

# Overview of organizations

## Match-making seminar of the Health Programme

16<sup>th</sup> January 2019, Prague

### Donor State institutions

#### List of participating Donor State institutions

Institution / Indicative focus with regard to the Health Programme Outcomes <sup>1</sup>	Children's mental health	Communicable and non-communicable diseases	Patient empowerment
ADHD Association Iceland	x		x
Regional Centre for Child and Youth Mental Health and Child Welfare	x		
Vestre Viken Hospital Trust	x		
Voksne for Barn	x		x
Mental Helse Ungdom	x		x
Norwegian Institution of Public Health	x	x	
ÖBÍ – the National Organisation of People with Disabilities in Iceland	x		x
Norwegian National Advisory Unit on Ageing and Health		x	x
Oslo University Hospital, Section for Drug Abuse Research		x	
Frambu Resource Centre for Rare Disorders		x	x
Norsk Revmatikerforbund			x
Norwegian Association for Persons with Intellectual Disabilities			X

Division into seminar groups	
ADHD Association Iceland	E
Frambu Resource Centre for Rare Disorders	C
Mental Helse Ungdom	A, C
Norwegian Association for Persons with Intellectual Disabilities	D
Norwegian Institute of Public Health	B
Norwegian National Advisory Unit on Ageing and Health	C
Norwegian Rheumatism Association	D
ÖBÍ-National Organisation of People with Disabilities in Iceland	D, E
Oslo University Hospital	E
Regional Centre for Child and Youth Mental Health and Child Welfare	A
Vestre Viken Hospital Trust	B
Voksne for Barn	B

<sup>1</sup> Indication based on the details in the seminar registrations.

## Description of participating donor state institutions & contacts

### **ADHD Association Iceland**

represented at the seminar by **Mr. Hrannar Arnarsson**

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ADHD Association Iceland is a key organization providing service for people with ADHD and their families that is also engaged in lobbying efforts to represent their needs. It is a publicly funded organization representing the first level of health service for those diagnosed with ADHD.

The main purpose is to assist those with ADHD and their families, namely to inform about ADHD and available services, as well as to create awareness among the public.

### **Regional Centre for Child and Youth Mental Health and Child Welfare**

represented at the seminar by **Mr. Oddbjørn Løndal**

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Regional Centre for Child and Youth Mental Health and Child Welfare (RKBU North), the Faculty of Health Sciences of the Arctic University of Norway, is one of four regional centres involved in research and education of professionals within child welfare and mental health in Norway, engaged in developing research-based practices for services that are working directly with children and youth. The research aims to improve the quality of services provided to children and adolescents.

RKBU North coordinates national implementation of the Incredible Years (IY) in Norway, actively offers IY services to healthcare institutions, kindergartens and schools, as well as provides supervision for parents. The number of staff is ca 50 with ca 35 researchers employed full-time. RKBU North was the pioneer in the implementation of The Incredible Years and has been actively involved in the program series since 1999. The RKBU North will collaborate with the University Hospital Motol on the Incredible Years program piloting in the Czech Republic (pre-defined project).

### **Vestre Viken Hospital Trust, Division of Mental Health and Addiction**

represented at the seminar by **Mr. Bror Just Andersen**

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Vestre Viken is one of the largest hospital trusts in Norway established 2009. It provides specialist health care with complete range of treatment services (both somatic, mental health and within the field of substance abuse) to approximately 490 000 people in 26 municipalities in the eastern part of Norway.

The Division of Mental Health and Addiction conducts research on preventive mental health and assertive outreach services including mental health interventions in schools through an evidence based modular program developed in accordance with the content of the general curriculum for upper secondary schools in Norway. The VIP (Very Important Problems) program offers guidance and information about mental health to students by providing answers on growing curiosity or uncertainty on inner development. It places the topic both on school and home agenda and teaches students where to seek help by focusing on dialogue and involvement. The program has been implemented in more than 160 schools in Norway and is included in their annual teaching plans.

Research activities of the division focus both on preventive mental health in general and the effects of VIP program for youth, specifically knowledge, help seeking behaviour, stigma and level of mental health problems.

### **Voksne for Barn**

represented at the seminar by **Ms. Randi Talseth**

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Voksne for Barn (Adults for children) is a membership NGO working for children's mental health and wellbeing that was established in 1960. The organization works with children and adolescents directly as the main target group but also with adults as parents and professionals that work with children. It is considered by the authorities to be a user organization for children within the mental health sector.

Its interventions focus on mental health promotion including promotion of good mental health for all children, prevention of mental illness in children as well as development of methods in the area of user participation. Special area of interest includes mental health programs at schools and their promotion. The main area of prevention focuses on work for children facing strains in their families, such as parental mental illness, substance abuse or other stress factors for children's upbringing.

### **Mental Helse Ungdom**

represented at the seminar by **Ms. Ranveig Stava and Mr. Adrian Tollefsen**

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FB, IG: Mental Helse Ungdom

Mental Helse Ungdom (the Norwegian Association of Youth Mental Health) is a member-based interest organization for children and adolescents up to 31 years, founded in 2005 and

acting as independent organization since 2011. It works for increased openness about mental health, prevention of mental disorders and better mental health services. The goal is to secure the best possible mental health for all children and adolescents in Norway. The most important tool is to visualize the experience-based knowledge of its members so that this knowledge can help develop better mental health services.

