



Coeliac and coeliacs in Estonia

Aive Antson

Chief of Board

About history of our society

- 1996 – Dr. Oivi Uibo and Külli Mitt invited families who had child of coeliac disease to join and organised meetings and etc
- 14.02.1998 – the foundation articles were certified. We are a non-profit organization.
- Since 1998 – member of the Estonian Chamber of Disabled People

The Estonian Chamber of Disabled People

- National Disability Organizations (30), including unions
- Work of the unions is carried out separately in all impairment groupings across the country.
- The Estonian Diabetes Association
- The Estonian Allergy Federation
- The Estonian Heart Association

The Estonian Chamber of Disabled People

- Organizations in the counties, including county chambers (16)
- Work of the chambers is regional in scope of all impairment groupings of the county.
- County of Viljandi, the Chamber of Disabled People included
- County of Võru, the Chamber of Disabled People included

About history of our society

- Since 2006 – member of AOECS (Association of European Coeliac Societies)

The Estonian Coeliac Society

- The Estonian Coeliac Society joins coeliac patients, their family members, medical staff and anybody else wishing to support the coeliac patients.
- The main lines of activity of the Estonian Coeliac Society are supporting of coeliac patients, distribution of coeliac information and protection of the interests of coeliac patients.

The Estonian Coeliac Society

- The activities are based on the projects financed from the Foundation of Estonian Disabled People.
- We have applied for additional funding also from the Gambling Tax Council and Estonian Health Insurance Fund.
- 6297.00 is budget of this year from Foundation of Estonian Disabled People.

The Estonian Coeliac Society

- About 4% of annual budget form memberships of our society.
- The memberships are
 - 10.00 for family a year (irrespective of persons amount in family). So they have free participation in summer camp, Christmas party etc
 - singlemother and single pensioners pay 7.00

The Board

- The Board includes 2 members
- Aive Antson and Riin Jõgi are the members of board

About active persons

- Kaire Kivirand is our manager for Foreign Relations Project
- Merle Maisla is a contact person for gastroenterologist
- Katrin Viljarand and Merike Tärk participate in fairs

The Estonian Coeliac Society

- There are 109 members in our society.
- There are 43 coeliacs, 3 persons with gluten intolerance and the others are members of family

What we do?

- The general meetings twice a year
- The Board meeting 5 – 6 time a year
- Information Day in autumn
- Health day in May
- Summer camp in July
- Christmas party in December

How many coeliacs are there in Estonia?

- Estonian Health Insurance Fund counts all diseases involved in small intestine up and doesn't separate out coeliac disease.
- Because of that we don't know how many coeliacs are there in Estonia.
- 700 – 800?
- Coeliac is underdiagnosed in Estonia
- There are some scientific work too in Estonia

About for products and its prices

- We can buy glutenfree products in big stores – Prisma, Selver, Stockmann
- Glutenfree products are about seven times more expensive than other food

Why to participate in the activities of our society?

- Specific help from the society – information, literature, close contact
- Self-realization
- New acquaintances

Major projects

- Publishing of the children's book "Ida and the Cake. When You Cannot Tolerate Gluten"
- Distribution of patient information to gastroenterologists
- Supply of family physicians with patient information

In this year

- New Patient Notebook
- Tomorrow Nanna Puntila and dr. Eglite lecture

Our achievements

- Availability of gluten-free products in stores (Selver, Prisma)
- Information days – trainings, lectures
- Distribution of coeliac literature
- Popular web page – operating forums with 5 different themes
- Solidarity

Our problems

- Cooperation with medical staff
- Low awareness of the community in Estonia
- Incompetence of some doctors in the field of coeliac disease
- Low awareness of commercial and catering staff
- Small assortment of glutenfree food at shops

Our problems

- Low interest of retail chains and stores in the sale of glutenfree food
- The adult coeliac patients do not receive financial support for the purchase gluten-free food products
- Contradiction in the knowledge of our and European physicians – alcoholic beverages; should a food product with gluten content of 20 mg/kg be considered as containing gluten or gluten-free?

Our problems

- Unawareness of Estonian food producers of “pure gluten-free” production
- Alternative medicine (acupuncture doctors, blood group diet) diagnose gluten intolerance, but doctors say that it is not disease

Problems related to coeliac awareness of family physicians

- Patients are not forwarded to a gastroenterologist
- Physicians do not recognise the disease – “I can recall it from the university, but I could not imagine that somebody could really suffer from it”
- Physicians do not know the precise diet – “all cereals are prohibited”

Development perspectives

- Increase of the assortment of gluten-free products in the stores
- Support also to adult coeliac patients
- New material for coeliac
- New information