UEGW
VIENNA 2008

PRESS RELEASE

Living with chronic Inflammatory Bowel Disease: a serious misfortune

Crohn's disease and ulcerative colitis are increasing rapidly – Quality of life is seriously impaired – Patients often still young

(Vienna, 21st October 2008) Crohn's Disease and Ulcerative Colitis are chronic inflammatory bowel diseases which cause serious inconveniences for people suffering from them. However, although the number of cases of these two diseases is increasing dramatically, particularly amongst the young, there is still very little public awareness of them. For this reason, more educational measures and an improved infrastructure for treatment were called for at the 16th United European Gastroenterology Week (UEGW) 2008 in Vienna, Europe's biggest congress for diseases of the gastrointestinal tract.

Patients with Crohn's Disease or Ulcerative Colitis suffer from diarrhoea and abdominal pain, which is often associated with blood in the stool and purulent fistulas in the bowel and anal region. "People afflicted with these diseases are often limited in their activities and must remain in close proximity to a toilet", explained Professor Doctor Walter Reinisch of the Medical University of Vienna (Austria) at the UEGW congress. "In serious cases, patients may also suffer from faecal incontinence and are forced to wear incontinence briefs."

Ostracism and social withdrawal

Many patients experience serious limitations to their physical activities as a consequence of the diseases. The symptoms are perceived to be embarrassing, become taboo subjects and can lead to ostracism. Up to 70 per cent of patients withdraw from social activities and suffer from anxiety disorders and depression. 30 to 40 per cent lose their jobs as a result of the disease and its consequences; young patients are often forced to drop out of school or higher education. "The quality of life for people suffering from a chronic inflammatory bowel disease is below that of people with diabetes mellitus or rheumatoid arthritis", continued Professor Reinisch. Studies show that 15 years after the diagnosis, 34 per cent of patients have had one operation, 14 per cent two and 22 per cent have even undergone three. The risk of developing colorectal cancer is up to ten times greater than for the rest of the population.

One per cent of the population is affected

Cases of chronic inflammatory bowel diseases have risen dramatically over the past two decades and for reasons which are not yet known. In light of this fact and the serious consequences of the diseases, the Professor expressed his alarm that the general awarness of this issue is so limited. According to estimates, up to one per cent of the population is affected, which also corresponds to the development of rheumatoid arthritis. However, doctors and politicians responsible for health issues continue to categorise Crohn's Disease and Ulcerative Colitis as rare diseases, although many know very little about them and the availability of treatment is still inadequate. The general public is either completely unaware of the diseases or at least does not know that they relate to the digestive tract. As Professor Jean-Frédéric Colombel of the University Hospital of Lille/France added, "This lack of knowledge and playing down the seriousness of the diseases results in delayed or incorrect diagnosis, unsatisfactory medical treatment and the use of ineffective medication – sometimes over a period of years. This only serves to add to patients' suffering unnecessarily."

High direct and indirect costs of illness

In Austria, for example, the disease is usually only correctly diagnosed on average three years after the first symptoms appear. In 30 per cent of cases, Crohn's Disease is only diagnosed after a period of five years – despite chronic complaints. "Unnecessarily delaying the introduction of effective treatment can cause irreversible damage and make operations essential", Professor Reinisch went on to explain. "Besides these direct costs of illness, there are other, indirect costs which result from patients' inability to work and the need to provide social benefits. These latter costs generally amount to much more than the direct costs."

Genetic links

The chronic inflammatory bowel diseases can certainly not be attributed to ageing. For the most part, they first present between the ages of 20 and 40 and sometimes even during childhood. The causes and conditions allowing them to develop are not yet known for certain. "The only thing we can be sure of is that there are genetic links and, particularly as far as Crohn's disease is concerned, a negative influence of nicotine", said Professor Colombel. Over 30 disease genes, which are related to the two diseases, are already known. An Austro-American research team recently showed that genetically-related stress in certain intestinal cells can also cause the disease. "The role of other factors, such as nutrition and environmental influences, is still unclear", added Professor Colombel.

Inflammations also attack other organs and joints

In Crohn's Disease, it is not yet known why the entire gastrointestinal tract from the mouth to the anus is subject to inflammation. Similarly, there are no explanations as to why more and more young people and children are developing the disease. A feature of Crohn's Disease is that the bowel may become a patchwork of healthy and diseased segments, as the disease develops progressively from an inflammation to intestinal stenosis and the formation of fistulas. Ulcerative colitis, by contrast, is limited to the colonic mucosa; in up to 20 per cent of cases, it can lead to the colon having to be removed. Both diseases can extend beyond the gastrointestinal region into the joints, spinal column, skin and eyes.

More information and education required

At the UEGW, Professor Reinisch and Professor Colombel demanded that considerably more information on chronic inflammatory bowel diseases be made available to both the general public and the medical community. "It is very important to raise the level of information available to the general public", stated Professor Colombel. "Well-informed patients have a significantly better prognosis: they consult their doctors at an earlier stage and play a more active role in their treatment." He also appealed for improved training for doctors and the installation of more specialised facilities in hospitals. Various medicines are already available for both diseases; 5-aminosalicylate and probiotics for the less serious cases and cortisone preparations, immunosuppressants and biologics (TNF-alpha inhibitors) for the more serious ones. According to the experts, there is increasing evidence of the effectiveness of biologics in positively influencing the natural course of disease, so that, at least in Crohn's disease, the concept of applying these medicines from an early stage should be pursued. To be able to achieve this, the disease must be diagnosed early on and properly treated – which still does not happen often enough.

Press contact:
impressum health & science communication
Adenauerallee 10, 20097 Hamburg
Phone: +49 (0)40 - 31 78 64 10
Fax: +49 (0)40 - 31 78 64 64
E-mail: info@impressum.de
Website: www.impressum.de