



For those who have ALK-positive lung cancer

Causes, symptoms, treatment and research

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ALK-positive lung cancer

Lung cancer is the world's most common cancer disease and can affect anyone. Each year, 1.5 million people are diagnosed with lung cancer. In Norway, more than 3,000 people are affected by lung cancer yearly, which makes it the third most common form of cancer, and lung cancer accounts for about 10 per cent of all new cancer cases in Norway.



Malignant tumours originating in the cells of the lung tissue are referred to as lung cancer. Lung cancer can develop in all parts of the lungs, but it most often appears in the lung's upper lobe.

Small cell and non-small cell lung cancer

Lung cancer is roughly divided into two types, small cell and non-small cell. Non-small cell lung cancer is the most frequent, accounting for around 85 per cent of cases. Small cell lung cancer is the most aggressive type of lung cancer as it often spreads quickly to other organs, and accounts for about 15 per cent of lung cancer cases.

Non-small cell cancer is divided into two main groups, based on the original cell where it arose:

- Squamous cell carcinoma: A tumour originating in the skin/mucous membranes. The tumour often grows in a central area in relation to the large bronchial branches. This is the second most common form of lung cancer.
- Adenocarcinoma: A tumour that originates in a gland. The tumour often grows on the outer edges of the lung. This is the most common type of lung cancer, and the type that is becoming more prevalent.
- Large cell carcinoma: These cancer cells are large and show no specific microscopic features.

ALK-positive gene and ALK-positive lung cancer

Around 2 to 5 per cent of patients with adenocarcinoma of the lungs have a genetic mutation called ALK in their cancer cells. ALK stands for anaplastic lymphoma kinase. Genetic mutations involving the ALK gene appears to be more frequent among younger non-smokers with an advanced stage disease, but it can occur at any age and also among smokers. These genetic mutations are only found in cancer cells, and patients with this type of cancer must be treated with targeted therapy.

Facts about the ALK gene

Genetic alterations (mutations) linked to lung cancer generally arise during a person's lifetime. This is the case with ALK-positive lung cancer. Genetic mutations occurring during a lifetime are referred to as somatic mutations. This type of mutation is not hereditary*, which means that there is no predisposition to the disease in the family. Somatic genetic mutations may be caused by environmental factors, but they often occur spontaneously without any evident cause.

Chromosomes contain genes, and each gene in the body contains information needed to form proteins. Proteins have special tasks and functions in the body. The ALK gene controls the production of the ALK receptor tyrosine kinase, a protein that is part of the signalling pathway controlling cell growth and cell division.

ALK-positive lung cancer* occurs when parts of the ALK gene are damaged and bind to another gene, which in turn results in a fusion of these two genes. This is sometimes referred to as a rearrangement or translocation.*

A genetic mutation of this type halts the signal that would normally have told cells to stop growing. This causes uncontrolled cell division, which results in the development of a tumour.

* You can find more information on the terminology page

Symptoms

The most common symptoms of lung cancer are coughing and shortness of breath, but these symptoms are also common for many other diseases. In lung cancer, the symptoms do not improve over time. It is therefore important to see a doctor if coughing and shortness of breath last longer than what is common for a respiratory infection.

Possible symptoms of lung cancer:

- Cough, especially a persistent dry cough that suddenly changes
- Shortness of breath
- Bronchitis or a cold that does not improve, even with antibiotics
- Repeated respiratory infections
- Wheezing or feeling out of breath
- Hoarseness and trouble swallowing
- Coughing up blood
- General weakness and fatigue
- Significant weight loss for no apparent reason
- Pain in the chest and upper part of the abdomen, headache, dizziness, and trouble swallowing may be signs of metastases (the spread of cancer cells). Spreading to the bones may result in pain and fractures. A referral for an x-ray would be necessary for such symptoms affecting the arms, legs or back. If the x-ray indicates lung cancer, the patient will be referred to a specialist.



