

Dear Child and parent/s

Celiac disease, also sometimes known as gluten intolerance, is a sensitivity to gluten which is found in wheat, rye and barley. The cause of celiac disease, which is a life-long and relatively common 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 important to find out why this is and if we can reduce the incidence of celiac disease by changing lifestyle in any way. We can increase awareness of celiac disease by following the pattern of illness across the country and through other research projects. That is why since 1998 there is a national register for celiac disease, supported by The Swedish Pediatric Association (Barnläkarföreningen/BLF), in which all children with newly diagnosed celiac disease are reported.

Your child is now being investigated for suspected celiac disease and personal data and parts of the investigation results will be reported to the National Register. You can now to decide if your child should be reported with their full personal ID number (the entire 10-digit personal number), or anonymously. Your decision does not imply consent to participate in any research, but you and your child can later receive such a request. Inform your child's doctor of your decision. Your decision will not affect the child's treatment in general.

The Swedish Pediatric Association (BLF) is ultimately responsible for the registry that is administered from Umeå University. In the future researchers may have access to the registry if BLF grants their application, but only after the application is also approved by The Research Ethics Committee. Of course, the same rules regarding confidentiality in health care in general also apply to register participation and data. The registry is approved under the Privacy Act and the goal is that all Swedish children and adolescents who develop celiac disease should be included. The register is administered at Umeå University, which has 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.

In order to facilitate future research, it is essential that as many children as possible report with their complete personal ID numbers. The choice, however, is entirely yours. You or your child, when they become of legal age, may at any time contact the registry to get information about what is on the registry regarding the child, or if you want the full personal ID number deleted (shift to anonymous registration).

If you have any questions, contact us!

Thanks for your help, Best Regards,

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