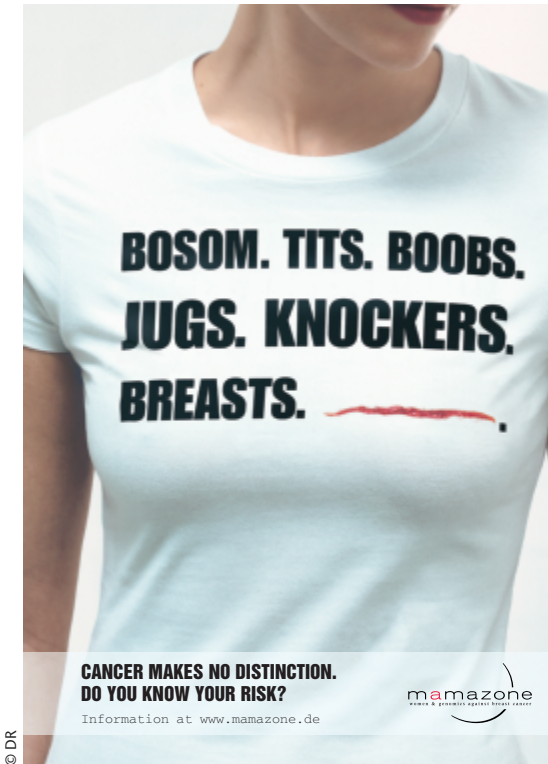
"I don't know why people become so metaphysical with cancer," he replies, rolling his eyes.

"Because this is not just about life but also about death," I reply, my voice firm. "Can you just ignore what's happening here?"

Now he remains silent, does not dare to object.

After a while, he tells me about his mother who had died from cancer as a young woman.





© DR

A patient's path towards becoming a competent "medical consumer", as one likes to say, is ambivalent and rocky.

Only physicians with a certain confidence consider independent patients a welcome addition to their professional life and their views an important complement of their own.

Less self-confident physicians don't know how to deal with curious patients; they even fear them as time-consuming know-alls. At best, they call this a *"eine differenzierte Persönlichkeit"* – a subtle personality – basically warning their colleagues, between the lines, about their difficult client.

In this regard, patients who are able to enter the patient-physician relationship with complete trust and assume the role of the sufferer who lets her doctors handle the rest fare much better. They experience less opposition and more attention. They are allowed to be weak and helpless.

With curious patients, people tend to forget or ignore the fact that they are not only competent and curious but also ill and in need of help and assistance.

Patients in the healthcare system who want to be treated as customers and not just as suf-

ferers seem to relinquish their rights to be ill and to lose their moral right to be in need of protection.

I quote again from my book:

*My lymph nodes are not affected and therefore it is not completely clear whether a supporting chemotherapy with CMF – a combination of cellular toxins – has any advantage for me, says Professor Albrecht, head of the oncology department. But given my age, the size of the tumour and its growth rate and also the fact that it does not respond to hormones, he would recommend it anyway.*

*I am slowly beginning to understand.*

*In almost two-thirds of all patients, metastases are latent somewhere in the body at the time of surgery and should be treated with a preventive chemotherapy or hormone therapy. And since my tumour was close to the sternum an additional 35 radiations at different places are recommended. But all this could also be superfluous. That was something I had to accept, the professor says.*

*I am slowly beginning to understand.*

*I am alarmed. My friends form a network of correspondents trying to get different opinions.*

*A few days later the "reports" come in. Sitting upright in my bed, two pillows behind my back, the black-green notebook open in front of me, I feel my power return. I know that this is where I belong: Research.*

*The report from Berlin says that women like me, women whose lymph nodes are not affected, belong*



© mamazone

**The mamazone chair — from left to right: Elizabeth Globber, Ursula Goldmann-Posch and Elizabeth Hantke**



© DR

**mamazone with other patient advocates as participants in a demo for a better screening in Germany in Berlin**

in a risk group that is not yet sufficiently researched and understood.

*"There are insufficient data and the therapy depends more or less on who does the treatment and their school of thought," Professor Niederberger tells me. I should also decide whether I wanted the maximum therapy or maybe even the excess therapy and therefore the feeling that I hadn't left anything out – but there was no complete guarantee either – or whether I simply wanted to wait and risk a relapse. Anyway, the recommended combination of cellular toxins CMF was old-fashioned. More modern substances are available now. But these harbour a greater risk of heart damage.*

*I take note.*

A friend from Munich reports what the cancer and radiation specialists there had to say. According to the leading physician in Professor Eichinger's group "no more than three low-dose preventive chemotherapies" were necessary, and no radiation, while Professor Eichinger himself recommends six cycles with radiation.

*I take note.*

*"I am at a loss for words," Professor Kindler, also from Munich, informs me when he learned about the planned radiation. The damage would be greater than the benefit, especially for the lungs. He wanted to congratulate me. I was lucky. And I should stay away from any other therapy.*

*I am at a loss for words.*

*I am sitting in bed, with my black-green notebook, my mind confused and fear in my heart. I*

## Mamazone – Women and Genomics against Breast Cancer

It was founded in Augsburg, Germany, in 1999, by breast cancer patients together with healthy women and supportive physicians. With a current membership of 500, spread across Germany, it aims to promote patient education, communication and active participation in the processes of science and research of the disease, through a number of initiatives:

- Mamazone recently launched the Patients' Tumourbank of Hope – the PATH Foundation – in Hannover. This is the first collection of tumour tissue in the world owned by cancer patients. Together with the operator of the bank, a specialized service provider, it offers women with breast cancer, but also other cancer patients, the chance to have their valuable tumour tissue cryopreserved and therefore fully useable in the future, especially in view of the expected molecular genetic diagnosis and therapy. Part of the tissue will be used as donations to research. This way, cancer patients can make an active and "living" contribution to the progress of research;
- each year, patients award the "Busenfreund", a patients' Prize for breast cancer researchers. Mamazone wants to encourage research trends in the big oncology market and highlight our preferences as consumers;
- Mamazone created the "Project Graduate Patient" – a training initiative for women with breast cancer. Breast cancer survivors, physicians, and researchers teach breast cancer patients how to become knowledgeable and therefore successful partners with their doctors;
- a Mamazone-mobile, containing educational tools, brings information about breast cancer to "orphaned places" where such information is not available.

