

The Swedish Prostate Cancer Federation

Pc in Sweden 9 million inhabitants
10 000 Pc-incidence/year
2 400 Pc-deaths/year
Prevalence: 75 000, (the double expected 2030)
10000 new cases every year, 2500 cases of death.
PC is the most common cancer diagnosis in Sweden.

Founded 1999

Organization

National federation constituted by 8 500 members, 26 regional associations constitute a national organization with a yearly assembly and an executing board. Office with two part-time employees. The board consists of 9 members, personally elected at the yearly assembly.

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Members

About 8500 members in 26 regional groups (10% of the population). Prostate cancer patients and people close to them.

Mission

Offer fellowship and personal support to men with PC. Demand better medical care and to influence decision makers and the general public.

Funding: Government, member fees, sponsoring

Context

Increasing interest for patient centeredness and influence.

New organization: Regional Cancer Centers to evaluate and stimulate the health care system

Objectives

- Promote good care and life quality for men with PC and their relatives.
- Support and coordinate the regional PC Associations constituting the National PC Association.
- Influence the health care system, politicians at national and regional level, clinics and staff members to raise the quantity and quality of the PC-care.
- Identify and call attention to shortcomings and propose improvements based on experiences from patients and their relatives.
- Raise the knowledge level among politicians and the general public on PC issues.
- Promote and influence PC-research.
- To offer support to men with PC-diagnosis and their relatives
- To influence the health care system, clinics and staff members, and calling attention to shortcomings and propose improvements based on experiences from patients and their relatives.

- To inform politicians and the general public about PC.

Challenges

The PC-care is fractionized, discontinuous and impersonal.

Lack of awareness and knowledge among politicians and people in common.

Access to new treatments and drugs

Activities 2013

- Nationwide September-campaign, activities, media, brochures etc. Questioner sent to all members to be published in 2012.
- Policy document: "Good Pc Care, a specification of requirements"
- 4 editions of our member magazine ProstataNytt.
- Fundraising, 2 miljon SEK and call for applications for research and training purposes.
- Negotiations and activities with ministries, national authorities and organizations. Support to the regional associations.
- Arranging conferences, seminars on regional and local level.
- Trying to obtain publicity for PC-issues
- Negotiating with politicians, key persons within the health care, other organisations etc.
- Arrange and participate in conferences and seminars.
- Drawing attention to PC-issues via mass media.
- Participate in investigations, the designing of care programs, budget negotiations etc. concerning PC.
- Negotiations with politicians, key persons within the health care, other relevant organizations etc.
- Fund raising for research purposes.
- Administration of the website.
- Participation in Euomo (European organisation)
- Participation in Cooperation between the Nordic Prostate cancer federations.

Financing

The national level is mainly financed by state subsidies. The regional level by member fees and subsidies from regional authorities. Public activities are usually co financed by pharmaceutical and insurance companies and other organizations.

Contact

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