



Coeliac Disease and Gluten Related Disorders in Russia and Former Soviet Republics

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Celiac Disease in Russia – 1980-s



The first diagnoses of CD in Russia refer to the late 1970-s – 1980-s. These were typical cases with severe malabsorption. The diagnose of CD was unknown by most pediatricians and gastroenterologists.

All such patients were treated as “chronic enteritis”, “enzymopathy” and “intestinal dysbacteriosis” (“diagnosis” much loved in our country, which means somewhat like bacterial overgrowths)

CD had been diagnosed only in Moscow, St-Petersburg and N.Novgorod, where pediatric endoscopy was available. Capsule (aspiration) biopsy had never been used in Russia.

Serologic methods were absent or restricted to antigliadin antibodies. No gluten-free foods were available.

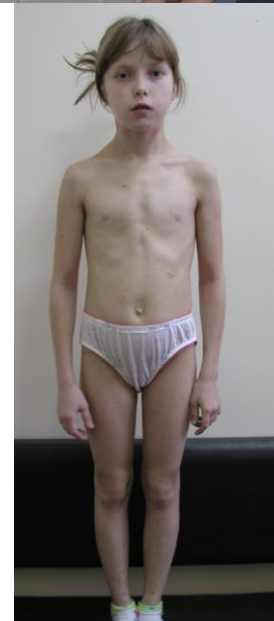


Celiac Disease in Russia – 2000-s

Now the “atypical”, extaintestinal forms are diagnosed more and more often, also in adolescents and adults, but severe typical forms in toddlers also exist.

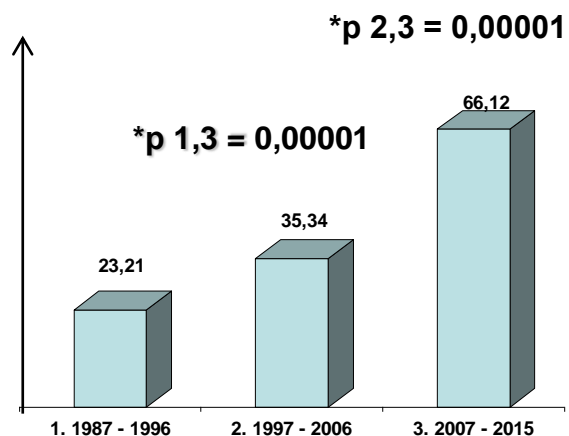
Celiac disease is well-known in most of the regions of Russia

Research work is being held in many universities and medical centers (Moscow, St-Petersburg, N. Novgorod, Tomsk, Krasnodar, Ekaterinburg, Smolensk, Ryazan, etc).

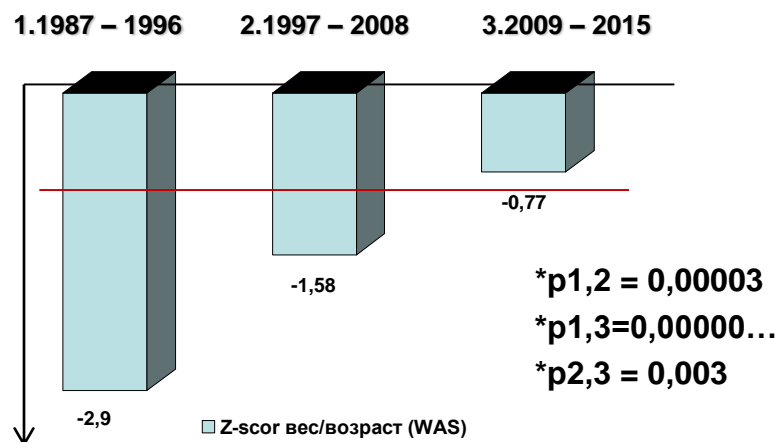


In Russia we find significant increase of age and improvement of nutritional indices at diagnosis from 1980s to 2015. Our data confirm the global trend of alleviation of CD symptoms, although we have no asymptomatic patients because of lack of screening programs (see our Poster)

