

Dear child and parent/s

Celiac disease, also known as gluten intolerance, is a permanent sensitivity to gluten which is found in wheat, rye and barley. The cause of celiac disease is still unclear but we know that both heredity and environment play a role.

In Sweden, celiac disease is more common than in many other countries. It is crucial to find out why this is so and if we can reduce the incidence of celiac disease in any way through lifestyle changes.

The Swedish Pediatric Association (Svenska Barnläkarförening/BLF) has therefore, for several years, supported a nationwide register in which all children with newly diagnosed celiac disease are reported. We can increase the awareness of celiac disease by following the pattern of the disease across the country as well as through other research.

Your child is now being investigated for suspected celiac disease. We hope you agree to let the child's personal identification number as well as some details regarding the investigation results to be reported to the registry. Your decision does not imply consent to participate in any research, but you may receive such a request later. Inform your child's doctor of your decision. If you change your mind, you or the child later can inform and decide to remove the child's social security number from the register. Decisions about being in the registry do not affect the child's care in general.

The register is administered from Umeå University, with the reference number: UmU 101-U2496-04. If you have any questions you can ask your child's doctor. You are also able to contact any of us responsible for the register. You will find contact information below.

The same rules of confidentiality in healthcare in general terms apply. The register is approved by the research ethics committee and conforms to the rules of the Privacy Act.

If you have any questions, contact us!

Thanks for your help and Best Regards

Anneli Ivarsson
Pediatrician and Head of Unit
Responsible for register
Department of Clinical medicine and Public Health
Epidemiology and Global Health
Umeå University,
SE-901 85 UMEÅ
E-mail; anneli.ivarsson@epiph.umu.se

Susanne Walther
Administrator
Department of Clinical medicine and Public Health
Epidemiology and Global Health
Umeå University,
SE-901 85 UMEÅ
Tel 090-785 12 11, Fax 090-13 89 77
E-mail; celiakiregister@epiph.umu.se

Olof Sandström
Pediatrician
Department of Clinical medicine and Public Health
Epidemiology and Global Health
Umeå University,
SE-901 85 UMEÅ
E-mail; olof.sandstrom@vll.se