### **The Norwegian Institution of Public Health**

represented at the seminar by **Ms. Svetlana Skurtveit**

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The Norwegian Institute of Public Health (NIPH) acts as a national competence institution placed directly under the Ministry of Health and Care Services, with employees in Oslo and Bergen. The NIPH is responsible for knowledge production and systematic reviews for the health sector and provides knowledge about the health status in the population, influencing factors and how it can be improved. The institute is a national competence institution in the following areas: infectious disease control, physical and mental health, environmental factors, substance abuse, tobacco, nutrition, physical activity and other factors that affects health status and inequality, health-promoting and preventive measures in the population and global health.

### **ÖBÍ – the National Organisation of People with Disabilities in Iceland**

represented at the seminar by **Ms. Þórdís Viborg** and **Mr. Stefán Hjaltalín Vilbergsson**

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ÖBÍ (Öryrkjabandalag Íslands in Icelandic) – the National Organisation of People with Disabilities in Iceland was established in 1961 and acts as the national organisation of persons with disabilities with the number of member associations totalling 43. The organisation's role is to represent people with disabilities and chronic illnesses and to safeguard their interests, for example regarding legislation including policy formulation in matters pertaining to the rights of disabled persons and the implementation of law and regulations.

The organisation provides consultations for disabled persons and their relatives. It is working towards social justice, improved quality of life and good living conditions, irrespective of individuals' physical or mental competence. ÖBÍ is also an active participant in cooperation with associations and organisations of disabled persons abroad. ÖBÍ's focus areas include e.g. mental health, costs of health care and access to health care. The member associations include for example ADHD Association Iceland, Parkinson Society of Iceland, Icelandic Autistic Society, Icelandic League against Rheumatism, Icelandic Diabetes Association etc.

### **The Norwegian National Advisory Unit on Ageing and Health**

represented at the seminar by **Ms. Kari Midtboe Kristiansen**

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FB, TW: aldring og helse

IG: aldringoghelse

The Norwegian National Advisory Unit on Ageing and Health (Ageing and Health) was established in 1997 and is responsible for securing national competency building and the distribution of such competencies on dementia, intellectual disability and ageing, physical disability and ageing and old age psychiatry. It provides competency building and guidance for the entire health service, both the municipal health care services and the specialist health services, to other service providers, clients (patients and their next of kin) and the population in general. Ageing and Health operates a number of research- and development projects and has its own publishing house and library. It offer courses, training programmes and runs a vocational school. Knowledge is also communicated through own journal and via digital platforms.

There are over 70,000 people with dementia in Norway. Ageing and Health is committed to furthering the development and evaluation of the services provided for the affected and their next of kin. It offers guidance and advice in connection with the development and testing of new models for treatment and care. Ageing and Health coordinates collaboration projects and research in the field of old age psychiatry. Its aim is also to spread competency, communicate knowledge and information and contribute to the development of better services for ageing people with intellectual and physical disabilities.

Ageing and Health provides extensive nationwide courses. Courses and conferences are primarily directed towards personnel in the municipal health care services and the specialist health care services. They cover a wide spectrum of subjects, lasting from 1 to 3 days. Ageing and Health has its own vocational school offering further education for assistant nurses, care workers and health workers; the ABC model with interdisciplinary study groups in the work place, and health worker education building on the ABC model, giving the participants the opportunity to qualify for a certificate of completed apprenticeship.

### **Oslo University Hospital, Section for Drug Abuse Research**

represented at the seminar by **Mr. Stig Tore Bogstrand**

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Oslo University Hospital is a highly specialised hospital in charge of extensive regional and local hospital assignments and the provision of high quality services for the citizens of Oslo. The hospital also has a nationwide responsibility for a number of national and multi-regional assignments and has several national centres of competence.

The Section for Drug Abuse Research focuses its research on health consequences of alcohol and drug use, specifically on assessing prevalence and development of interventions for somatic or injury patients with a harmful drug or alcohol use. The aim is to provide more knowledge about impact of drugs of abuse and alcohol on mortality risk, acute disease and injuries, mechanisms of action and continuous improvement of analytical methods and

techniques. The topic of harmful alcohol use and somatic health consequences is also emphasised in international collaboration projects since non-communicable diseases (NCDs) are identified as one of the leading causes of mortality worldwide. Considering this, prevention of NCDs, underscores the importance of research on alcohol-attributable health effects and alcohol consumption, which is one of the main four risk-factors for NCDs, particularly cardiovascular diseases, cancer and liver diseases.

### **Frambu Resource Centre for Rare Disorders**

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Frambu has more than 25 years of experience in gathering, developing and disseminating knowledge regarding rare and unfamiliar disabilities with patients, their families and the professionals. This is done through a comprehensive and targeted course program, consultations and guidance, documentation, research and development work. It is responsible for approximately 100 different diagnoses. Frambu is a government funded supplement to the regular support apparatus and acts as a meeting place for families and professionals in the field.

Frambu's methodology includes all kinds of communication tools such as video conferences, e-learning programs, podcast programs and social media. This unique Norwegian model is a tool to empower people with rare diseases and their families to achieve the best quality of life as possible. Many years of developing these types of information has enabled Frambu to share the best practice on how to reach these target groups. Frambu works actively to stimulate networking across local and regional levels. The professionals at Frambu have worked thoroughly to support the municipalities to implement responsibility groups. The importance of dissemination at national level is crucial and as an expert partner, Frambu's experiences may be shared in a mentoring program.