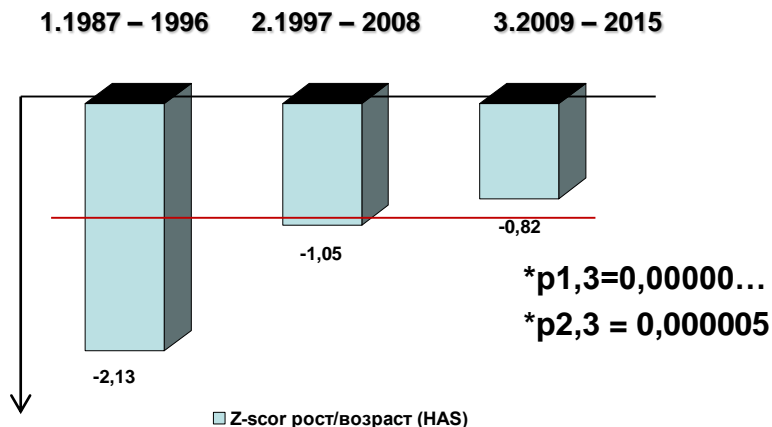
Age at diagnosis, months



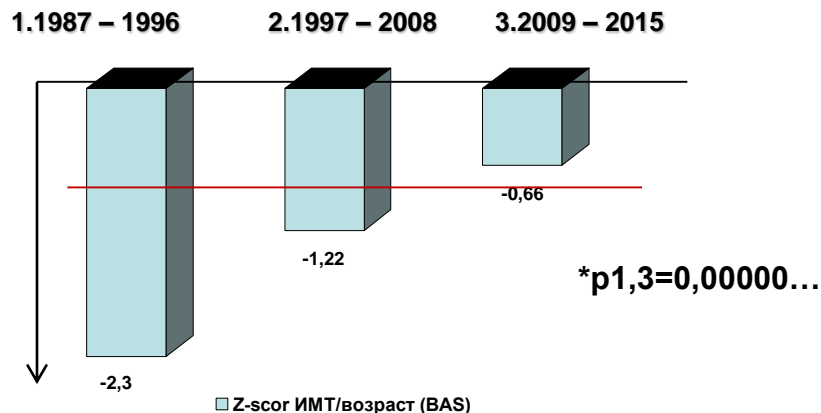
Z-scores, weight/age



Z-scores, height/age



Z-scores, BMI/age



Epidemiology

- Since 1990s mass screening was held in Romania, Slovakia, Slovenia, Estonia, Brasilia, Argentina, Mexico, India, Turkey, Iran, Iraq, Libya, Algeria, Tunis, Saudi Arabia, Kuwait, Jordan, Cameroon, New Guinea (prevalence of 0,2 – 1,3%),
Bedouins of Sahara (prevalence 1:18)

