

SOSTE and POTKA network

Finnish Federation for Social Affairs and Health

Network for Patient Organisations

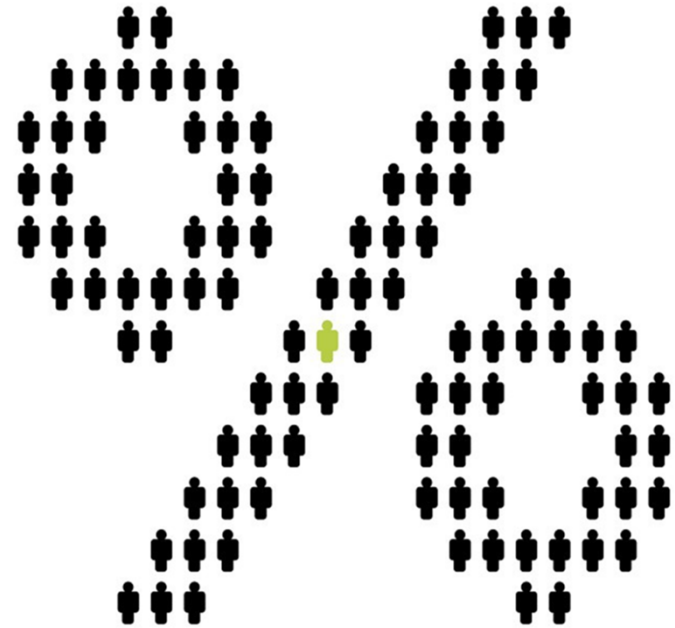
European Patients' Forum, Regional Advocacy Seminar,

Lund 24-25 Nov 2015

Sari Tervonen, President of Potka

SOSTE

SOSTE Suomen sosiaali ja terveystyö ry
SOSTE Finlands social och hälsa rf
SOSTE Finnish Federation for Social Affairs and Health

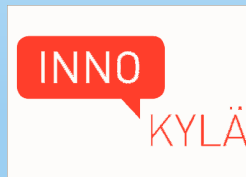


SOSTE

Network for patient organisations POTKA

Voice of patients

- 42 members, in which there are more than 0,5 million members (Finnish population 5,6 mil.)
- Advocating for patient's health issues
 - *Not registered*
 - *www.innokyla.fi / POTKA*



Chronic illnesses familiar to anybody at least as a caregiver in some life situation.

Members

- ADHD Association • Allergy and Asthma • Federation Alzheimer Society of Finland
- Association of Finnish Cancer Patients • Association for Backbone Health • Association for patients of accidents and illnesses • Cancer Society of Finland • Inflammatory Bowel Disease association • Eating Disorder Association of Finland • Epilepsy Association • Finnilco • Finnish Association for Autism and Asperger's Syndrome • Association for Respiratory Health in Finland • Finnish Association of People with Physical Disabilities • Finnish Association of the Deaf • Finnish Bone and Joint Association • Finnish Brain Association • Finnish Central Association for Skin Patients • Finnish Coeliac Society • Finnish Diabetes Association • Finnish Federation of Hard of Hearing • Finnish Federation of the Visually Impaired • Finnish Heart Association • Finnish Kidney and Liver Association • Finnish Central Association for Mental Health • Finnish Migraine Association • Finnish Osteoporosis Association • Finnish Osteoarthritis Association • Finnish Pain Association • Finnish Polio Association • Finnish Neuromuscular Disorders Association • Finnish Neuro Society • Finnish Psoriasis Association • Finnish Parkinson Association • Finnish Rheumatism Association • Finnish Traumatic Brain Injury Association • Inclusion Finland • Finnish Thyroid Association • National Family Association Promoting Mental Health in Finland • Pro Mama (for breastfeeding) • Rehabilitation Foundation • Women

together against addictions

How SOSTE is organised:
does it gather both chronic
diseases and disability
organisations?

POTKA works under SOSTE

SOSTE

- “Fusion” of 3 separate umbrella organisations since 2012
- Registered umbrella and networking organisation for Finnish NGO’s on the social and health care field
- 202 members, NGOs and also municipalities as associate members
- Influences on social and health policy and other relevant sectors of societal policy
- Advocates for NGO’s funding and positioning
- See more <http://www.soste.fi/soste/soste-in-english.html>

Networks on social and health care sector among NGOs in Finland

- SOSTE has about 30 networks (also other than POTKA)
- There are many national networks and organisations (same advocacy interests)
 - Disability forum (registered)
 - Neurological
 - Organisations of separated sense impairments (Deaf, Visual)
 - Brain – Heart – Diabets
 - Etc.
 - Funding – Slot Machine Association (governmental funding)
 - Service providing

How is Potka organised?

