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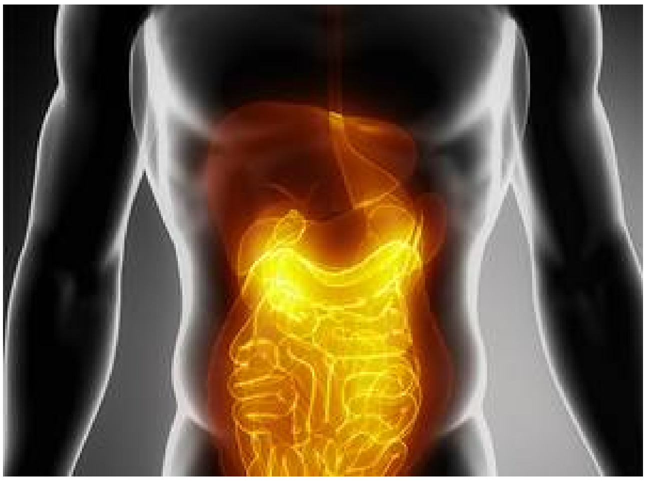
Towards awareness and action against IBD’s



Last week in the European Parliament representatives of the European Commission, professors and patients were brought together by the European Greens to exchange information on the alarming raise of IBD’s amongst the youth. The meeting was a fist one of more to come to exchange information on how to improve European attention for these diseases leading to more and better research, awareness and possible legislation for the patients of IBD’s. The Greens in the European Parliament found out, also out of personal interest, that on IBD’s there is lack of knowledge, training and research. They are determined to change this. Their co-chair **Rebecca Harms** and French MEP **Michelle Rivasi** explained how to give IBD’s more attention than they get at the moment. *“We are shifting for example our focus to Health when we look at the discussions on Food and agriculture,”* told **Harms**. Both patients and medical doctors at the meeting welcomed this focus since they also see that food is one of the issues, which so far does not get the attention it should get in research on IBD’s. Chair of the youth patient’s organization **Daniel Sundstein** told he has his own diet in his head. *“I can eat nuts, I can eat raisins. But if I combine the two, I immediately will get a flare.”* Strangely enough there is hardly any research available for patients on the relation between food and their disease: mainly because most research is allocated to pharmaceutics instead of behaviour. Professor **Guy Willems** told the group that he and his daughter are cured from Crohn’s disease thanks to a very strict diet. Therefore he also called for more and better research on nutrition, since so far only case studies are done. The Greens are fighting for a European database with patient’s information in order to do proper research on the influence of food on the IBD related disease. This database still not exists. One of the reasons why this database is not in place is mainly because the pharmaceutical industry does not have much interest in this side of fighting IBD’s. To change this patients, doctors and politicians need to work together. That way we can fight the rise of IBD and maybe even stop it. In a memorable speech of all the problems you face as a patient **Sundstein** summed it up: *“If you would not wish this disease for your worst enemy, why not fight to try to change the situation for the better. So that your child* *and my child will not be affected by this horrible disease. If we would join the forces of patients organisations, doctors, the pharmaceutical industry, governments, the EU and all the other persons living with or living for people with IBD: life, blood, tears and sorrow would be spared. And that is why we are here today."* Awareness is also a big issue when looking at IBD's. Every country in Europe is acknowledging IBD at its own pace. Still, as one of the participants told, it strange that when a child is suffering from IBD, teachers at school usually do not have an idea what the disease entails. There is obviously a task for governments to make sure at schools teachers are aware of this disease and how to cope with it. Nowadays out of every 1000 children, three suffer from IBD, which might seem a low percentage, but if schools are not familiar with IBD's it is even harder for children and their parents to make clear what needs they would have to live a normal life at school. Different laws are in every country. Denmark for example sees IBD as a handicap with according subsidies and rights. In Germany you will receive a special card that gives you priority or access for toilets for handicapped, in other countries nothing has been established for patients suffering disease. *"Europe could help creating the necessary awareness so people know what it is. With some simple rules and rights people suffering IBD could live a much easier life,"* concluded **Harms** after the several testimonies given by medical doctors and patients. The European Commission has quite some money allocated for research, also for IBD. At the same time, the research done is mainly beneficial for the pharmaceutical industry. **Michelle Rivasi** therefore pointed out the need to come up with a program to get more money for better research together. In Horizon2020 is a lot of money available, but a program and network between patients, universities, laboratories, hospitals and other stakeholders needs to be set up. This way it would be easier to get access to money from the EU to support research on IBD's. The European Commission told the participants they are always willing to provide workshops on how to allocate money for specific projects. Also the European Commission acknowledged the importance for registers when fighting diseases such as IBD. Also she said there is a possibility to apply for such registers in 2015. This meeting was the first one organized by the Green Group and Harms said more meetings will follow. *"IBD has no borders neither should IBD research have. We should get united, to improve care and quality of life of the patients. The Greens want to be part of this and we promise to fight to get this done."*

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Responsible MEPs

Rebecca Harms

Member

Michèle Rivasi

Member

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