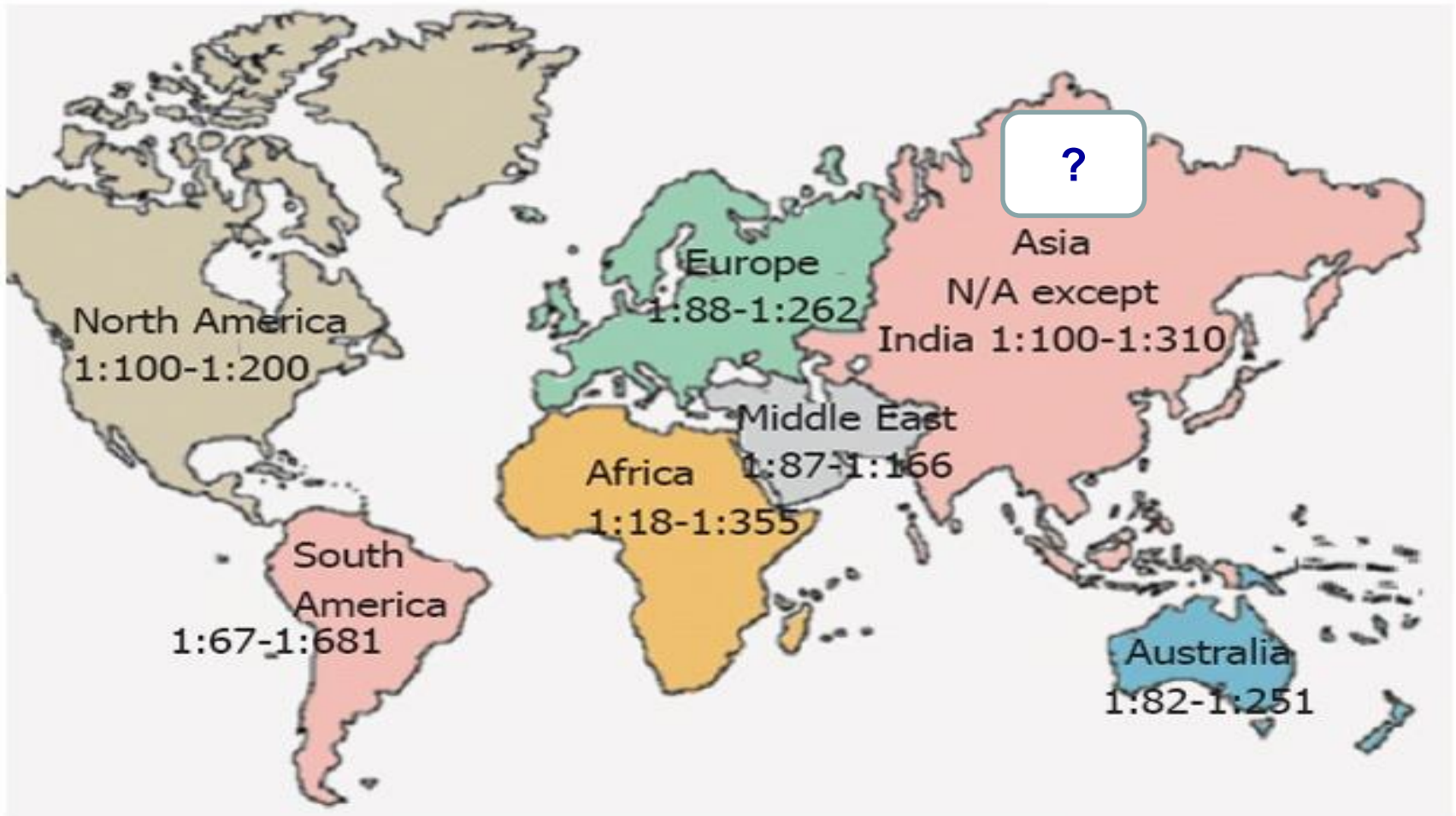
On the assumption, CD is the most wide-spread inherited disease in the world!

- The absence of mass screening – at present we do not have any certain data of CD prevalence in Russia
- Official registration of CD patients is mostly absent, except for a few regions
- There are few screening studies in the risk groups (*Стройкова М.В., Мухина Ю.Г., 2006; Репин А.А. и соавт.2008, Сабельникова Е.А., 2008, Парменова Л.П. и соавт., 2009*) which show that the prevalence of CD within these groups does not differ much from the Europeans'

- The expected number of CD patients in Russia is **1.039.000 people** (*Holteimer W., 2007 Schaer Professional N 3, p.9*)
- **Please compare!** The approximate number of CD patients based on the data provided by key specialists is very low:

St. Petersburg	1500 - 2000
Moscow	800-900
Novosibirsk	130
Ekaterinburg	250 - 300
Nizhnii Novgorod	100-150
Samara	100
Omsk	20
Kazan	20
Cheljabinsk	30
Rostov-na- Donu	50
Ufa	30
Krasnoyarsk	15-20

Epidemiology



N Gujral, HJ Freeman, ABR Thomson. Celiac disease: Prevalence, diagnosis, pathogenesis and treatment. World J Gastroenterol. 2012 Nov 14; 18(42): 6036–6059.

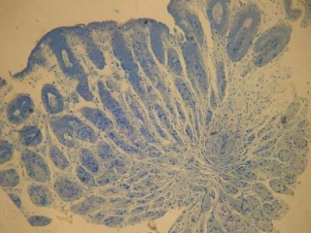
Serologic Diagnostics

Serological diagnostics became more available now

- But non-specific anti-gliadin (IgG) antibodies test is still most widely used
- The anti-tTG assessment is also available in regional centers
- EMA-antibodies and antibodies to deamidated gliadin peptides are available at few commercial laboratories and are not wide used