### **Norsk Revmatikerforbund**

represented at the seminar by **Ms. Anna Fryxelius**

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Norsk Revmatikerforbund (NRF; the Norwegian Rheumatism Association) is a patient organization working to prevent and combat rheumatic diseases and musculoskeletal disorder and to improve lives of the 800 000 people in Norway who suffer from these health problems. The association was founded in 1951 by people with a rheumatic diagnosis. The NRF is one of Norway's largest patient organizations with over 34 000 members and 220 local groups spread throughout Norway.

The NRF has been at the forefront of digitalization in its field of interest, using web solutions and digital tools to reach more people and work effectively. Some of the tools used include live streamed webinars, customer relationship Management system, e-learning. The special

areas of expertise of the NRF include patient-centred programmes, patient involvement, e-learning for patients and digital tools for cost-effective communication. The NRF will collaborate with the Ministry of Health of the Czech Republic on the Patient Hub project (pre-defined project).

### **The Norwegian Association for Persons with Intellectual Disabilities**

represented at the seminar by **Ms. Gunn Strand Hutchinson**

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The Norwegian Association for Persons with Intellectual Disabilities (NFU) was established in 1967. It is a national advocacy organization that fights for the inclusion of persons with intellectual disabilities into society. The NFU was founded to make life easier for people with developmental disabilities and their families with the vision of an inclusive society.

The NFU informs parents about what kind of help the families of children with developmental disabilities are entitled to. The NFU has lawyers and other workers who provide advice and guidance. It organises courses, seminars and social gatherings. The courses are intended for people with developmental disabilities and their parents so that they can learn about the help they can get. It wants children with developmental disabilities to receive the best possible care and education in kindergartens and schools and people with disabilities to have jobs that they enjoy. The NFU wants services, which suit each individual. The user can talk to the assistant and they can agree on a good solution.

## Czech institutions

### Match-making seminar of the Health Programme

16<sup>th</sup> January 2019, Prague

Organizations & division into seminar groups	
<b>Group A</b>	MIKASA z.s.
	Motol University Hospital
	Naděje pro děti úplňku z.s.
	National Institute of Mental Health (NUDZ)
	SYMPATHEA, o.p.s.
	Psychiatric Hospital Opava
	Za sklem o.s.
<b>Group B</b>	Centre of Health Support
	Czech Alzheimer Society
	E-clinic - Institute for Study, Prevention and Treatment of Eating Disorders
	High School of Economics, Social and Medical services in Most
	FOKUS České Budějovice, z.ú.
	Klíček Association
	Motol University Hospital
	National Institute for Autism (NAUTIS)
	Nevypušť Duši, z.s.
Sdružení D	
<b>Group C</b>	Celiac Club Brno
	CEREBRUM
	Czech Association for Rare Diseases
	Diagnosis FH
	Motol University Hospital
	Parent Project
	Smáci
	Society for Mucopolysaccharidosis
<b>Group D</b>	Association of Individuals Afflicted with Civilization Diseases in the Czech Republic
	Association of Prosthetic Patients
	Czech Association of Paraplegics - CZEPA
	Czech Civic Association against Pulmonary Diseases
	Czech League for Rheumatism
	Dobré místo
	Nedoklubko
	ParaCENTRUM Fenix
	ROSKA Union - Czech Society for Multiple Sclerosis



<b>Group E</b>	ALEN - Women's Association in Prague
	Alliance of Women with Breast Cancer
	Charles University - Faculty of Medicine in Hradec Králové
	Czech Association of AIDS help
	Czech Association for Rare Diseases
	DIAKTIV CZECH REPUBLIC
	Mamma HELP
	Popálky

## Participating institutions in Outcome 1: Mental health promotion and prevention of mental illness in children<sup>2</sup>

### **Za sklem**

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Za sklem is a NGO focused on providing services for people with autistic spectrum disorder in order to be able to live, study and work in standard environment. Their clients are not only people with autistic spectrum disorder themselves, but also their families. They also hold expert trainings for teaching assistants, teachers, social workers and others.

### **Centre of the Health Support**

represented at the seminar by **Ms. Lenka Plizáková**

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Centre of the Health Support pursues not only healthy diet, but also emphasizes physical activities, which are essential parts of healthy lifestyle. Part of centre activities is implementing programs of primary prevention. They also focus on eating disorders in children, primary prevention of obesity in pre-school children and nutrition of children in socially-excluded areas.

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<sup>2</sup> Indicative focus with regard to the Programme areas based on details stated in the seminar registration.

### **Czech Alzheimer Society**

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FB: Česká alzheimerovská společnost

Czech Alzheimer Society helps people with dementia and people who take care of patients with dementia. The help is provided mostly by counselling for carers as well as people with dementia (in form of consultations or self-help groups for both groups of clients) and by offshore care. They also promote the issue of early detection of cognitive impairment and are interested in rising awareness of dementia.

### **Nevypust' duši**

represented at the seminar by **Ms. Marie Samolonová**

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The organization is focused on education, destigmatization and prevention in area of children and adolescent mental health. They are active on social networks, they raise awareness in society and organize seminars at high schools in the Czech Republic, where they carry out evidence-based programme for students and teachers. Already about 1300 students completed the programme during last two years.

### **E-clinic – Institute for the Study, Prevention and Treatment of Eating Disorders and Comorbid Disorders**

represented at the seminar by **Ms. Jana Gricová**

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website: www.ecinstitut.cz

E-clinic is a NGO with more than 20-year experience in treatment and prevention of mental disorders. Their focus is to develop quality and easily accessible services, which help in early detection of mental illness, support mental health and contribute to prevention and destigmatization of mental disorders and their treatment. They also participate in education of experts and increasing their special qualification by implementation of new efficient methods and foreign training programs.