Patient care pathway

A standard patient care pathway describes how assessment, treatment, communication and dialogue with the patient and family members, distribution of responsibilities, and specific trajectory schedules are all organised. The purpose of a patient care pathway is to ensure that cancer patients receive a well-organised, comprehensive and predictable trajectory without unnecessary delays in assessment, diagnostics, treatment and rehabilitation. Among other things, a patient care pathway for lung cancer ensures that all hospitals treating lung cancer will have regular decision-making meetings with a multidisciplinary team (MDT) to ensure quality assurance of assessments and treatments. Participants in meetings for assessing lung surgery should include pulmonologists, thoracic surgeons(), nuclear medicine radiologists, and patient care pathway coordinators.

A patient care pathway has been designed for diagnostics, treatment and follow-up of lung cancer. See www.helsedirektoratet.no for more information on patient care pathways.



Assessment

If the patient is diagnosed with lung cancer, doctors will try to determine the stage of the disease. The stage tells us how advanced the disease is, whether it has spread, and how it should be treated. It is generally easier to cure lung cancer when the disease is detected early.

The assessment should lead to a choice of treatment based on the diagnosis of the type of lung cancer, the location of the tumour and its extent, as well as the patient's level of function.

Methods used to determine the diagnosis will vary depending on the case. The patient's general physical condition, medical history and other diseases will affect both the assessment and choice of treatment.

How is lung cancer diagnosed?

Step 1 involves radiological examinations. A CT scan of the lungs and abdomen is essential. Afterwards, the pulmonologist will determine whether to also perform a PET-CT scan or MRI scan of the brain and/or the bones.

- X-ray of the lungs
- A chest x-ray may lead the doctor to suspect a tumour.
- CT scan of the lungs and abdomen
- With the aid of a CT scan, doctors can get a very accurate picture of the size, location and spread of the tumour as well as possible spreading to other organs.
- MRI of the brain and bones An MRI scan provides precise images with the use of a powerful magnetic field.
- PET scan: A PET scan produces images of tumours and metastases. Before the examination, the patient is given a weak radioactive glucose solution. During the examination, the patient is slowly led through a scanner where images are taken of their entire body. Cancer cells need a large supply of energy and have a high rate of metabolism, so the glucose collects in these cells. It is easier to see the affected tissue on these images through the glucose solution.

Step 2: Tissue or cells samples are taken from the tumour for biopsy to determine whether they are benign or malignant, and if possible to identify the type of tumour.

- Tissue samples can be taken from different parts of the body. The choice of the source of samples and the method of taking samples will vary according to the patient.

- **Bronchoscopy:** During a bronchoscopy, the doctor guides a bronchoscope, which is a flexible tube about the thickness of a pencil, through the patient's nose or mouth down through the trachea and into the bronchi and its branches. The aim of the bronchoscopy is to determine the extent of the tumour and to take tissue samples with a small forceps or to take cell samples with small brush.
- **EBUS:** An endobronchial ultrasound examination (EBUS) combines a bronchoscopy and an ultrasound. The doctor inserts an ultrasound probe at the end of a bronchoscope tube, and then takes tissue samples.
- **A CT- or ultrasound-guided tissue biopsy from the lung or metastases.** The doctor will take a sample of the tumour tissue using a thin needle that is inserted through the skin.
- **Ultrasound:** With the aid of an ultrasound, the doctor can take samples of fluid in the pleural sac of the lung (pleural effusion) through the chest wall.

Biomarker test:

Tumour cells from all patients with non-small cell lung cancer are tested for various mutations and biomarkers (PD-L1 expression that is important for immunotherapy, and genetic mutations such as EGFR, ALK, ROS1, etc.). Tissue or cell samples are analysed in a laboratory that specialises in pathology. When such genetic mutations are detected, specialised, targeted therapies can be initiated to attack a specific characteristic of the tumour.

Patients diagnosed with ALK-positive lung cancer will often already have an advanced disease at the time of diagnosis. Many patients who are diagnosed in earlier stages are accidentally diagnosed after having a chest CT scan for other reasons.

It is important to keep in mind that there are several treatment options that can slow down or stop the spread of ALK-positive lung cancer.

Further assessment

Heart and lung function tests can provide important information prior to other treatment, such as surgery.