Nyrkki (The Fist) – Management Committee / Task Force of POTKA



Advocacy group by Finnish sisu
Activity of the members of POTKA

What are the main activities?

Do you cooperate with the institutions and other health stakeholders?

(including hospitals, health professionals, industry)

Potka - Network for patient organisations

- Not formally registered, Secretary in SOSTE, the Fist is run and works by some NGO professionals
- In SOSTE a need for joint advocacy for health issues of people with chronic illnesses
- Activities:
 - Meetings (special themes)
 - Statements and resolutions, attitude changing
 - Expertise in advisory boards and for decision makers and municipalities (influencing on legislation)

”CV of POTKA”

- 09.11.2015 Survey to the network about the proposal of increasing employee’s responsibility of his sickleave – 1. day 100 %, 8 following days 80 %. Need to advocacy?
- 21.10.2015 Speech in the seminar about equality in the health care
- 29.09.2015 Speech about the planned reform of social and health care system/regional areas of municipalities, organised by the Ministry of Social and Health Affairs
- 03.09.2015 Media release: ”Threatening economic conditions of people with chronic illnesses – new client reimbursement principles of drugs, health services and travelling for using services
- 31.08.2015 Meeting of the network. The plan of social and health care reform –towards new reimbursement and structure of social and health services and the expenses
- 01.06.2015 Media release: The action plan of the Finnish government mean to people with chronic illnesses
- 4.5.2015 Meeting of the network. The expenses of drugs stated by the municipalities. New IT services, for patient information also to the citizens
- 24.02.2015 Meeting of the network. The services of health care financed by taxes by public sector
- 20.11.2014 Meeting of the network. Health care policy; what is on the agenda now?
- 08.10.2014 Launching POTKA network in a cruise.

Statements for some proposals of legislation changes in the area of social and health issues

There has been an expert in every meeting.
In addition to that the work by the Task Force (The Fist).

Is POTKA also involved in cross-border cooperation or more generally cooperation with patient organisations abroad? What are your main activities?

International activities of POTKA

- Launching now!
- The members of POTKA collaborate at international level more or less according to diseases and syndromes
 - IBE, MS-Platform, Alzheimer Europe, European Heart Association etc.
- Alliances with the specific scientific societies (mostly medicine) according to diseases and syndromes in Europe and globally
- Alliances also by group of diseases and syndromes (for example EFNA=European Federation of Neurological Associations)

POTKA IS INTERESTED IN
KNOWING THE
OPPORTUNITIES FOR
EUROPEAN LEVEL ADVOCACY

Where do we have the same
focus and interests? Is there
some funding available?

What have we in common?

- Social and health policy – at national level, but also at European level, like the directives of EU (such as the “Patient directive”)
- Funding opportunities like E-technology (dissemination of patient information about services and health issues)
- Other funding opportunities?
- Nordic similarities in health issues in EU – Nordic co-operation
- NGO – voice of patients – patient platforms needed!



International Epilepsy Day

EPILEPSY is more than SEIZURES



Five-year-old Emilia Salminen, from Finland, underwent extensive frontal-lobe surgery in the spring of 2014. Emilia's operation was performed in Helsinki. She was in surgery for eight hours.

Emilia's epileptic seizures were caused by a congenital developmental disorder of the frontal lobe. When the condition was at its worst, she suffered dozens of episodes a day. Medications did not seem to help. After many and exacting examinations, epilepsy surgery was decided upon. Although Emilia no longer suffers from seizures, she continues to take epilepsy medication and her progress is being very carefully monitored.

The results of the operation surprised her parents and grandparents. Her seizures stopped and she became more outgoing and self-confident. Her frequent nightmares are gone, and her daily life is easier.

Emilia now goes to a specialised day-care facility, and her mother can rest assured that she is receiving the best possible care and support from the expert, friendly personnel. Emilia has joined a swimming group. The aim is, of course, to learn how to swim on her own. Emilia has also started skating and finds it an enjoyable hobby.

Emilia's mother Tiina and Emilia have also taken part in an adaptation family training course organised by Finnish Epilepsy Association. The best things about the course were peer support and learning how to approach and cope with epilepsy issues.

Tiina is quick to emphasize the importance of her own attitude. With this positive attitude Emilia's family can now look to the future of their lovely child.

epilepsy.org



EMILIA SALMINEN
Finland

Emilia's mother thanks epilepsy surgery