### **FOKUS České Budějovice**

represented at the seminar by **Ms. Aneta Vedralová**

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FB: Fokus České Budějovice

FOKUS České Budějovice provides medical and social services in field as well as outpatient services and also residential type services. They also implement BNA prevention programme and annual destigmatization campaigns. They are interested in programmes focused on reduction of negative impact of mental disorders in youth (their relationships, education, free time etc.).

### **High school of economics, social and medical services in Most (VOŠ-SOŠ Most)**

represented at the seminar by **Ms. Hana Elexová**

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website: www.vos-sosmost.cz

The institution is focused on education of children and adolescents in the areas of health, psychology, medical competencies, social work, prevention of diseases, education of pre-school children. The school is interested in programme of prevention of mental illness for children – for students and/or as an education programme for kindergarten through students.

### **Naděje pro děti úplňku**

represented at the seminar by **Ms. Markéta Křečková**

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The organization aims at associating parents and other family members of children with autistic spectrum disorder. It operates in area of law, education and analytic work, through which is trying to assert change in the system of complex care for autistic children. In the pilot project “Homesharing - shared care for children with autism” they plan to verify and set parameters of introduction of shared community care for people with autistic spectrum disorder in the Czech Republic. Homesharing is support service for families and children with autistic spectrum disorder, which helps children by natural and sensitive way to adapt to the contact with surrounding world. It significantly helps whole family with healthy development.

### **MIKASA**

represented at the seminar by **Ms. Sandra Štěpánková**

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organization e-mail: [info@mikasa-detem.cz](mailto:info@mikasa-detem.cz)

MIKASA is NGO with 10 years history of providing its service of daily stationary for children and youth with combined disabilities (mid-severe and severe mental disability, autism and problematic behaviour) and social rehabilitation for people with autistic spectrum disorder. Another project is focused on parents and other carers for children with autism and on professionals working with autistic children.

### **Motol University Hospital**

represented at the seminar by **Ms. Světlana Havlíčková** and **Mr. Michal Goetz**

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Motol University Hospital is the biggest medical facility in the Czech Republic which is providing medical care as general as specialized. Prevention of children mental disorders is one of many areas, which are hospital specialists deal with. They are interested in implementation of new diagnosis procedures, therapeutic methods and/or creating multidisciplinary teams to provide care for mentally ill children or for children with high risk of occurrence of mental disorder.

### **National Institute for Autism (NAUTIS)**

represented at the seminar by **Ms. Zuzana Daňková**

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FB: NAUTIS

The National Institute for Autism is a NGO which provides wide range of services for autistic people and people around them – parents, siblings, classmates, teachers, doctors and other professionals. They currently provide a comprehensive range of services, especially in Prague, Central Bohemian Region, but also in other parts of the Czech Republic (e. g. early care services, relief services, social activation services, special social counselling, personal assistance or education of professionals or parents).

### **National Institute of Mental Health (NUDZ)**

represented at the seminar by **Ms. Barbora Veselá**

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The National Institute of Mental Health (NUDZ) is focused on research of neurobiological mechanisms leading to development of the most serious mental disorders (schizophrenia, depression, anxiety, reactions to stress etc.). Part of the research is focused on developing and testing new diagnostic and treating methods. NUDZ also collaborates in using new technologies on improvement mental health. We also run clinical centre, which is reference psychiatric department in the Czech Republic.

### **Psychiatric hospital Opava (Psychiatrická nemocnice Opava)**

represented at the seminar by **Ms. Jana Bartošová**

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The Child and adolescent department of psychiatric hospital in Opava provides diagnostic-therapeutic care (inpatient department) focused on whole spectrum of psychopathology in childhood and adolescence (age 5 – 18). The hospital provides complex treatment and offers services of elementary school at their premises. Psychiatric hospital collaborates with families, schools, social department, courts and police.

## **Participating institutions in Outcome 2: Prevention of communicable and non-communicable diseases<sup>3</sup>**

### **Motol University Hospital**

represented at the seminar by **Mr. Milan Macek**

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Motol University Hospital participates in the National Coordination Centre for Patients with Rare Diseases. The centre is focused on rising awareness about rare diseases among experts and whole society, improvement of diagnosis and medical preventive care for patients with such diseases. The centre also cooperates on model pharmacologic studies of chosen diseases with Institute of Biology and Medial Genetics of 2nd Faculty of Medicine, Charles University.

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<sup>3</sup> Indicative focus with regard to the Programme areas based on details stated in the registration.

## Participating institutions in Outcome 3: Civil society empowerment in the health sector<sup>4</sup>

### **Czech association of AIDS help (CAAH)**

represented at the seminar by **Mr. Július Szabó**  
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CAAH is a patient organization uniting HIV patients. The association provides services to its clients and patients (education, promotion of adherence treatment, social and psychological help, etc.) and is also active in the field of prevention of HIV infection and de-stigmatization. The association is interested in activities concerning the improvement of services provided to patients, such as counselling or psychotherapeutic services, especially in the area of comorbid (HCV coinfection).

### **Czech Association for Rare Diseases**

represented at the seminar by **Ms. Monika Němcová** and **Mr. René Břečťan**  
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The association represents the interests of the patients with rare diseases. It has 32 members, mainly other patient's organizations, but also individual patients. The association focuses on promoting the rights of patients with rare diseases, the education of patients, doctors and other professionals. Organization also manages projects of early diagnostics, palliative care, education and others. They already cooperate with Frambu from Norway and are keen to further develop this cooperation.