Checklist for consultations on diagnosis and treatment

Once you have undergone the initial examinations and been diagnosed with lung cancer, it is a good idea to bring a checklist along to a consultation with your doctor. Make sure to have everything explained to you as precisely as possible so that you can better understand the findings and consequences. We have collected a few tips for the checklist:

Questions about the diagnosis:

- Is the diagnosis certain or are there still uncertainties?
- Where exactly is the tumour located?
- How large is the tumour?
- What is the stage of the disease? Localised, locally advanced or extensive?
- Has the tumour spread outside the lungs?
- Should I have more tests done to confirm the diagnosis?

Questions about treatment:

- What is the prognosis?
- Which examinations and measures should I expect going forward?
- Should I be treated at a clinic or a hospital specialising in lung cancer?



Causes and risk factors associated with ALK-positive lung cancer are unknown

Genetic mutations leading to the lung cancer may be caused by environmental factors, such as smoking, but they often occur spontaneously without any evident cause.

Certain people have a higher probability of ALK mutations than others:

- Younger people (age 55 and under)
- Non-smokers
- Women
- People with East Asian ethnicity

ALK-positive lung cancer and the brain

Sometimes cancer spreads from one part of the body to another. Lung cancer may, for instance, spread to the brain. This would still be lung cancer, however, so we refer to it as “brain metastases”. All types of cancer can spread to the brain, but this occurs more often in certain types, such as ALK-positive lung cancer. Some patients experience symptoms of brain metastases, while others do not.

Cancer that has spread to the brain may cause symptoms such as:

Headache, muscle weakness, nausea, mood swings, behavioural changes, seizures, difficulties with coordination, fatigue, or problems with reading or speaking.

Contact your doctor immediately if you experience many of these symptoms.

Treatment

There are several treatment options for patients who have ALK-positive lung cancer. You may be offered surgery, traditional cancer treatments such as radiotherapy and chemotherapy as well as drugs targeting your type of cancer. You should discuss the different options with your doctor. The treatment selected largely depends on the stage of the disease, as well as the age and general condition of the patient.

Several drugs have been specially developed to attack the gene mutation that is the cause of your type of cancer.

Patients with lung cancer are discussed at multidisciplinary team meetings (MTD).

Surgery or radiotherapy may cure early stage lung cancer (localised and locally advanced). Chemotherapy alone is not curative, but it can increase the possibility of a cure when provided together with surgery and/or radiotherapy.

Surgery

Surgery with a curative aim can be a treatment option in earlier stages of lung cancer. Surgical removal of tumour tissue in the lungs is done with the intent of curing the patient. Surgery for lung cancer is a good option if the tumour can be removed completely as possible. This treatment option is only used if the tumour is still limited to one area. Other measures may be implemented before surgery. At the first checkup after surgery (approx. 1 1/2 months), the doctor will determine whether there is a need for additional treatment, such as chemotherapy, immunotherapy or radiotherapy.

Radiotherapy for localised lung cancer.

Radiotherapy is used to damage the DNA of the irradiated cells, thus killing the cells. There are two types of radiotherapy with a curative aim. Stereotactic radiotherapy is a very precise, targeted and high dose of radiation that is administered a few times, 3-8 treatments approx. every other day.

Fractionated radiotherapy consists of many (approx. 33) smaller doses of radiation administered 5 days a week with a break on weekends.

If the patient is too weak to tolerate the two above-mentioned radiotherapies but is still in good shape with a good general physical condition, it may be determined to administer a few doses to keep the disease in check. This will be decided in consultation with the patient.

Radiotherapy combined with chemotherapy for locally advanced cancer (spreading to the lymph nodes between the lungs)

Combined chemotherapy and radiotherapy is given with a curative aim. The patient is given many (approx. 33) smaller doses of radiation administered 5 days a week with a break on weekends. In addition, two courses of chemotherapy are administered, one at the start and one at the end of the treatment. If the patient has PD-L1 above 1 %, they can receive immunotherapy for one year afterwards.

Treatment of metastases

Radiotherapy can be used to stop the growth of metastases. Such radiotherapy may include stereotactic radiotherapy that provides a very precise, targeted and high dose of radiation, or a fractionated, flat dose. The type of radiotherapy is determined partly by the location of the tumour. Radiotherapy is often administered parallel to drug therapy.