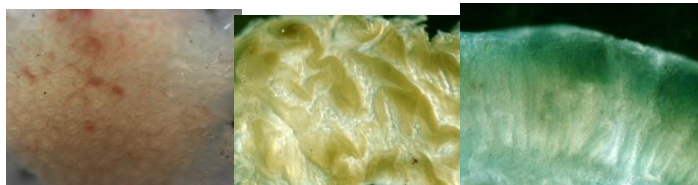
Problems:

1. The diagnosis of CD in Russian regions is frequently based on the clinical symptoms and raised antigliadin antibodies only (without anti-tTG, HLA-typing and intestinal biopsy)
2. Laboratory tests when CD is suspected are made by commercial laboratories, therefore not being covered by state medical insurance (patients/parents must pay)



Morphologic Diagnostics

- Quality morphological diagnostics is available only in a few centers (Moscow, St-Petersburg, N. Novgorod, Novosibirsk)
- The results of morphological examination made in regions are often questionable and unsatisfactory; the Marsh-Oberhuber (or Corazza-Villanacci) classification is not being used
- But: **morphometry** is used in most advanced clinics (Moscow, SPb), no problems with proper orientation
- We use morphometric scale to diagnose CD (*Lysikov Yu, 2006*)
- Stereomicroscopy is also available
- Immunohistochemical investigation, typing of IEL's: practically absent
- IgA-tTG deposits on basal membrane of enterocytes: method is not in routine practice (*Vochmyanina N.V. Saint-Petersburg*)



	norm	Celiac disease (not treated with GFD)
Villous height (mkm)	325-400	0-250
Crypts' depth (mkm)	150-200	200-600
Mucosa thickness (mkm)	525-650	350-650
Villous/crypts' ratio	1,6-2,7	0-0,8
Lymphocytic infiltration of epithelia (IELs, %)	15-27	40-150
Lymmplo- plasmocytic infiltration of lamina propria (4-ball scale)	0,5-1	3-4

Genetic Research

HLA-typing:

- Is not a routine method of investigation
- Is made by commercial laboratories in Moscow, St-Petersburg (paid by patients/parents)

Prevalence of DQ2/DQ8-alleles:

- In Finland (*Polvi et al. 1998*) DQ2 and/or DQ8 - **97%**
- In Northern Europe (*Margaritte-Jeannin P., 2004*) **98,9%**
- In Kazakhstan (*Исабекова Т.К., 2007*) DQA1*0501, DQB1*0201 **62%**
- In Uzbekistan (*Камилова А.Т., 2007*) DQA1*0501, DQB1*0201 **69,2%**
- In Russia (Tomsk) (*Кондратьева Е.И., 2006*) DQ2 and/or DQ8 **70%**
- **But in Moscow (*I. Zaharova, Yu. Dmitrieva, E. Kasatkina, E. Roslavl'tseva, 2012*) and St. Petersburg (*M. Revnova 2005*) DQ2 (DQ2,2) and/or DQ8 had **100% of patients****

Reasons:

1. The local peculiarity of genotypes - **???**
2. We consider that low percentage of DQ2/DQ8 alleles is due to **incorrect diagnosis of CD**

CD in Uzbekistan

(prof. A. Kamylova, Tashkent)

CD is diagnosed in a single clinic in Tashkent

No official registration of CD patients is taken, but around 400 patients are reported
The IgA-anti-tTG assessment is available. In children younger than 5 years old the upper GI endoscopy cannot be performed, so in symptomatic cases with 10-times elevated IgA-tTG, HLA-alleles is used to confirm the diagnosis, but not EMA. In children older than 5 years CD is always confirmed by biopsy with morphometry.

EMA-antibodies and antibodies to deamidated gliadin peptides are not available now but are coming soon.

1st degree relatives, children with failure to thrive, short stature, anaemia, and autism are screened by IgA-tTG and HLA-typing.

Patients with established CD diagnosis receive governmental support in form of a disability pension)

The diagnosis of Non-Celiac Gluten Sensitivity is made upon ESPGHAN recommendations after CD and wheat allergy exclusion. Meanwhile, growing incidence of the latter condition is reported.