### **Smáci**

represented at the seminar by **Mr. Václav Hradilek**  
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FB: Smáci

Smáci is an organization associating patients with Spinal muscle atrophy and their families. The organization helps to promote new standards of treatment. They help to educate and inform the members through online conferences, web page and Facebook discussion forum. They also help families to get a medicament which is not reimbursed from health insurance. The aim of the organization is to carry out with the help of the EEA Grants their existing

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<sup>4</sup> Indicative focus with regard to the Programme areas based on details stated in the registration.

activities more conceptually and get into closer contact with the members, especially in order to share information.

### **Czech Association of Paraplegics - CZEPA**

represented at the seminar by **Ms. Veronika Friebová**

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FB: CZEPA

The association provides counselling in all fields of health care for spinal patients (for example with secondary health complications such as decubitus, urology, autonomic dysreflexia, sedation pathology and other problems). They also deal with the prevention of injuries resulting from spinal cord injuries. The aim is to expand personal capacities with the help of the EEA Grants in order to provide better targeted and effective counselling.

### **Parent Project**

represented at the seminar by **Ms. Karolína Podolská**

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website: www.parentproject.cz

The activities of Parent Project include providing better health care for patients with muscular dystrophy, setting up a specialized centre and providing information for families of patients and broad public about the topic of muscular dystrophy. The aim is to achieve better education for their staff and to expand personal capacities with the help of the EEA Grants.

### **Dobré místo**

represented at the seminar by **Ms. Tereza Klenorová**

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The mission of the organization is to integrate people with disabilities into the labour market and offer them working opportunities in a safe environment of editorial staff of web page www.LideMeziLidmi.cz and in other activities. The organization is considering a possibility of creating its own patient organization to protect interests of people with experience of mental illness and establish a group of representatives who would be involved in implementation of the Nation mental health reform on national level.

### **Czech Civic Association against Pulmonary Diseases (COPN)**

represented at the seminar by **Mr. Stanislav Kos**

e-mail: St.Kos@seznam.cz

website: www.copn.cz

The organization is engaged in raising general awareness of pulmonary diseases, cooperating on improvement of the quality of life of patients with pulmonary diseases and keeping them informed about modern trends of treatment as well as improving the mutual awareness of the professional and general public and emphasizing the interests of pneumological patients in dealing with other organizations and institutions. The aim of COPN is to develop, with the help of the EEA Grants, activities and services of patient's organizations provided to patients (setting up an assistance line, strengthening counselling activities, etc.) and carry out awareness-raising activities on prevention/illness, including the implementation of media campaigns and awareness raising campaigns.

### **Czech League for Rheumatism**

represented at the seminar by **Ms. Edita Müllerová**

e-mail: edita.mullerova@revmaliga.cz

website: www.revmaliga.cz

FB: revmaliga

The aim of the organization is to educate patients suffering from rheumatic diseases in their rights and duties, to inform them about treatment and healthy life style and to strengthen the role of the patient in the treatment, to defend the patient's interests and also to cooperate with doctors and other institutions as well as raising awareness of rheumatic diseases. The organization intends to expand, with the help of the EEA Grants, its personal capacities, to educate and train employees in order to improve their knowledge and skills and also to develop patient counselling services and so-called self-management of illnesses.

### **Alliance of Women with Breast Cancer**

represented at the seminar by **Ms. Mirka Phillips**

e-mail: mircuska@email.cz

other contact person: Eva Knapp (evaknapp@breastcancer.cz)

website: www.breastcancer.cz

The Alliance operates an information and educational centre for the public and oncological patients, provides methodological assistance to organizations of oncological patients, implements projects and campaigns for the prevention and treatment of breast cancer, represents patient organizations and individuals in order to promote their rights and equal conditions in treatment and for the treatment and convalescence of women with breast cancer and represents Czech oncology patients in international structures. The aim of the organization is to strengthen, with the help of the EEA Grants, the prevention of breast cancer (amongst the public and in schools) and to establish a partnership with Donor State partner(s) in order to share experience and impact of long-term campaigns.



## **Diagnosis FH**

represented at the seminar by **Ms. Kristýna Čillíková**

e-mail: cillikova@me.com

website: www.diagnozafh.cz

www.fheurope.org (English umbrella organisation)

FB: diagnozaFH

IG: @diagnoza

Diagnosis FH aims to support patients with familiar hypercholesterolemia (FH) and their families. The challenge in this field is to advocate in favour of greater availability of modern efficient treatment. However, the scope of the association's activities is much broader: they put a great emphasis on public awareness in the field of cardiovascular prevention, they carry out educational weeks, campaigns on social networks, prepare brochures, articles in the media, press conferences, etc. With the help of the EEA Grants the association is interested in continuation in public awareness campaigns for different age groups and level of education groups and to promote further strengthening of the role of patients as equal health care partners and to support projects for this purpose.

## **CEREBRUM**

represented at the seminar by **Ms. Jana Dobrkovská**

e-mail: reditel@cerebrum2007.cz

website: www.cerebrum2007.cz

CEREBRUM provides support to clients who have suffered serious brain injury and are in need of professional help. The form of assistance is non-acute care in the form of individual and group therapies. The main objective is to raise awareness among public about broad range of consequences of brain injury and possibilities of rehabilitation. The organization provides advisory in this area and maps the services that are intended for people after the injury. With the help of the EEA Grants the association would like to coordinate the support for carers in order to include patients in home care and provide home rehabilitation. Furthermore, they intend to establish facilities and community centres for these individuals and carers, and to build a network of shared information and advisory centres in this area.

