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# Overcoming Breast Cancer

*A network for breast cancer patients and survivors*



Mari Helenedatter Aarbakke  
KUN Senter for kunnskap og likestilling



Senter for kunnskap  
og likestilling

[www.kun.nl.no](http://www.kun.nl.no)



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## Background

In 2012, we collaborated with the Russian organization Socium + to implement psychosocial activities for breast cancer patients in the Oncological Hospital in Murmansk – by model of activities within the Norwegian Cancer Society. We found the structure rather complicated, and wished we had collaborated directly with the hospital instead of through an organization. We thought it would have been good for both the economy and the sustainability of the project. In October 2012 we applied for a continuation of our project, as we felt we needed to do more to sustain the project. However, the climate for collaboration worsened as the year drew to a close.

Through the project leaders' conference in Lillestrøm in December 2012, we were offered to be connected with the hospital in Arkhangelsk. They were said to be very professional, and eager to participate in these kinds of projects. We therefore asked that our application for continuation in Murmansk instead was turned into a fresh start in Arkhangelsk with the same activities as we had already implemented in Murmansk. The revised application, which is attached in this report, was accepted by the Ministry of Health and Care Services in June 2013.

## Project activities

This project had its' vantage point in the psychosocial activities and holistic patient care that the Norwegian Cancer Society and Norwegian hospitals collaborate on. The project aimed to implement some of these activities in the Oncological Hospital in Arkhangelsk, mainly by means of voluntary work. At the same time, the project enabled medical personnel from both Tromsø and Arkhangelsk to exchange knowledge and practices in this field.

The project activities were:

- One seminar with health workers from both Arkhangelsk and Tromsø. The seminar encouraged discussions about holistic treatment for patients – taking into consideration both the physical and psychosocial aspects of their disease, treatment and healing. The seminar included three radiographers, one physiotherapist/lymphedema therapist, and one oncological nurse. Participants from Arkhangelsk included two professors and surgeons, and 15 nurses.
- The visitor's service that we created in Murmansk was also introduced in Arkhangelsk. The Association for Gynecological Cancer once again agreed to provide training for former breast cancer patients who will work as volunteers and visit current patients.
- The translation and making of brochures.

## Commitment of the partners

This project had four main partners.

KUN Center for Gender Equality represented by Mari Helenedatter Aarbakke was the project leader, and administrated everything regarding applications and finances, travel arrangements and the general overview of the project.

Arkhangelsk Regional Nursing Association was the Russian partner in the project. We were set into contact with them through former member Raisa Grosheva who now lives in Sweden. Lead by director Anna Andreeva, the nurses ensured good communications with the management, staff and patients of the Arkhangelsk Regional Oncological Hospital. They also recruited all of the volunteers, and made all the logistical arrangements for the seminar, such as location, interpreters and catering. They naturally took part in the dialogue about what the program of the seminar should contain, and invited all relevant parties in the hospital to participate. They held well-prepared presentations and lectures, and were very generous and welcoming hosts for the seminar and the travelers from Norway.

The Breast Diagnostic Center underlying the University Hospital of Northern Norway has been an invaluable third partner in this project. Radiographer Anna Vlasenko Dahl comes from St.Petersburg, lives in Tromsø, and is very passionate about this project. She was a major contributor in the project in Murmansk in 2012, and has contributed as strongly this time. She has written countless e-mails to ensure good communications between all parties, and she arranged for us to bring with us breast prosthetics donated by the Norwegian Breast Cancer Society. Helga Parr had taken the initiative to make a brochure, and all of the participants from BDS had prepared very good presentations for the seminar. This project could not have taken place without the generosity and interest of the management of BDS, with Rica Gueco Mortensen and Tina Blix Mortensen providing us with so much of the employees' time.

The Norwegian Gynecological Society represented by leader Jeanette Hoel and co-worker Turid Andersen, has generously provided the project with their time and their knowledge on voluntary peer work and building a patients' organization.

## Implementation

In the attached program of the seminar, there is detailed information about the contents of the two seminars. All seminar and volunteers' course attendants were given certificates of participation. The certificates are shown in the final pages of this report.

### Seminar for health workers

The seminar for health workers was held in a beautiful auditorium within the oncological hospital in Arkhangelsk. It was opened by the the regional minister of health care Larisa Men'shikova, the director of the hospital Andrey Krasil'nikov, the leader of the breast cancer foundation the White Rose, Tatyana Orlova, and the project leader at KUN, Mari Aarbakke.

The seminar enabled discussions about screening, sentinel node surgery, breast preservative surgery, radiation therapy, lymphedema therapy, information to patients, and many other aspects of cancer treatment and patient care. Both parties felt that these conversations were interesting and necessary for finding common ground to build further collaboration on.

Helga Parr is a physiotherapist with a specialization in treatment of lymphedema. She held a course about treatment of scar tissue and lymphedema that was open to everyone in the hospital. Almost 50 people crammed into the room to listen to her lecture; patients, nurses and doctors. She had brought a lot of medical gear with her from Norway, both support bandages for legs and arms, measuring tape and creams. She was asked by many patients to write autographs in her brochure afterwards, and her knowledge and approach to the audience was praised by many.