CD in Belarus

(I. Savanovich, Minsk)

The official record of CD in Belarus is 153 patients

They use anti-tTG and anti-gliadin assessment

The gastroscopy and small intestinal biopsy is obligatory

EMA-antibodies and antibodies to deamidated gliadin peptides are not available

HLA-typing is not available in most cases

The ESPGHAN 2012 diagnostic protocol is not used

Gastroscopy/biopsy is used for screening in risk groups

All diagnostic procedures are free for patients and are financed by Government

**Children under 18 years with established CD diagnosis receive Governmental support
(disability pension)**

**The diagnoses of Non-Celiac Gluten Sensitivity are made after CD and wheat allergy
exclusion.**

CD in Georgia

Prof. Michael Lentze, Germany -Georgia

- There is no register in Georgia for CD patients. The prevalence in Georgia is unknown. For the one year Michael had been working in Georgia he was able to find 20 patients, the majority with classical symptoms: chronic diarrhea, small stature and failure to thrive
- He is starting a study on diabetes mellitus and CD. Screening program is planned for diabetics first.
- tTG, DPG, gastroscopy, small bowel biopsy and pathology after Marsh are available, but most patients don't have a biopsy, because the parents have to pay for it. Insurance does not cover the biopsy. In most cases possible patients are put onto a gluten free diet after positive tTG antibodies. Sometimes even gliadin antibodies are still determined.
- The ESPGHAN guidelines are not followed by Georgian doctors. HLA testing is not available in Georgia.
- CD patients don't receive any help from insurance or government.
- Before Michael started there was no dietetic guideline for CD. Together with a Georgian nutritionist they have written guidelines for CD in Georgia. And they are using also the Russian book on CD, because everybody speaks Russian. Gluten free products are available, because buckwheat, corn bread and chumiza (a sort of millet) is part of Georgian nutrition. Therefore these products are readily available in supermarkets. Ready made products are not available in the country, they need to be imported from abroad and are very expensive.
- Non-celiac gluten sensitivity is so far not diagnosed in Georgia, because it is not known

CD in Latvia

Ieva Pukite, MD, Irina Rubinchik

The prevalence of CD in Latvia based on serologic screening among adults range from 0,35% to 0,49%, depending on criteria used (*Leja M, Nikitina-Zake L, Gavars M et al. United European Gastroenterol 2015 Apr; 3(2) 190-9*)

There is a register of CD children aged 0-18 since 2005, but not for adults. The number of CD children in the record is approximately 1500. The overall number of patients, including adults, is around 4000.

IgA, IgG-tests for antibodies to tissue transglutaminase , HLA-typing and duodenal biopsies are available

ESPGHAN 2012 diagnostic protocol is in use

Children and students with CD beyond 24 years of age receive monthly aid of 106 Euro from the Government

Mandatory CD screening is held in patients with IDDM and AIT

Since 2014, the Eurocomission Regulation No. 1169/2011 works in Latvia, in accordance with that, all products are labeled with 14 food allergens, including gluten

The diagnosis of NCGS was established in few patients by medical consilium

CD in other Baltic Countries

Estonia: The Estonian Coeliac Society was established in 1996 by the initiative of parents and paediatricians of the Children's Clinic, Tartu University Hospital. (K. Mitt, O. Uibo) The Society has 122 members, of whom 43 are CD patients.

No new cases of CD were found at the 10-age serological follow-up in Estonian population of school children and young adults, 2002-2012 (*Lillemae K, Ress K, Harro S et al, Eur J Gastroenterol Hepatol. 2012 Jan;24(1):55-8*)

Lithuania: The prevalence of CD in Lithuania is 0,2% (*Vaidotas U, Sadauskaite J. Abstracts of the 14th ICDS, June 20-22, 2011, Oslo, Norway*)