## **Mamma HELP**

represented at the seminar by **Ms. Jelena Burianová**

e-mail: Jelena.burianova@suro.cz

website: www.mammahelp.cz; www.udelejuzel.cz

FB, IG: mammahelp

Mamma HELP (MH) provides individual psychosocial counselling for women patients and their relatives in eight MH centres. They run free AVON Healthy Breast Lines and professional medical on-line advisory centre. They also conduct rehabilitation stays, community programs and events for the public to improve awareness of the incidence, prevention and treatment options for breast cancer. With the help of the EEA Grants the organization would like to participate in the creation of patients HUB, educate employees, to

develop activities and services (such as psychosocial individual counselling) and to raise public awareness of the incidence, prevention and treatment options.

### **Association of Individuals Afflicted with Civilization Diseases in the Czech Republic**

represented at the seminar by **Ms. Marie Říhová**

e-mail: rihova@spcch.cz

website: www.civilky.cz; www.spcch.cz

Organization coordinates 247 local organizations with 26,000 members permanently afflicted with serious civilization diseases. The main activity of the association in the Czech Republic is the promotion of association of people with a civilization disease, the defence of their rights and interests, the dissemination of information about the given disease and the exchange of experience among patients. An important part of its activities also comprises the primary, secondary and tertiary prevention of civilization diseases. The association provides educational-rehabilitation activities, such as recondition stays, diet and nutritional courses and rehabilitation exercises for cardiac, diabetic, oncological patients, adults and children with respiratory diseases.

### **Popálky**

represented at the seminar by **Ms. Jana Tlustá**

e-mail: jana.tlusta@popalky.cz

website: www.popalky.cz

FB: Popálky

The organization Popálky provides follow-up care for patients with burn injuries and their family members. It attempts to raise general awareness of this type of injury and first aid. As part of its activities, Popálky implements preventive programs in schools and kindergartens, organizes lecture for the elderly and the general public across the Czech Republic to reduce the incidence and severity of burn injuries. The organization is based in Brno, where it operates a Counselling centre.

### **ROSKA Union – Czech Society for Multiple Sclerosis**

represented at the seminar by **Ms. Jiřina Landová** and **Mr. Radoslav Hýl**

e-mail: landova@gmail.com

website: www.roska.eu

organization e-mail: roska@roska.eu

The primary mission of the Society is to support patients with multiple sclerosis, to create the necessary conditions for a dignified, quality, full-fledged life, thereby contributing to their desirable integration into society. It implements specific health actions (rehabilitation stays with health programs, physiotherapy, swimming and hippotherapy) as well as other activities (organizational, methodological, educational, publishing, consulting and information activities, negotiation and allocation of state subsidies, etc.). The organization would like to expand its activities so that it can complement the services provided by state, mainly in the area of

counselling and support in communication with state authorities and health insurance companies, by the establishment of a counselling line and support for home care.

### **Nedoklubko**

represented at the seminar by **Ms. Lucie Žáčková**

e-mail: zackova@nedoklubko.cz

website: www.nedoklubko.cz

Nedoklubko is an NGO supporting mainly parents of premature babies across the Czech Republic. It was founded in June 2002 as a civic association. Today, Nedoklubko is a registered association which has several projects supporting parents of preterm infants and perinatal centres. It cooperates with all perinatal centres in the Czech Republic as well as Czech Neonatology Society of Czech Medical Association of J. E. Purkyně. It is also one of the 65 active members of the international organization EFCNI and is newly involved in professional research.

### **ParaCENTRUM Fenix**

represented at the seminar by **Mr. Ladislav Loebe**

e-mail: loebe@pcfenix.cz

website: www.pcfenix.cz

FB: ParaCENTRUM Fenix

ParaCENTRUM Fenix organization focuses on people after spinal cord injury (SCI). The organization provides various services (social assistance, legal advice, help with return to the labour market, psychological counselling, barrier-free area, facultative transportation services, short-term accommodation, leisure time activities) as well as health services (ergotherapy, physiotherapy) to the patients. It is also engaged in advocacy and defending the rights and improving the situation of people after spinal cord injury.

### **Diaktiv Czech Republic**

represented at the seminar by **Ms. Pavlína Mirschová**

e-mail: mirschova@post.cz

website: www.diaktiv.cz

The DIAKTIV is an association of active diabetics and educators. It is one of the few organizations carrying out educational activities primarily for type 1 diabetics, their family members, friends and other interested parties. DIAKTIV realizes educational projects focusing on motivation for active approach to treatment. It also advocates the legitimate interests of not only its members, but patients with diabetes in relation to health insurance companies and healthcare facilities, helping to negotiate sustainable conditions for healthcare, reimbursement of medicines and medical procedures.

### **Society for Mucopolysaccharidosis**

represented at the seminar by **Ms. Petra Tomalová**  
e-mail: metodik@centrumprovazeni.cz  
website: www.centrumprovazeni.cz; www.mukopoly.cz  
FB: Centrum provázení

Society for Mucopolysaccharidosis (MPS) focuses on providing support for families of children with MPS from the very first detection of illness. For this purpose, the MPS Society established the Centre of Guidance. Among other activities, the Society organizes national meetings of families having children with MPS, provides compensatory and rehabilitation aid and appliances, offers personal assistance and assistance in legislative area. It is also engaged in an effort to increase the awareness of the professional public on the rare diseases and increasing the competencies of parents and decision-makers.

