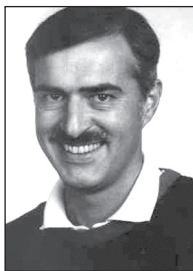


## Key persons in the seminar “Baltic Bridge”



### Jens Harhoff

I was born in 1945 in Århus, Denmark. In 1965 I became a student. I was Lieutenant in the army until 1970. After army I worked for 5 years in Odense University as a teacher of sports but I did not feel that this was the right place for me. Therefore I became a chief purser on a ferry. I also worked as a manager of 3 camping sites until I got the diagnoses in 1998. I started to use feeding tube in 1999 and ventilator in 2000. I became active in the Danish Foundation of Muscular Disorders and I have been the Danish representative in the International Alliance for some years. After Gudjon I became chairman in the Nordic Alliance. I also arrange courses for people with ALS In Denmark.

I am interested in helping people who are suffering from ALS and are living in a country that could have better conditions for handicapped people.



### Urmas Reinsalu

I was born in 1975 in Tallinn, Estonia. I have studied law in Tartu University and currently I am doing PhD degree there. I work as a politician and belong to Pro Patria and Res Publica Union (Isamaa ja Res Publica Liit). I am also a member of Estonian parliament and lead there the Social Affairs Committee.



### Riina Mõim

I am working as a physiotherapist in Haapsalu Neurological Rehabilitation Centre since January 2009. Our rehabilitation centre is providing modern treatment for various diseases by experienced and cooperative specialists. I love our rehabilitation centre because besides physical rehabilitation it also provides psychological well-being, socialising, support and sharing experiences. When I see happy faces of our patients and workers and hear thankful words, then I know that I have the best occupation and working place.



### Gunnar Rúnar Matthiasson

I was born in Akureyri, town in the northern part of Iceland on April 4th 1961. I live in Kopavogur, a suburb of Reykjavik with my wife and three children.

I studied in the University of Iceland and I was ordained as a pastor within the Icelandic Lutheran Church. I specialized in Pastoral Care at the University of Iowa Hospitals and Clinics in Iowa, USA 1987–1989. I served in the Evangelical Lutheran Church of America as a Hospital Chaplain in interfaith ministry in Chicago Illinois, USA 1989–1996 and specialized in supervision of Pastoral Care and was certified Supervisor of Clinical Pastoral Education in 1996. I have served as a Hospital Chaplain and supervisor of Clinical Pastoral Education at Landspítali, University Hospital in Reykjavik since 1996. I have served on the Hospital's MND team since 2002. I taught at Abbott Northwestern Hospital in Minneapolis 2003 and at Chandler School of Theology, at Emory University in Decatur Georgia 2003–2004.



### Jette Møller

I am 66 years old. I have worked for more than 30 years as a counselor in neuromuscular diseases, for the last 15 years only MND/ALS. In 1971 I was one of the founder of the Danish association of Neuromuscular diseases “ Muskelsvindfonden”. I am trained as occupational therapist (ergotherapeut) and in 1976 I started with physiotherapist Birgit Steffensen a centre for guidance and treatment of neuromuscular diseases, which to day is called Rehabilitation Centre for Neuromuscular Diseases. I was leader of the first Danish study about ALS-patients in Denmark about 1988. After 3 years as members-counselor in Muskelsvindfonden for people with ALS/MND the Rehabilitation

center succeeded in financial support to the first ALS-counselor scheme. From 1996 to 2003 I was ALS-counselor and from 2003 until I stopped in 2007 I worked on an interview-study about the choice of mechanical ventilation for persons with ALS. I have been the Danish representative in the International Alliance of MND/ALS Associations for many years and member of the board for 3 years.

I have a daughter and a grandchild and I live with my boyfriend near Copenhagen.



### **Gleb N. Levitsky**

I was born in 1976 and I work as a neurologist. I am the author of the first molecular genetic study of ALS in Russia. After that I started to implement the international standard of ALS management – in-patient and out-patient treatment, management of ALS patients taking Rilutek and palliative therapy. I am the first specialist in Russia who managed ALS patients after gastrostomy with enteral feeding, and who for the first time started to treat ALS patients with non-invasive positive pressure ventilation in Russia. I have had a practice in foreign neurological clinics with specialized ALS center (Carlos Tercero Hospital, San Carlos Hospital, Madrid, Spain). I participate in European ALS Registry program and I am the co-author of clinical guidelines on ALS of the All-Russian Neurological Society (2006).



### **Jens Dalsgaard-Jensen**

I was born in 1941 and I live in Denmark. I am educated hand moulder (1958–1962) and foundry engineer (1962–1965). I have worked in different steel and iron foundries as an engineer, manager and director. Physical problems appeared late 1990s and in 2001 I was diagnosed with ALS.



### **Kristiina Jokinen**

I was born 53 years ago in Turku. I have three adult daughters with my husband Mikko. In 1979 I acquired a diploma as a rehabilitation physiotherapist. I got a job as a physiotherapist in the Muscular Disorder Association in 1987 and have been working there for over 20 years now. In the past few years the nature of my work has changed – I have fewer exercise sessions with individual customers and instead give courses to specialists and people with muscular disorders. I also take part in the rehabilitation courses arranged by the Muscular Disorder Association. The association gives 10 courses each year for people with ALS and their family, all of which take place in different parts of Finland. During the years I have become specialized in breathing therapy and teach the usage of breathing equipment to people with MD and medical workers. I believe that exercising in water and pool therapies are very beneficial for my customers.