Brain metastases can be treated with surgery and stereotactic radiotherapy directed at a certain area or the entire brain.

Radiotherapy of bone metastases can provide effective pain relief.

Drug therapy

Targeted therapy – ALK inhibitors

First-line targeted therapy (therapy that is administered first) is the standard treatment for ALK-positive, non-small cell lung cancer with metastases. Some patients will also benefit from second-line targeted therapy (therapy recommended for treating a disease that has progressed during first-line therapy), or therapy in subsequent lines. The choice of second-line treatment will depend on previously administered therapy.

The ALK gene mutation in lung cancer was discovered in 2007. ALK-inhibitors, also known as tyrosine kinase inhibitors (TKI) or protein kinase inhibitors, inhibit the activity of the protein ALK receptor tyrosine kinase, thereby inhibiting tumour growth. ALK inhibitors are taken daily in the form of tablets or capsules.

Several drugs that are specifically aimed at inhibiting ALK are currently under development. Various ALK inhibitors can be given as first-line or later line treatments, depending on the existing data.

Regardless of what targeted therapy you receive, you will undergo radiological examinations and take blood tests taken before and during your treatment to monitor the effect

and blood cell levels, and to check if your liver and kidneys are functioning properly.

Your doctor will explain how to take the ALK inhibitors – how many times a day, with or without meals, and any food or other drugs you should avoid taking at the same time.

Usually, the therapy will be continued as long as it is effective unless you experience severe side effects. Do not stop the treatment on your own – talk to your doctor first.

Symptoms and side-effects during treatment for ALK-positive lung cancer

If you have ALK-positive lung cancer, you may experience symptoms of the lung cancer and side effects of the treatment. It is a good idea to talk to your doctor about all signs and symptoms or side effects – especially if you start feeling worse.

Common signs and symptoms of lung cancer include:

- Persistent cough, coughing up blood
- Chest pain
- Shortness of breath
- Recurrent infections (such as bronchitis or pneumonia)
- Feeling tired and weak

Many experience an intense fatigue that makes it difficult for them to engage in normal activities and that affects their quality of life.

Those who are given targeted therapy for ALK-positive lung cancer may also experience side effects directly related to the therapy that resemble some of the signs and symptoms described above, such as:

- Intense exhaustion (fatigue)
- Nausea and vomiting
- Diarrhoea and constipation
- Vision changes

Other potential side effects include: a low white blood cells count, swelling/inflammation, liver problems, nerve damage (neuropathy - may be experienced as a tingling or burning sensation in the hands or feet), heart arrhythmia or confusion.

Talk to your doctor if you experience any of the symptoms or side effects mentioned here, if your physical condition worsens.

Resistance in the cancer cells (the treatment stops working)

Although more than 50 per cent of patients respond to ALK inhibitors, most ALK inhibitors stop working after a while, as the cancer cells develop resistance and begin dividing again. Unfortunately, resistance may develop as early as in the first 3 months after starting therapy, but in some patients these drugs can be effective for many years.

When resistance occurs, the patient can usually switch to a new ALK inhibitor and can stay on this as long as possible. In addition, new ALK inhibitors and other drugs for ALK-positive lung cancer are constantly being researched and developed, and the patient may benefit from participating in a clinical trial, if possible. Sometimes, resistance developed because ALK-positive cells have developed several mutations other than ALK. Therefore, in some cases, drugs that target other mutations may be effective for continued treatment, even if the tumour did not originally have this exact ALK mutation.

Several of these resistance mechanisms may occur in the same tumour. Because this can happen, it can be useful to be able to do another tissue biopsy if the disease progresses. If this is difficult for the patient, it may be better to take a blood test to find traces of DNA from the cancer cells. Some cancer mutations have been reported using this technique.

It may be beneficial to continue therapy with ALK inhibitors even if the cancer progresses. When a patient does not experience symptoms and the progression seen on the CT or MR scan is minor, the doctor may consider continuing treatment with the same ALK inhibitors while carefully monitoring the patient's condition, as there is a risk that the tumour growth will spike when the ALK inhibitor is discontinued. This means that the cancer growth is under control in most metastases, but there may be progression in a few of the metastases. In this case, ongoing treatment with the ALK inhibitor can be continued simultaneously with local radiation therapy directed at the progressing metastases. The patient may then have a prolonged response to the same ALK inhibitor.