### **Celiac Club Brno**

represented at the seminar by **Ms. Helena Pernicová**  
e-mail: pernicovahk@gmail.com  
website: www.klubceliakie.cz  
organization e-mail: info@klubceliakie.cz  
FB: Klub celiakie Brno

Celiac Club Brno supports meeting and association of adult Celiacs and parents of children with celiac disease and provides them with relevant information and services. An important task of the organization is to inform patients about the ways of preparing a gluten-free diet, to collect and publish recipes for the preparation of gluten-free dishes as well as to give practical tips to parents. The organization therefore focuses on educating patients and parents, creating educational materials and, last but not least, organizing events for children and adults.

### **ALEN women's association in Prague**

represented at the seminar by **Ms. Daniela Mikulejská**  
e-mail: dmikulejska@seznam.cz  
other contact person: Hana Kudelová (kudelovi@seznam.cz)  
website: www.alen.tym.cz

ALEN is a non-profit patient organization gathering women who have suffered breast cancer and underwent a demanding oncology treatment. The mission of the organization is to help women who suffer or did suffer from breast cancer return to their standard full-fledged lives. ALEN seeks and shares information about the illness, treatment and available physical and mental rehabilitation, so that patients receive the needed help and support to make their own choices, to overcome fear and actively fight cancer. A very important part of this work is meeting and personal contact. ALEN thus organizes meetings, rehabilitation exercises, swimming, reconditioning in the spa, hiking trips to nature, sightseeing tours, concerts and theatre visits.

### **Klíček Association**

represented at the seminar by **Ms. Markéta Královcová** and **Mr. Jiří Královec**

e-mail: [marketa@klicek.org](mailto:marketa@klicek.org)

[klicek@klicek.org](mailto:klicek@klicek.org)

website: [www.klicek.org](http://www.klicek.org)

FB: [klicekfoundation](https://www.facebook.com/klicekfoundation)

Klíček is a voluntary non-profit organization that originated from a group of parents of hospitalized children, several elderly patients and volunteers. The association supports the development of children's hospice and respite care in the Czech Republic. It has been supporting the establishment of a self-help parental centre at Motol Hospital in Prague and strives for the introduction of new roles in children's departments throughout the Czech Republic. Klíček advocates the rights of ill and hospitalized children (especially support for joint hospitalization of the parent along with the child) and also provides assistance for the bereaved of deceased children. It strives to promote civic attitude and conscious approach to one's own life and health, and to remove the existing barriers between healthy and ill people.

### **SYMPATHEA**

represented at the seminar by **Ms. Jana Poljaková**

e-mail: [jpoljakova@seznam.cz](mailto:jpoljakova@seznam.cz)

website: [www.sympathea.cz](http://www.sympathea.cz)

organization e-mail: [sympathea@sympathea.cz](mailto:sympathea@sympathea.cz)

Sympathea is a nationwide association of the relatives of mentally ill patients, which was established as a community service in 2003 in Prague. Activities of Sympathea are implemented throughout the Czech Republic and include clinic care, helpline, lectures, lobbying, counselling, etc.. The members provide each other mutual support, they benefit from the social contact with similarly affected people, share useful advice on health and social services and exchange information on mental disorders. Families experiencing the first occurrence of psychosis are assisted by a telephone counselling which operates in 24/7 mode.

### **Association of prosthetic patients, z.s.**

represented at the seminar by **Ms. Olivie Lánová**

e-mail: [protetickypacient@seznam.cz](mailto:protetickypacient@seznam.cz)

website: [www.protetickypacient.cz](http://www.protetickypacient.cz)

FB: [asociacePP](https://www.facebook.com/asociacePP)

Association of prosthetic patients is a voluntary, non-governmental, non-profit organization of prosthetic, orthopaedic, handicapped and otherwise disabled people who are active in the field of protecting the rights of patients and want to provide them with material, cultural or psychological assistance. The Association organizes educational (lectures, seminars), cultural, sportive and other social events as well as campaigns, surveys and petitions for the promotion and protection of the rights and wellbeing of patients. It provides material and financial assistance to disabled citizens and their families. When advocating the interests of

prosthetic and orthopaedic patients, Association of prosthetic patients participates in administrative and other proceedings and also cooperates with doctors, physiotherapists, healthcare and social workers.

**Dr. Kateřina Javorská, The Society of General Practice (GP), Charles University - Faculty of Medicine in Hradec Králové**

e-mail: k1.javorska@gmail.com

website: www.svl.cz; www.lfhk.cuni.cz

FB: pracovní skupina venkovského lékařství, SVL ČLS JEP

Dr. Kateřina Javorská works as a general practitioner and is a member of the Society of General Practice (GP) of the Czech Medical Association, which supports collaboration with patient organizations in the form of joint activities (educational workshops, lectures, etc.). Dr. Javorská participates in international initiatives under Europe Network for New and Future General Practitioners (VdGM and WONCA) and represents the Czech Republic in the European Rural and Isolated Practitioners Association (EURIPA). As a member of the EURIPA team, she has been involved in the pilot project on care for chronically ill patients which aimed at mapping the possibilities of involving all stakeholders (healthcare professionals, patients and their family members) in the healthcare of these patients. She seeks opportunities for activities that would improve the communication and discussion between healthcare professionals and lay people mostly in primary care settings.