These projects are models. Signals for better partnerships and patients' involvement in health care decisions.

They aim to give courage to other patients.

■ **You can find out more about Mamazone by visiting their website (in German) at [www.mamazone.de](http://www.mamazone.de).**

■ **The organisation can be contacted at:**

Mamazone, P.O. Box 310220, 86063 Augsburg, Germany,  
e-mail at [buero@mamazone.de](mailto:buero@mamazone.de),  
Tel.: +49 821 5213144; Fax: +49 821 5213143

■ **Ursula Goldmann-Posch can be contact at:**

Kornhausgasse 8, 86152 Augsburg, Germany,  
e-mail: [goldmann-posch@mamazone.de](mailto:goldmann-posch@mamazone.de),  
Tel.: +49 821 3494548; Fax: +49 821 5080318

**Ursula Goldmann-Posch  
in the mamazone office,  
with the computers  
for patients' internet  
research**



© DR





© DR

**Karoline Erdmann, 46, member of mamazone: with her program "mamatango" she wants to encourage women with breast cancer in the battle against the taboo**

*must digest this first, although there is actually no time for digestion. A decision must be made soon. Who should make it? Not me, the one-breasted patient, the weakest link. That's what happens when one is not satisfied with the first therapy recommendation. But I couldn't expect this many contradicting opinions regarding the post-treatment phase of my illness. I only wanted a confirmation. This is quite a mess. I am trapped. In the thicket of science where nothing seems to be clear-cut. I have entered the Garden of Eden of research and eaten from the fruit of knowledge because I absolutely wanted to know. Because I always want to know everything to the last detail.*

*Because this is my life and my death.*

*How naïve on my part to assume that doctors were always in agreement with each other.*

In such moments I wonder whether it was a mistake to learn about all the details of my illness. In such situations I would like to retreat to the shell of ignorance. In such moments I wonder whether knowledge is power or the lack thereof.

But I have no regrets for having chosen the path of knowledge.

Knowledge gives the patient a hint of power in a situation of complete powerlessness.

And this powerlessness hits each of us when the diagnosis "breast cancer" descends like lightning from a clear sky.

It was with great difficulty that I became an independent patient during my "cancer

career". I contradicted my doctors every now and then – that also boosts the immune system. I armoured myself with knowledge against an abyss of fear – like a protective shield. And in this painful way I almost automatically became a "graduate patient".

I wanted to question what was happening with me and my body. I wanted to look my arch enemy in the eye. And I wasn't afraid to visit my pathologist so that I could see my tumour tissue under the microscope.

This was a milestone on my way out of speechlessness. To tell my tumour: "Hi, I'm here. I am not afraid of you".

"I didn't expect you but you didn't expect me either."

Today the physician-patient relationship – thanks to the globalization of communication and information tools and other changes – is undergoing a fundamental transformation.

More and more patients are beginning to think for themselves, to speak up and to take part in the decision process – they are beginning to leave the role of victim behind and take an active role in quality control and therapy decisions.

And more and more physicians are beginning to understand that the willingness to communicate – especially for an illness based on a lack of communication between cells – is an important prerequisite for more progress in the battle against cancer.



© mamazone

**The first Busenfreund Award, 2001, given to Pr Axel Ullrich – the "father" of Herceptin**



**Elizabeth Hantkle, Ursula Goldmann-Posch and Elizabeth Glogger receiving the silver thistle award from the Augsburg Allgemeine regional newspaper**

Each woman with breast cancer can turn a piece of her experience, of her very personal cancer history, of her visions into a contribution to the community of people who are affected.

So we can give courage to one another.

The courage to fight for cancer therapies not on the basis of budgets but on the basis of quality of life and survival.

The courage to demand our basic right to the best possible treatment. Because quality of life is not enough. We want quality of survival.

The courage to be more honest with our doctors. We must learn how to be not only competent but sometimes also difficult partners.

It cannot be our goal to die as polite patients. But it can be our goal to survive as curious and demanding patients with breast cancer. 🌸

The physician's seemingly unlimited power and the patient's apparent powerlessness are changing into responsibility and emancipation on both sides. Until this change is completed, however, and until physicians and patients become real partners for life, the parties concerned must work hard.

### ***What can patients do to change things?***

Each patient needs to take their own small step forward. My personal contribution was helping to found Mamazone, and writing the book from which I have quoted, "The Lump Above My Heart". I wrote it to get rid of my fear. I wrote down everything that breast cancer patients and their doctors should know.



**Ursula Goldmann-Posch speaking at...**

The quotes are from Goldmann-Posch *Der Knoten über meinem Herzen. Brustkrebs darf kein Todesurteil sein: Therapien und andere Hilfen* (The Lump Above My Heart. Breast Cancer Must Not Be A Death Sentence: Therapies and Other Forms of Assistance), published by Karl Blessing, Munich, 416 pages.