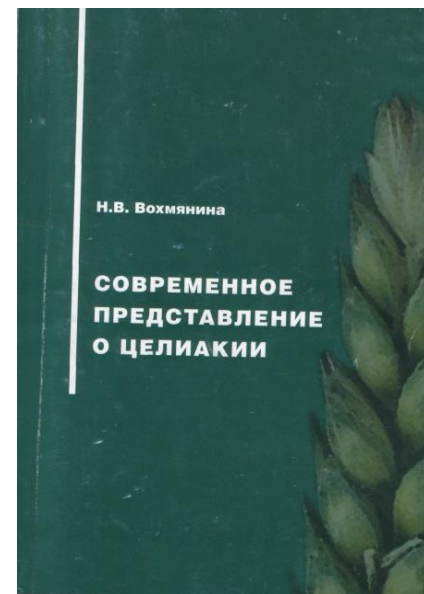
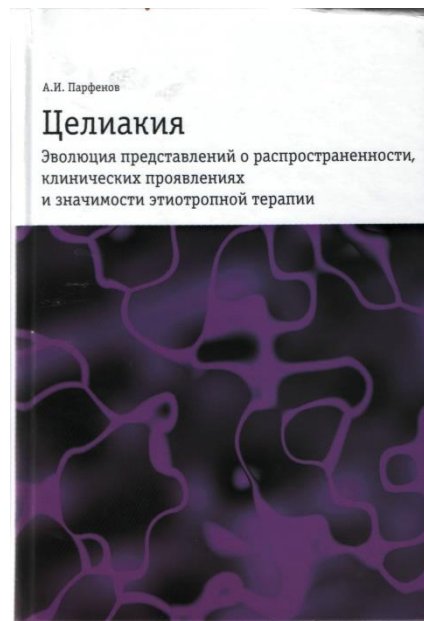
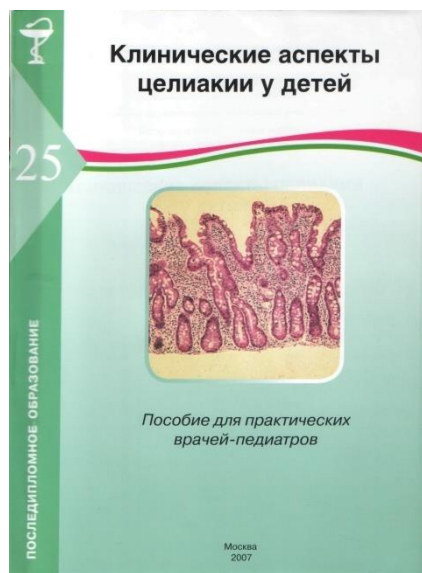
Summary- Problems

- Absence of mass screening, few screenings in risk groups lead to absence of CF prevalence data in Russia. Absence of state programs of scientific research on celiac disease.
- Low availability of well-timed serologic and genetic examination when CD is suspected. Main analyses are held by commercial laboratories.
- Limited facilities for timely endoscopy with intestinal biopsy and quality histological examination of biotates. Low skills of pathomorphologists in CD diagnostics.
- The use of antigliadin-IgG-antibodies at CD diagnosis
- *Widespread prescription of a gluten-free diet “ex juvantibus”, which leads to diagnostic mistakes, necessity of gluten challenge, delay of diagnostics for years*
- The diagnosis of NCGS becomes much known by pediatric gastroenterologists and is made according to ESPGHAN recommendations (2011). The number of patients with NCGS is growing despite the fact that NCGS is absent in the ICD-10.

Problems with GFD compliance in Russia

- **Traditional Russian cuisine is rich in gluten ingredients**
- **Insufficient understanding of the necessity of strict and life long compliance to the GFD by patients, their relatives (especially grandmothers) and doctors**
- **Impossibility of GFD in kindergartens, schools, sanatoriums, summer camps, restaurants – social deprivation of a child**
- **Paucity of domestic gluten-free substitutions, imported gluten-free products are expensive and in some regions unavailable**
- **Presence of “hidden gluten” in manufactured products, no appropriate labeling. No state documents which can force the manufacturer to label the gluten-containing substances in their products, including drugs and medications.**
- **No social support of CD patients in most Russian regions**

**But the things are not so bad that they may seem
We are enthusiastic: monographs on CD 2007-2015**



**Our patients are involved in ProCeDe study
(Moscow, Astrakhan)**

Patients' Societies

- **Saint-Petersburg**
- **Krasnoyarsk**
- **Kazan'**
- **Lipetsk**
- **Moscow**
- **Krasnodar**
- **Saratov**
- **Ekaterinburg**
- **Samara**
- **Tomsk**
- **Novosibirsk**
- **Chabarovsk**
- **Cherepovets**
- **Yakutsk**



**Thank you for your
attention!**



Gluten free



GLUTEN FREE

