

(NOGGO) NORD-OSTDEUTSCHE GESELLSCHAFT FÜR GYNÄKOLOGISCHE ONKOLOGIE

Germany



GLOBAL
OVARIAN
CANCER
CHARTER
a World Ovarian Cancer
Coalition initiative

“As a Champion, North-Eastern German Society of Gynecological Oncology (NOGGO) supports the Global Ovarian Cancer Charter and its efforts to improve opportunities to improve access to, and diversity of participants in clinical trials, so to improve outcomes for all women with ovarian cancer - no matter where they live. ”

NOGGO
e.V.



DATA IMPROVEMENT

Carolin meets Hanna
Studying Long Term
Survivors

..... CHARTER
CHAMPION

carolinmeetshanna.com

CHAMPION PROJECT: CAROLIN MEET HANNA - STUDYING LONG TERM SURVIVORS

Originating in Germany in 2015, this study was inspired by two women – Carolin Masur, a German opera singer diagnosed more than ten years ago, and sister Hanna, a Catholic nun who lived with the disease for more than eight years.

This global study aims to characterize long term survivors of ovarian cancer filling a very important data gap, that could potentially help other women in the future live longer with the disease. In addition to biological and immunological factors, it also examines patients' quality of life and resilience, and their lifestyle including diet, physical activity and sleep. Basic data such as age at first diagnosis, received therapies, comorbidities, comedications, social network, beliefs and education are collected. It has already published a number of papers, and recently showcased how fatigue impacts on women who have survived long term, and how important it is to manage it effectively.

Originally women could participate if they had a diagnosis over 8 years ago, but this has now been brought down to women diagnosed over 5 years ago. The study involves more than 1000 women from 19 countries but is open to women all over the world. For the 200 women who live within accessible distance of Berlin, they are regularly examined and assessed physically and asked about their state of health. Very recently the study has received some €4million from the German Ministry of Health to start a long-term survivor clinic.

In addition to the study, women have the opportunity to train as potential mentors for other women, and to be featured in an exhibition of photographic portraits. Some of their stories are also shared in newsletters or on the website. Women are still able to join in the study.

We chose to showcase this programme because it is focused on a previously understudied but very important area. It demonstrates the impact Carolin and Hanna had on their clinician – Jalid Sehouli, director of the European Competence for Ovarian Cancer at Charité University of Berlin who set up the study. It is very clearly inspired by women, and listens closely to their experiences and concerns, yet also provides opportunities for celebration and engagement. The creative blend of women's experience and scientific rigour has also been very successful in attracting major government backing.

Although this project is initiated and legally owned by NOGGO and the Charité University of Berlin, it also involved the Gynaecology Cancer Inter Group (GCIg) and ENGOT, enabling widespread participation. It receives funding from the German Ovarian Cancer Foundation.

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