### Volunteers' course

The volunteer's course was conducted by leader Jeanette Hoel and co-worker Turid Andersen in Gynkreftforeningen – The Norwegian Gynecological Cancer Society. The course itself was an example of how the entire Society is based on voluntary work, as neither would accept payment for their work. Hoel and Andersen are skilled and experienced in giving this type of course, and they encouraged an interactive form of course, and an openhearted dialogue. There were 10 participants in the course, including three nurses. One of the nurses was a breast cancer survivor, the other two were there to listen and learn. We had expressly wanted all participants to have finished all treatment and have the necessary distance to their own illness, but this was not the case for all participants. The recruitment work has been one of the most challenging activities, because it is difficult to engage former patients in Russia.

The course started with everyone presenting themselves and talking about their diagnosis. Some said they speak openly about their disease, and others said only their families knew. Some said they even hid the truth from their families. As a group, they seemed somewhat reserved against committing to a group of volunteers. They seemed to depend on the hospital staff and the patient school that is organized through the nurses to provide an offer. They liked the idea of gathering as a group and doing different activities together, such as visiting a swimming pool. However, the thought of organizing anything themselves without staff involvement seemed very foreign to them. This model of organization is perhaps uncommon in Russia. It may also have been affected by the attendance of three nurses in the course, making them lean on their resources in stead of their own. The course would probably also have profited from lasting more than two days, where it could have been filled with more group work and practical tasks.

The demand for more knowledge and information as patients became evident in questions like “Can one think away the cancer?” and “Is cancer dangerous?”. The support for alternative medicine is also strong within this group, and not by means of complementary treatment, but as an alternative to medical treatment.

## **Results and dissemination**

Through this project we intended to translate or produce one or more brochures with accessible information to patients about their new situation. Anna Dahl at the Breast Diagnostic Center suggested several brochures that already are in use in Norway, but the Russian partners did not think they were transferable to a Russian context. Instead, they began the process of making a brochure themselves. This proved to be time-demanding, and the editing and testing will still take a while. Therefore, we have not financed a brochure in this project. However, Norwegian physiotherapist Helga Parr had a brochure made in Russian for just this occasion; with post-operative exercises to reduce symptoms of scar tissue and lymphedema. This brochure was distributed during Helga’s presentation, and more than a hundred copies ran out fast. There is little or no information given to patients about how they can ease symptoms of lymphedema and other side effects to the operations, so the brochure was very welcome.

Both the volunteers’ course and the health workers’ seminar offered good discussions and exchange of important knowledge. At the end of the seminar, all participants from Norway and the local nurses in charge of the seminar were invited to meet the director of the hospital in his office. We were encouraged to share the results of the seminars with him. The meeting was very positive and both parties expressed gratitude that the seminar had taken place. Both parties also felt that this should only mark the beginning of our collaboration. The director ensured that he would make room for a volunteer organization so that they could meet and be active within the hospital. It was bravely proposed by the Nurses’ Association (ARNA) that nurses should be able to spend more time with each patient, to ensure a holistic, high-quality patient care. The director did not give any promises regarding this question, but many said afterwards that it was a big step forward just to be able to discuss this concern with him. Helga Parr criticized the hospital rather sharply for neither offering lymph-preserving surgery nor lymphedema treatment. The director thanked her for her open hearted concern and advice, and gave her a book to say thank you. He supported what the surgeons had said earlier about starting up sentinel node surgery in the following year.

In the evening of our second day in Arkhangelsk, we were invited to the grand opening of the new treatment center of the womens’ health foundation The White Rose. The center will offer free breast screening and gynecological consultations for the public. In speeches given both there and in the opening of our seminar, we tried to point out the important roles of nurses, a holistic approach to treatment and how volunteer work can offer something special in terms of psychosocial rehabilitation.



## **Sustainability**

The health workers participating in this project see a lot of subjects that are interesting to pursue in a future collaboration. The three most important fields are prophylaxis and treatment of lymphedema, improving the quality of diagnostic images in mammography, and deeper discussions about how oncological nurses work to include the patients in their treatment and healing.

The volunteers from the Norwegian Gynecological Cancer Society see the need to support the volunteers in forming an organization, and provide more training for them.

There is however no current agreement as to whether the project should continue in 2014. Since the initiative to start this project came from the Norwegian side, we have agreed that the initiative to continue the project should come from the Russian side.

We are hoping to enter an application for continuation this spring.

## **Acknowledgments**

In addition to the invaluable contributions of our partners and seminar participants, we would like to thank the following contributors to this project:

The Norwegian Breast Cancer Society through Marianne Marhaug and bandage shop Medi-Nor in Tromsø for providing us with many free high-quality breast prosthetics. They were deeply appreciated by the patients in Arkhangelsk.