Chemotherapy

Chemotherapy, or cytostatics are drugs that kill cells or inhibit cell growth and cell division. Chemotherapy is often used in combination with immunotherapy.

Immunotherapy

Immunotherapy is cancer treatment that utilises the body's own immune system to attack the cancer disease.

For ALK-positive lung cancer, chemotherapy combined with immunotherapy is recommended for later lines of treatment after all relevant ALK inhibitors have been tested.

If the cancer progresses while you are on this therapy, it could be that you will need other drugs. This is known as moving from one line of therapy to another. The good news is that new drugs are continually be tested in clinical trials.

Some advice on how best to cope with treatment

- Be aware of any changes related to your health: It may be useful to keep a journal where you can write down your feelings, symptoms and side effects. These are things you can discuss with healthcare personnel, which can help you feel you have better control over your life.
- Share your experiences: Let your doctor know about any side effects. Do not stop taking your medications – talk to your doctor instead.
- Learn more: If you would like to learn more, ask questions and find out as much as you can about ALK-positive lung cancer and its treatment. Obtain information from reliable sources.



Clinical trials

All potential new drugs must be carefully tested to see if they work as they should and can safely be used by humans. These tests are done in clinical trials. Ask your doctor about clinical trials that may be suitable for you.

Clinical trials may be a good option for patients who need treatment for progressive cancer, as it has been shown that participation in clinical trials may result in a better prognosis. Patients who participate in a clinical trial are always closely monitored through tests, hospital visits and other follow up. In a clinical drug trial, patients are usually divided into groups for comparison in order to ensure clear results. Neither you nor the doctor will know whether you are receiving the drug to be tested in the study or whether you have randomly been placed in the control group.

Your doctor may ask you if you wish to participate in a clinical trial. It costs nothing to participate and it is entirely voluntary.

If you are considering taking part in a clinical trial, you should try to find out as much as possible about the study before you decide whether to join:

- What are the researchers trying to find out?
- Are there potential side effects linked to the drug?
- What do I have to do?
- Where do I have to meet up?
- What are my rights and duties as a participant?
- What is the alternative if I do not wish to participate?

You can find an overview of ongoing clinical trials at www.clinicaltrials.gov (search for ALK + lung cancer), or go to www.helsenorge.no/kliniske-studier where you will find a list of all clinical trials in Norway.

Current research

Improved screening

Treating lung cancer in the earlier stages will give better results, which is why there is a strong interest in being able to detect lung cancer before symptoms appear. It has been proven that CT screening increases life expectancy for lung cancer patients, and such a study has already begun at Akerhus University Hospital. Researchers are investigating better screening techniques, such as genetic testing, to understand who may be at higher risk of developing lung cancer. So far, there is no evidence of this.

Advances in treatment

Research is being done to find ways of improving the effect of different types of treatment when combined, such as surgery or radiotherapy combined with immunotherapy, while also reducing the side effects of these therapies. Much of the research on ALK-positive lung cancer focuses on treating lung cancer the same way we do with other chronic illnesses: with lifelong drug therapy and other therapies. New drugs are being researched in clinical trials that include patients who have developed resistance.

Liquid biopsies

Researchers are studying whether DNA released from cancer cells in patients' blood samples can help identify molecular changes that can be used to plan treatment.

Patient story

Stian is living with ALK-positive lung cancer

When Stian Aagnes (age 38) started on a tyrosine kinase inhibitor, it had an immediate effect. He went from lying in a hospital bed with oxygen mask to running 500 metres two weeks later.

“Before I started treatment, my lungs lit up on the PET scan, I had 50 percent lung capacity and lesions in my spine and ribs. I was simply full of cancer all over. Three months after starting treatment with an ALK inhibitor, a CT scan showed that all visible cancer was gone. It had an absolutely incredible effect!”