### **Arne Lykke Larsen**

I am 45 years old and I was diagnosed with ALS 10 years ago. Got a ventilator 5 years ago. I am single and live alone (with my assistants). I still go to work everyday as an associate professor of theoretical physics at the University of Southern Denmark in Odense.



### **Mart Saarma**

I was born in 1949. I am the Academy Professor and Director of the Centre of Excellence in Molecular and Integrated Neuroscience of the Academy of Finland at the Institute of Biotechnology, University of Helsinki, Finland. I have studied neurotrophic factors and their receptors in the development and in neurodegenerative diseases. I am also the member of several academies and EMBO. I have received several domestic and international scientific prizes and awards. In 2009 I received a prestigious Nordic science prize.



### **Pille Taba**

I am an Associate Professor of Neurology, and Head of the Department of Continuing Medical Education at the University of Tartu, Estonia. I am also a President of the Estonian Society of Neurologists and Neurosurgeons, and a founding member of the Estonian Movement Disorder Society.

I received my medical degree from University of Tartu, and medical training at the University of Vienna, the Karlstad University Hospital, and the Minneapolis Clinic of Neurology. My clinical activities and research interests have been focused on neurodegenerative disorders, mainly

movement disorders: epidemiology, management, and psychosocial aspects. I have been involved in the activities of the patients' organizations in Estonia in organizing patient meetings, and editing patient informational materials. I serve as a member of Medical Advisory Board of the European Parkinson's Disease Association.



## Mae Pindmaa

I received my degree in 1985 from University of Tartu, Faculty of Medicine and continued my studies in Moscow, Helsinki and London. Having obtained qualifications as a cardiologist and pediatrician, as a young doctor I treated sick newborn and premature babies at the Tartu University Children's Hospital. Later I dedicated myself to diagnosing and treating congenital heart diseases in the cardiac surgery department of the Tartu University Clinic. I have been involved in sleep medicine since 2001. I have participated in practical trainings in Germany, Finland and the USA, which contributed to my knowledge in this field. In 2005 I was elected president of the newly established Estonian Sleep

Medicine Association.

At present my everyday work consists of diagnosing and treating sleep disorders of different origins. I aim to find the deepest causes and backgrounds of my patients' discomforts. Our practice performs sleep studies at Tallinn and Võru sleep clinics. If necessary, we prescribe additional studies and tests, aiming to treat patients holistically, concentrating on the whole body, not only relieving a certain discomfort. Our doctors and patients work as a team – good health is what we all strive to achieve.



## Gudjon Sigurdsson

I was born in 1960 in Iceland. I am married to Halla for 25 years and we have 3 beautiful daughters. I have been taking part in all kinds of social work since I started in high school.

I am educated as a plumber and I worked as such as long as I could. Until in march 2004 I was diagnosed with ALS/MND.

Since June 2005 I have been the chairman for the Icelandic ALS/MND association. Now I am also the chair for the International alliance of ALS/MND associations.



## Andres Metspalu

I am director of the Estonian Genome Center and full professor of biotechnology of University of Tartu. I graduated from the University of Tartu in 1976 as physician, obtained Ph.D. in 1979 in molecular biology. I was as a postdoc at Columbia University in New York and Yale University in 1981–1982. I have published about 100 papers and chapters on ribosome structure, molecular diagnostics and human genetics. From 1996 to 2008 I was also the founder and head of the Molecular Diagnostic Center of the Tartu University Hospital. I am the past (2006) president of the European Society of the Human Genetics (ESHG) and current president of the EstSHG. I am one of the founders and directors (2002–2007) of the P3G international consortium of biobanks.



## Annely Soots

I am the president of the Estonian Association of Nutrition Therapy, the headteacher of Annely Soots Health School and a nutrition therapist at Via Naturale.

I graduated from the University of Tartu in 1982 as a physician and in 1992 as a psychologist and studied social sciences during 1997–1999. Acquired a diploma as a nursing teacher from the Tallinn Pedagogic University and learned cognitive behavioral psychotherapy and family therapy.



## Maruta Solvita Iveta Naudina

I have been working as a neurologist for 45 years. First ten years of the career I worked in a countryside hospital but since 1979 I have been working in Paula Stradina Clinic Univerisity Hospital (Riga) and now I am in charge of neuromuscular disease consulting-room. I have a vast experience in working with patients with myasthenia and myopathy. I have been working with the Patients Association and developed guidelines for patients' needs, care, algorithms for diagnostics and treatment. I am teaching neurology students as well as conduct lectures that raise my qualifications. I participate in interdisciplinary seminars for patients with suspicion of neuromuscular pathologies.

I frequently take part in international seminars and congresses. I gained more knowledge in Norway through summer school on Medical Care and Health service.

I am married; husband Gunars Naudins is neurosurgeon. We have two children – daughter Laima and son Maris and five grandchildren.

I love to travel, I like gardening and floriculture, I am engaged with beekeeping and passionate for swimming.