Magne Johnsen, advisor to the management of the University Hospital of North Norway (UNN), for supporting Helga Parr's initiative to make the brochure on lymphedema and patient exercises. Thank you also to Svetlana Manankova Bye for translating and Geir Guttormsen at UNN's own printing office for printing.

Rolf Davidsen in MEDI Norway AS for providing Helga Parr with many compression bandages, creams, measuring tapes and other medical gear for the treatment of lymphedema, that she could give away after her lecture on the topic.

The Norwegian Cancer Society for providing us with discounted pink ribbon-pins and reflectors to give away during the seminar.

## Attachments

### Schedule of Seminars, 27th and 28th of November in Arkhangelsk.

<b>Wednesday 27<sup>th</sup> of November</b>	<b>Seminar for health workers</b>	<b>Course for volunteers</b>
10:00 – 12:00	Welcome. Tour of the Hospital – We learn about cancer patient care in Arkhangelsk.	Welcome. Tour of the hospital – We learn about cancer patient care in Arkhangelsk.
<b>12:00 – 13:00</b>	<b>Lunch</b>	<b>Lunch</b>
13:00 – 14:30	Radiographer Sonja Stormo presents the screening program and radiographer Anna Vlasenko presents the Breast Diagnostic Center (BDS). She also talks about the work of the Norwegian Cancer Society.	Introduction to the course for volunteers – What is the idea of voluntary work between former and current cancer patients? How we work in Norway. What you will learn in this course.
<b>14:30 – 14:45</b>	<b>Coffee break</b>	<b>Coffee break</b>
14:45 – 16:00	Physiotherapist Helga Parr gives a presentation on how she treats the side effects of treatment, such as scar tissue and lymphoedema.	We take part in the seminar for this session. Physiotherapist Helga Parr shows how she works with breast cancer patients with regards to scar tissue and lymphoedema.

<b>Thursday 28<sup>th</sup> of November</b>	<b>Seminar for health workers</b>	<b>Course for volunteers</b>
10:00 – 11:00	Professor Mikhail Valkov presents overall approaches to treatment in AROCC.	The tools of volunteer work with cancer patients
11:00 – 12:00	Nurse Ruth Selseth gives a presentation on how nurses work with cancer treatment at BDS	How to give hope and strength to patients
<b>12:00 – 13:00</b>	<b>Lunch</b>	<b>Lunch</b>
13:00 – 14:00	Professor Mikhail Levit gives a presentation on activity in the cancer patient school in Arkhangelsk	Know your limits when you are a volunteer
<b>14:00 – 14:15</b>	<b>Coffee break</b>	<b>Coffee break</b>
14:15 – 15:30	Radiographer Linda Hansen talks about patient care in radiation therapy.	Ideas for voluntary work – how to organize activities for patients and volunteers.
15:30 – 16:00	Summary. What have we learned from each other? How do we put this new knowledge to use?	How to make an organization for the volunteers and patients? How to put what you have learned into practice?
16:00- 16:30		Anna Vlasenko will present gifts from the Norwegian Cancer Society and Breast Cancer Society: Prosthetics, pins of the pink ribbon etc.

## Certificate for health workers

### ***Certificate of participation***

*in*

### **Seminar for Health Workers in Arkhangelsk 27<sup>th</sup> -28<sup>th</sup> of November, 2013.**

This certificate confirms that \_\_\_\_\_ has participated in this two-day seminar in Arkhangelsk, for health workers from Arkhangelsk, Russia, and Tromsø, Norway.

The focus of the seminar has been to exchange knowledge and experience in cancer patient care, with a special focus on breast cancer. A holistic perspective on patient care includes the psychosocial aspects of illness and treatment. This seminar has debated the measures and considerations that health workers must take to defend this perspective.

This certificate is authorized by

Mari Helenedatter Aarbakke

Project manager

KUN Center for Gender Equality

## Certificate for volunteers

### ***Certificate of participation***

*in*

### **Seminar for Volunteers in Arkhangelsk 27<sup>th</sup> -28<sup>th</sup> of November, 2013.**

This certificate confirms that \_\_\_\_\_ has participated in this two-day seminar in Arkhangelsk, for volunteers who wish to contribute to cancer patient care in Arkhangelsk.

The focus of the seminar has been to provide knowledge about how a volunteer's efforts can have a major impact on the hope, spirit and mental health of a patient. Meeting on equal terms is one of the keys to helping someone through illness.

The Gynecological Cancer Society of Norway has shared their experience on how to run a voluntary organization, and create a sense of positive community between cancer patients.

This certificate is authorized by

Mari Helenedatter Aarbakke

Project manager

KUN Center for Gender Equality

Jeanette Hoel

Director

The Gynecological Cancer Society



KUN

Senter for kunnskap og likestilling  
N-8286 Nordfold

Kunnskapsparken  
Jakob Weidemannsgate 9  
N-7713 Steinkjer

Telefon 75 77 90 50  
Faks 75 77 90 70

[post@kun.nl.no](mailto:post@kun.nl.no)



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[www.kun.nl.no](http://www.kun.nl.no)