

## Purpose of RESF

At NAFKAM we have given priority to the establishment of this registry. We think it is important for patients and their relatives, health personnel, and health authorities that there is an agency collecting patients' knowledge and experience with diseases that do not develop according to the textbook of conventional medicine.

The registry constitutes a foundation that can contribute to explaining which factors influence exceptional courses of disease. This may make it easier for patients and treatment providers to choose treatments based on knowledge.

## We want to get in touch with

- Persons who have experienced exceptionally good or bad courses of disease.
- Relatives of persons who have experienced exceptionally good or bad courses of disease.
- Alternative treatment providers who have experienced patients with an exceptionally good or bad course of disease.
- Medical doctors and others within the public health services who have met patients with exceptionally good or bad courses of disease.

## Information from the Registry

The registry provides annual reports at NAFKAM's web site. The annual reports may also be obtained by contacting NAFKAM.

## Who are we?

The National Research Center in Complementary and Alternative Medicine (NAFKAM) is responsible for research, guidance, teaching, and research dissemination within alternative treatment in Norway. The Center is funded by the Ministry of Health and Care Services. One of NAFKAM's tasks is to run The Exceptional Patient History Registry.

## Contact Information

### NAFKAM

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Tell us about  
an exceptional course of disease

Foto: Trym Ivar Bergsmo

# We need you to share your experience with alternative treatments!

## Contact us if:

you have a chronic disease like cancer, multiple sclerosis, asthma, allergy, migraine, rheumatism, chronic fatigue syndrome, etc.,

and

you have experienced unusual treatment results after the use of alternative treatment,

and

you had a confirmed diagnosis before you started the alternative treatment which gave you the unusual treatment results.



## An exceptional course of disease

is one where you have achieved other results after the use of alternative treatment than after the use of conventional medicine. The development of the disease may either have been exceptionally good or exceptionally bad.

An exceptionally good course of disease may for instance be disappearance of symptoms after a period of time, or complete healing, or experiencing that the symptoms of the disease have been considerably alleviated after the use of alternative treatment. An exceptionally bad course of disease may be a worsening of the disease because of the use of alternative treatment, or that the alternative treatment provider has advised you to stop using an important medication without consulting your doctor, or that an alternative treatment provider has recommended you not to see a medical doctor when this was needed.



## Alternative treatment is

a wide concept with many different definitions. In this project we include all initiatives that the patient him/herself defines as alternative in relation to the public health service. It could include both self-treatment, and visiting a treatment provider. Some examples are, acupuncture, reflexology, homeopathy, massage, mental practices, religious healing, other types of healing, and special herbs, etc.



## Registry of Exceptional Courses of Disease

The National Research Center in Complementary and Alternative Medicine (NAFKAM) has established a registry of courses of disease involving the use of alternative treatment modalities. We have chosen to call these unusual case histories 'exceptional'. When we use the word exceptional, it is in relation to what is usual within conventional medicine.

NAFKAM is collaborating with patient organizations in Scandinavia, and case histories from Denmark, Norway, and Sweden are being registered.



## Procedures for registration and evaluation of exceptional courses of disease

If you as a patient, relative, or treatment provider would like to tell about an unusual course of disease, NAFKAM can be contacted by telephone, letter, web registration or e-mail. We ask you to briefly say something about the type of disease and the results experienced when using alternative treatment. The project coordinator will check if the criteria for participation in the registry are met. More information may be asked for in order to make a decision. This usually happens by the coordinator calling the person who has made the initial contact.

If the course of disease meets the criteria for inclusion in the registry, the patient will receive information, a registration form (contact information, personal information, disease history, conventional medical treatment, alternative treatment, self evaluation) and a patient consent form. The papers are to be filled in, signed and returned to NAFKAM in a pre-stamped envelope.

When NAFKAM has received the registration form and the patient consent form, a request for medical records will be sent to the doctors, hospitals and alternative treatment providers registered by the patient.

For information about deceased persons, the Directorate of Health has allowed exemption from professional nondisclosure. Data regarding deceased persons may therefore be collected from hospitals, the Cancer Registry, and the Registry of Cause of Death, even though no consent can be given.

A doctor employed by NAFKAM receives all the materials gathered for each participant and undertakes the medical assessment.

Some patient histories will also be assessed by external experts who are not affiliated with NAFKAM. The courses of disease presented to alternative treatment providers and external experts will be made anonymous.

The courses of disease will end up in three categories:

“Medically exceptional courses of disease”

“Possible medically exceptional courses of disease”

“Not medically exceptional courses of disease”

All courses of disease that are registered, no matter in what category they end up, may be used for research purposes. For researchers outside NAFKAM the material will be made anonymous. NAFKAM will communicate inquiries from researchers to patients.