



Please return this copy to NAFKAM.  
Thank you!

## INFORMATION ABOUT THE REGISTRY OF EXCEPTIONAL COURSES OF DISEASE

The Registry of Exceptional Courses of Disease is a permanent registry run by the National Research Center in Complementary and Alternative Medicine (NAFKAM), UiT The Arctic University of Norway. NAFKAM is funded by the Ministry of Health and Care Services.

The purpose of this registry is to provide a systematic collection of patient experiences related to complementary and alternative (CAM) treatments that constitutes a basis for research.

We register good as well as bad courses of disease related to the use of CAM therapies. By “an exceptionally good course of disease” we mean that the patient is experiencing full recovery or symptoms disappearing or becoming weaker and/or fewer. By “an exceptionally bad course of disease” we mean that the patient is experiencing an increase in the number of symptoms or in the intensity of the symptoms.

### REGISTRATION

The registration papers that you have received consist of a registration form and informed consent. You are asked to provide personal and contact information and a description of your exceptional course of disease, including the use of conventional medicine and CAM therapies. After completion, the forms are to be returned to NAFKAM in the enclosed prepaid return envelope.

### ETHICS, DATA PROTECTION, AND SECURITY

The registry is given a license by the Data Inspectorate and has been recommended by the Regional Committee for Medical Research Ethics. All information provided in connection with the registry is confidential, and written materials are kept locked-in. Persons working with the collected data observe professional secrecy.

Personally identifiable data are kept locked-in in fireproof filing cabinets and in a secure database. The data controller for the registry is UiT The Arctic University of Norway, Department of Community Medicine.

When your course of disease is included in the registry, NAFKAM may, based on your written personal consent, collect confidential information from medical records and records/reports from CAM practitioners. Cancer and MS-courses and possibly courses of disease related to other diagnoses included in the registry are reviewed by a physician affiliated with NAFKAM. Some of these courses of disease will also be assessed by external specialists. All medical assessments are performed on de-identified material. This means that those who make the medical assessments cannot link the material to you as a person. You will get feedback about any medical assessment of your course of disease if you ask for it.

Interested researchers can apply for access to the registry data in an anonymized form. This means that all information relating to you as a person is removed prior to the data being delivered. Participants in the registry can be contacted by NAFKAM with an inquiry about participation in research projects or other activities associated with the registry. Research based on the registry requires new applications to the Regional Committee for Medical Research Ethics and/or the Data Inspectorate. Participants in the registry can, without giving any reason, refuse requests they might receive.

Participation in the registry is voluntary and you may at any time and without justification withdraw from the registry. The information you have submitted will then be anonymized. Your data will no longer be linked to you as a person, and your data will not be included in new research projects or reports from the registry. If you withdraw your consent, this will not affect your future treatments.

Those responsible for the registry have no financial interest in the registry, and there is no insurance for participants. Participation in the registry does not imply that NAFKAM provides any kind of health care. If you agree to participate in the registry, you have the right to have access to the information registered about you. You also have the right to correct any errors in the information that is recorded. The registry will not be of direct benefit to the individual who contributes to the registry.

If you do not wish to participate in the registry, you do not need to return this consent form.

Kind regards

Anita Salamonsen PhD  
Chairman of the Steering group of  
the Registry of exceptional courses of disease

Brit J. Drageset  
Manager of the Registry of  
exceptional courses of disease

### **Kontaktinformasjon**

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Tel.: +47 77 64 66 50, Fax: +47 77 64 68 66  
E-mail: resf@helsefak.uit.no, Web site: www.nafkam.no

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## **CONSENT**

\_\_\_\_\_  
Name

\_\_\_\_\_  
Date of birth

I confirm having read or been explained "Information about the Registry of Exceptional Courses of Disease" and I give my consent to participating in the registry. I also agree to be contacted by NAFKAM with possible inquiries about participation in research projects or other activities related to the registry. I am aware that when my course of disease has been registered, NAFKAM may, based on my written personal consent, collect confidential information from medical records and records/reports from CAM practitioners.

yes

\_\_\_\_\_  
Place and date

\_\_\_\_\_  
Signature

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yes

\_\_\_\_\_  
Place and date

\_\_\_\_\_  
Signature

**Participant’s copy.**