Misdiagnosed for a long time

It took one year and three months from the time Stian began noticing that something was not quite

right in his body until he was diagnosed with ALK-positive lung cancer. He had lymph nodes that came and went and a persistent dry cough. The doctors first decided he had hypersensitivity pneumonitis, which is a type of lung disease caused by an inflammatory reaction in the lung tissue due to inhaling organic dust such as fungi, bacteria and the like. Stian had lived in a house where fungi had been found, so the conclusion was not illogical. But the medicines he was given did not help, and new examinations were



performed. On 17 May 2020, he was diagnosed with lung cancer. At the same time, gene sequencing was performed, which showed that Stian was ALK-positive. On the same day that he was diagnosed, the doctors explained that there was an ALK inhibitor (tyrosine kinase inhibitor) that might work and treatment was initiated immediately.

Focused on the future

“Naturally it was a shock to get the lung cancer diagnosis, but I was able to adapt quickly. The cancer diagnosis has not taken over my life. Cancer is something I have, not something I am.”

Stian is keen to keep up to date on new drugs and research on ALK-positive lung cancer.

“I am focused on the future and have learned a lot about my diagnosis. There are very few people in Norway who have an ALK mutation, so I don't expect doctors to always be up to date with the latest information. That's why I've chosen to take responsibility for it myself. I read a lot about research in the area, both in Norway and abroad. The tyrosine kinase inhibitor I am on won't cure the disease, but it does mean I practically have no signs of the disease. At the same time, I also know that few signs of illness and a good effect are not necessarily synonymous with me continuing to do well. On average, this type of treatment with a tyrosine kinase inhibitor is effective for 32 months, but I have to believe that another treatment will appear when what I'm on now no longer has an effect. I am convinced that ALK-positive lung cancer will be cured within the next 5-10 years.”

“I am committed to the lung cancer cause. There is still a lot of stigma attached to lung cancer and I am passionate about putting an end to that.” That's why I try to have an influence where I can, partly through involvement in the Norwegian Lung Cancer Association.”

Four tablets morning and evening

Every morning and evening, Stian takes the medicine that keeps him healthy. He does notice a few side effects.

“My muscles get tired quickly. For example, I can feel the lactic acid quickly and have lost my explosive strength. Running feels heavy, like I have bricks around my ankles. I also have some muscle pain, but have found that exercise and activity help with these pains.”

His daily life is almost unchanged, apart from the fact that due to his diagnosis, he can no longer work as a helicopter pilot. But Stian has a full-time job and is an active father to three small children. Even when he sometimes forgets that he has cancer, it has affected those closest to him.

“My wife worries more than I do. If I cough, she immediately thinks the worst. I may feel a little uneasy if I notice changes in my body, or right before the checkups I have every five months. But I have a close and good collaboration with my oncologists, which gives me both peace of mind and makes me worry less.

Terminology

ALK: A gene that ensures the production of a protein in the body called ASL receptor tyrosine kinase.

ALK mutation: An ALK mutation (genetic alteration) occurs when the ALK gene is damaged and attaches itself to another gene.

ALK inhibitors: Anti-cancer drugs that act on and block (inhibit) the growth of cancer cells caused by ALK mutations.

Biopsy: A procedure that involves taking a tissue sample from the body in order to look for signs of disease. The tissue sample is examined for any changes or growth patterns.

CT scan: computer tomography is cross-sectional photography of relevant areas of the body using X-rays.

Brain metastases: When the cancer has started in one place in the body, such as the lungs, but spreads to the brain. This is still considered lung cancer, not brain cancer.

Cancer: A group of diseases caused by an uncontrolled division and growth of abnormal cells in parts of the body.

Central nervous system: Part of the nervous system that consists of the brain and spinal cord.

EGFR: A gene that ensures the production of a protein in the body called the epidermal growth factor receptor. A

mutation of the EGFR gene may cause EGFR-positive lung cancer.

Fatigue: Another word for exhaustion.

Gene: Basic units made up of DNA sequences (genetic material) that determine such things as hair colour and eye colour.