## Icelandic institutions interested in cooperation<sup>5</sup>

### MUNICIPALITY OF HAFNARFJORDUR

Project Manager: **Hulda Björk Finnsdóttir** (hulda@hafnarfjordur.is)

Head of School Support Services: **Eirikur Thorvardarson** (eirikurth@hafnarfjordur.is)

Hafnarfjordur Municipality is the 3rd largest municipality in Iceland with 30000 people, 17 pre-schools and 8 compulsory schools. Hafnarfjordur offers comprehensive support services for children up to 18 years through its school and social services. Most children with behavioral problems (mental illnesses) are serviced/partly treated by municipality services (1st stage) while the state provides secondary psychological assessment and psychiatric treatment (2nd and 3rd stage). In order to prevent behavioral and psychological problems to escalate to 2nd stage, Hafnarfjordur Municipality has designed an early intervention model. Aim of the model is to improve the quality of life of children and youth in Hafnarfjordur. Through cooperation between the school and social services and all pre-schools and compulsory schools the model consists of following aspects:

- Solution teams located within each school;
- Increased collaboration –The Social and School Services;
- Better use of the expertise and resources available at schools;
- Better use of expertise and resources at the Social-and School Services;
- Fewer psychological assessments;
- Fewer notifications to the Child Welfare Board.

Potential Partners include municipalities, school district offices, healthcare services, social services interested in implementing a holistic early intervention programmes to prevent developmental and psychological problems in children.

### Kara Connect

General Manager: **Thorbjorg Helga Vigfusdottir** (Thorbjorghelga@karaconnect.com)

website: karaconnect.com

Youtube: [www.youtube.com/watch?v=6AGtHbHbQko](https://www.youtube.com/watch?v=6AGtHbHbQko)

<https://www.youtube.com/channel/UCAOp-M3g46oJB7rFumGLtsg>

Kara Connect is an Icelandic start-up company established in 2014. To date over 1500 clients have used the services (10000 therapy sessions). Kara Connect is a browser-based secure tele-therapy platform (SaaS) and a virtual office for professionals. The platform offers a virtual office for professionals and tele-therapy (video sessions) for children and adults who need special education services (speech therapy) or psychological therapy. Kara offers professionals a secure platform to provide treatment, optimize their administrative needs and gives all people, irrespective of location, equal access to help, support or training. Kara thus connects children and adults in need of help to different professionals in a quick and affordable way. The platform gathers and stores statistical data on length of therapy sessions, outcomes of therapy and is GDPR compliant.

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<sup>5</sup> These organizations were not present at the seminar.

## **Hugarafli**

Contact person: **Audur Axelsdottir** (audur@hugarafli.is)

website: www.hugarafli.is

Hugarafli is non-profit organisation located in Reykjavik Iceland. Hugarafli was founded on Judi Chamberlin theories of empowerment of people with mental illnesses. Hugarafli offers individual empowerment approach for those who have experienced mental illnesses and their next to kin (families/friends). Hugarafli offers individuals support to recover and regain control of their own lives through an individualized approach. Hugarafli's unique approach crystallizes in an individualized approach, cooperation between different specialists and the users of the mental health services on a peer basis. Hugarafli's users create their own rehabilitation programmes and provide other users support. Hugarafli's main objectives are:

- Impact Icelandic mental health care system;
- Eliminate prejudice in Icelandic society;
- Promote knowledge about recovery and the process of recovery;
- Increase the human rights of people with mental illnesses and support more diversity in service to people with mental illnesses;
- Strengthen the cooperation between specialists (nurses, psychologists, psychiatrists) and users;
- To be visible in Icelandic society through hosting of different initiatives and participation in public discussions.

Potential partners include NGOs, health organisations, public health care administrations looking to implement empowerment services/user oriented rehabilitation programmes for people with mental illnesses.

## **North Consulting**

General Manager: **Maria Kristin Gylfadottir** (maria@northconsulting.is)

website: www.northconsulting.is

For more information about potential partners in Iceland and project ideas you may contact Maria.



## Other Norwegian institutions interested in cooperation

Institution	Topics	web-site	Contact	e-mail
National competence Service for Rare Diseases	Rare diseases, diagnose, training	<a href="https://sjeldnediagnoser.no/home/sjeldnediagnoser/Englsh/15011">https://sjeldnediagnoser.no/home/sjeldnediagnoser/Englsh/15011</a>	Rebecca Tvedt Skarberg	<a href="mailto:retska@ous-hf.no">retska@ous-hf.no</a>
National competence service for simultaneous substance abuse and mental illness	Simultaneous substance abuse and mental illness	<a href="https://rop.no/">https://rop.no/</a>	Lars Lien	<a href="mailto:lars.lien@sykehuset-innlandet.no">lars.lien@sykehuset-innlandet.no</a>
Regional Centre for mental health of children and youth (RBUP)	Provide good academic support to leaders for the children's and youth services in municipalities, specialist health services and in child welfare.	<a href="http://www.r-bup.no">www.r-bup.no</a>	Arild Bjørndal	<a href="mailto:ab@r-bup.no">ab@r-bup.no</a>
SUPEREGO	Digital self-help programs	<a href="http://www.aidoru.no/">http://www.aidoru.no/</a>	Svein Øverland	<a href="mailto:svein@superego.info">svein@superego.info</a>

For more information about potential partners in Norway and project ideas you may contact **Solfrid** at [Solfrid.Johansen@fhi.no](mailto:Solfrid.Johansen@fhi.no).