

Patients involvement in organizations - why it is important

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EURACAN - European reference network for rare adult solid cancers

- ▶ EURACAN is the ERN for all rare adult solid cancers
- ▶ ERNs are virtual networks involving healthcare providers across Europe to enable the sharing of expertise and to improve access to care for patients across the European Union, especially for complex or rare medical diseases that require highly specialised healthcare and a concentration of knowledge and resources
- ▶ EURACAN groups together all rare adult solid cancers into ten “domains”
- ▶ EURACAN G2 domain is for Rare Gynecological Cancers
- ▶ Engage has a representant in EURACAN G2 domain
- ▶ Important to have cooperation between healthcare professionals and patient representatives

ERN EURACAN



NGPO - Nordic Gynecological Patient Organisations

- ▶ Active patient advocates in the Nordic countries and gynecological cancer associations discussed for many years about cooperation between Nordic countries.
- ▶ Gynecological cancer organizations working in the Nordic countries.
- ▶ Representatives from Nordic patient organizations met to discuss this issue and came up that the best is to build a network.
- ▶ This network will speak for the patient in every Nordic country.
- ▶ We in the Nordic countries need good and qualitative cooperation between patient organizations and doctors.

Who is in the network

- ▶ **Finland** is represented by Gynecological Cancerpatients in Finland (Suomen Gynekologiset Syöpäpotilaat ry).
- ▶ **Sweden** is represented by Nätverket mot gynekologisk cancer and Gyncancerförbundet Värmland.
- ▶ **Denmark** is represented by KIU, Kräft i underlivet.
- ▶ **Norway** is representing by Gynkräftföreningen.



Our goals and what we want to work for

- ▶ 1. Good Palliative Care wherever you live
- ▶ 2. Access to adequate drugs in every Nordic country and faster drug approval
- ▶ 3. Rare cancers need to gain visibility
- ▶ 4. Long-term side effects should be discussed more with the patient



- ▶ NGPO is going to strongly work for the patient in every Nordic country
- ▶ Important for us that the patient get equal care wherever they live in a Nordic country.
- ▶ Patients also have the right to good palliative care
- ▶ Cancerpatients with a rare gynecological cancer need to get their diagnosis in time.
- ▶ The rare gynecological cancerpatients also has to have the opportunity to find others suffering from a rare cancer and get the possibility to talk to each other.
- ▶ Peer support important
- ▶ Longterm side-effects needs to take serious and the doctors need to inform the patient about them



Patients involved in organisations

Why?

- ▶ Important that patients together with doctors and healthcare professionals can develop the care and find new good solutions if there is a problem.
- ▶ Patients usually have good ideas how to, for example, do the processes easier and smoother in the hospital.
- ▶ The patient's experience can be completely different from the organization.
- ▶ Things are imagined to be done in a patient-oriented manner but often good plans are not implemented in practice.

- ▶ Despite the fact that even today things are imagined to be done patient-oriented, many times good plans are not realized in practice and the patient's experience is completely different from the organization's representatives
- ▶ Therefore important that patients are active in organizations and talk to healthcare providers about things that are important for the cancerpatients wellbeing.
- ▶ Patients are the best experts in their own situation and even though professionals have professional expertise, they are not always able to put themselves in the patient's position, so sometimes there can be things left unnoticed.
- ▶ As a professional, you might also become blind to your own actions and the operating methods of your own organization, so the perspective from outside, for example a patientperspective, is valuable in that sense as well.

THANK YOU FOR LISTENING
KIITOS ETTÄ KUUNTELIT
TACK FÖR ATT DU LYSSNADE