Genetic mutation: An abnormal alteration of the DNA sequence in a gene. A somatic mutation is a mutation occurring in a gene that is not hereditary. These mutations are usually caused by environmental factors, but they can also occur spontaneously. A germline mutation can occur in cells that have developed into egg or sperm cells. These can be passed on from parents to offspring. Gene mutations have various effects on our health depending on where they occur.

Hereditary: Something passed from parent to offspring through the genes. Characteristics or diseases children inherit from their parents.

Line of treatment (first-line, second-line, etc.):

First-line treatment is the first drug or treatment given to a patient for a specific disease (usually regarded as the best treatment for this disease). Second-line treatment can be given if the first drug is not effective enough for the patient.

Metastases: When cancer spreads from one part of the body to another.

Molecular testing: A lab test that analyses certain changes in a gene or chromosome that could cause a certain disease or condition.

MRI scans: Produces digital images of internal organs with the aid of a very strong magnetic field and radiofrequency pulses.

Neuropathy: Nerve damage that may be caused by drugs, tumours or surgery. The symptoms vary depending on which nerves have been affected. You may experience pain, extreme sensitivity, numbness or weakness. Symptoms are often most noticeable in the hands, feet or lower part of the legs. The nerves that control digestion and blood pressure may also be affected, which can lead to constipation, dizziness or other symptoms.

NSCLC: Non-small cell cancer. Approx. 85% of all lung cancer cases are NSCLC. ALK-positive lung cancer is one form of NSCLC and comprises approx. 4% of all NSCLC cases.

PET-CT: Positron emission tomography (PET or PET-CT) is a diagnostic examination that enables the production of physiological images of the body, i.e. Images that show activity in cells and tissues through the detection of positrons.

ROS1: ROS1 is a receptor tyrosine kinase (codes for the ROS1 gene), with structural similarities to the anaplastic lymphoma kinase (ALK) protein.

Somatic (mutation): Non-hereditary genetic mutations that occur after birth, during a lifetime.

Targeted therapy: A type of cancer treatment that targets specific genes and proteins and disrupts the way specific cancer cells send signals or interact with each other. This can stop cancer cells from dividing and growing.

Translocation: Where a piece of DNA moves from one place to another. ALK-positive gene translocation refers to the rearrangement of the ALK gene.

Tumour: A mass or lump caused by abnormal tissue growth. These can be benign (not harmful) or malignant (cancer).

Tyrosine kinase inhibitors (TKI): Drugs that block chemical messengers (enzymes) called tyrosine kinase. Tyrosine kinase helps to send signals to cells that trigger growth. TKI blocks the signals to stop cells from dividing. The tumour then stops growing and starts shrinking.

Norwegian Lung Cancer Society

The Norwegian Lung Cancer Society is a patient organisation for those who have or have had lung cancer, and for family members of lung cancer patients.

We provide advice and support, and we protect the interests of lung cancer patients. Together, we work to improve treatment and rehabilitation for lung cancer patients. We work to spread knowledge of lung cancer prevention, and to promote the issue of lung cancer before health authorities and politicians.

The Norwegian Lung Cancer Society has 800 members. We have local organisations, contacts in the county and peer support persons throughout the country. More detailed information about us and our peer support services can be found on our website: lungkreftforeningen.no

Contact us:

E-mail Sekretariat: post@lungkreftforeningen.no

Phone Sekretariat: **93470121** – the phone line is open Monday–Friday, 09:00–15:00

Peer support services

Living with a serious illness involves experiences that can make us feel alone. Family members may also feel alone with the uncertainties and concerns this entails. The Norwegian Lung Cancer Society therefore aims to provide a community for people in the same situation. We have peer support persons who are patients, as well as family members who have gone through the process of the disease and have been trained to provide support to others who have found themselves in the same situation.

You can contact the Norwegian Lung Cancer Society's peer support persons directly. See the list of our peer support persons on our website: www.lungkreftforeningen.no/likepersonstjenesten

You can also send an e-mail to likeperson@lungkreftforeningen.no

Join our community – become a member of the Norwegian Lung Cancer Society:

lungkreftforeningen.no/stott-oss/bli-medlem



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For sources and references, see: www.lungekreftforeningen.no/referanser-diagnosebrosjyrer

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