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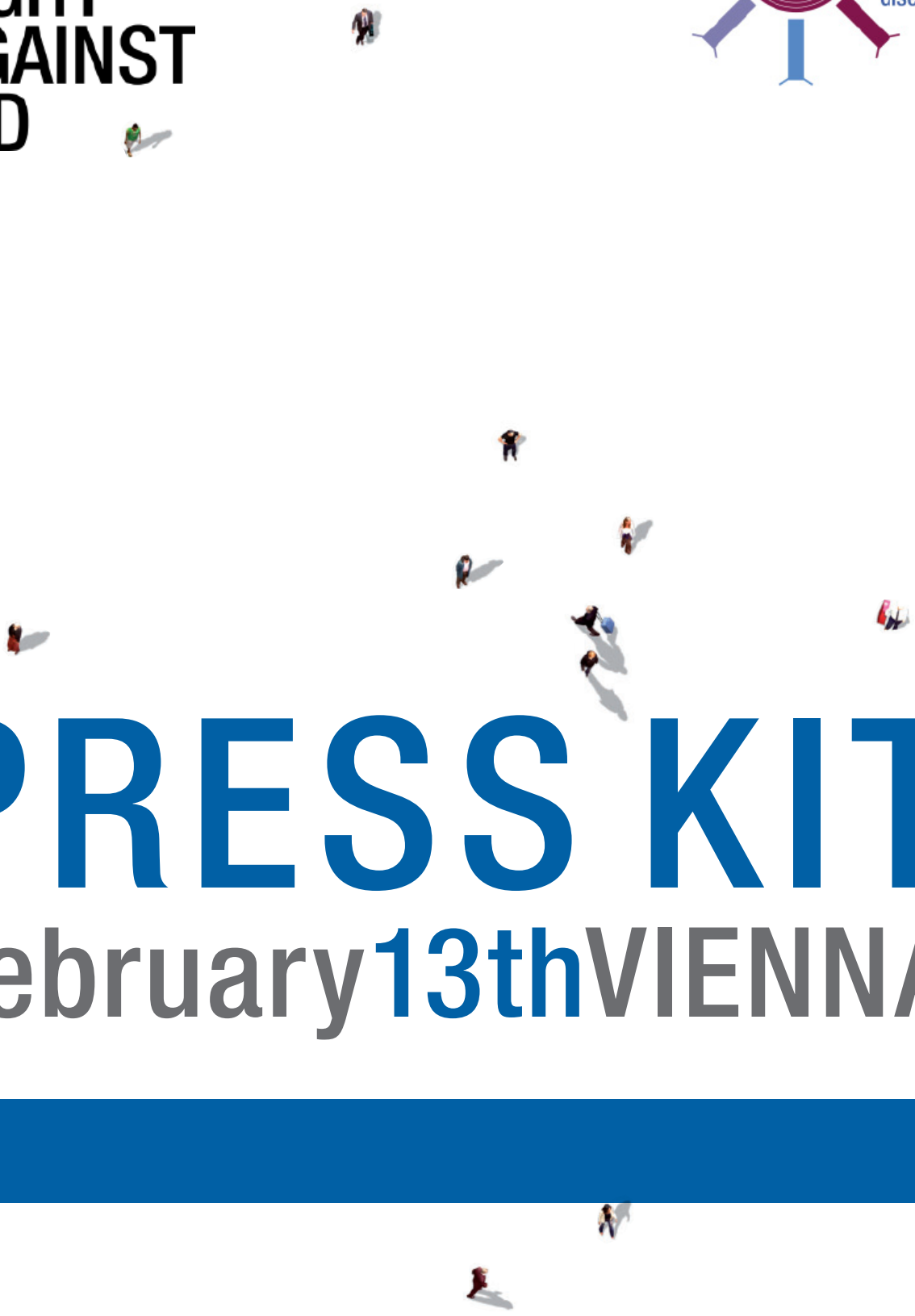

PRESS KIT

February 13th VIENNA

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Environmental factors as major triggers:

Major increase of chronic inflammatory diseases among young people

Over the last five decades the number of chronic inflammatory diseases has increased by ten to 15 times in highly developed countries. Even more alarming is the fact that young people, including children and adolescents, are increasingly affected. Chronic inflammatory diseases include Asthma, Diabetes mellitus type 1, Multiple Sclerosis and Inflammatory Bowel Diseases (IBD). The European Crohn's and Colitis Organisation (ECCO), the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) and United European Gastroenterology (UEG) call for attention and collective action. Therefore on February 13th 2013 various press activities concerning chronic inflammatory diseases, with a focus on IBD were presented in the run-up to the annual international ECCO Congress in Vienna.

"The genetic disposition can only explain a small amount of these diseases. The major triggers of chronic inflammatory diseases appear to be environmental factors", warns Univ.-Prof. Dr. Walter Reinisch, Vienna General Hospital – Medical University Vienna. An unbalanced diet, drugs like antibiotics, smoking, stress, the lifestyle and living environment in cities and increased hygiene seem to be reasons which could promote to development of chronic inflammatory diseases. Reinisch: "Chronic inflammatory disorders are associated with genetic polymorphisms which are partly shared among them, for example for IBD over 150 genetic polymorphisms have been described, partly shared with rheumatoid arthritis or psoriasis. Whereas these genetic polymorphisms may have existed for decennia or more likely for millenia and may have provided a benefit for its carriers in the past, they confer a risk of chronic inflammatory disorders in our present environment.

Inflammatory Bowel Diseases: Only the tip of the iceberg

The intestinal tract is the largest external surface of our body and therefore prone to exposures from the environment. It has been shown that smoking, antibiotics or the composition of our diets are affecting the intestinal microbiome which is the composition of our gut flora with microbial agents, potentially in an irreversible manner. The intestinal microbiome is also skewed in patients with Inflammatory Bowel Disease and more recently, associations between the intake of antibiotics during childhood and the risk of Crohn's disease has been reproducibly reported. "Inflammatory Bowel Disease may represent only the tip of the iceberg, on how the intestinal microbiome might be turned to its lower end of diversity and richness. Changes in the gut flora have also been associated with other chronic inflammatory disorders such as rheumatoid arthritis or multiple sclerosis", says Reinisch.

The new ECCO-EpiCom Study: The Burden of IBD in Europe

Inflammatory Bowel Diseases (IBD) are chronic disabling gastrointestinal disorders affecting every aspect of the individual's life and account for substantial costs to the health care system and society. The disease cannot be cured. "New epidemiological data suggest that the incidence and prevalence of IBD are increasing", says Dr. Tine Jess, National Health Surveillance and Research, Statens Serum Institut, Denmark. The

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incidence of ulcerative colitis and Crohn's disease in Danish children has increased by almost 50 % in just nine years, which is matched by data from Scotland, Ireland and Spain, where the incidence of Crohn's disease in children has trebled since 1996. An estimated 2.5–3 million people in Europe are affected by IBD, with direct healthcare costs of 4.6–5.6 billion € per year.

Jess: "In the Epidemiological Committee of ECCO we felt that a comprehensive review was needed to provide accurate information to European patients, doctors, and politicians on the burden of IBD in Europe. This study includes data on disease course, risk of surgery and hospitalization, mortality and cancer risks, as well as the economic aspects, patients' disability and the impact on work."

The occurrence of IBD, Crohn's disease and ulcerative colitis, is subject to considerable variation, both between and within geographic regions. The highest occurrence of IBD is found in developed countries and within Europe, especially in Northern Europe. In Southern and Eastern Europe the incidence is increasing. The majority of the patients with IBD in Europe experience a relapsing disease course with 20–25 % of patients experiencing chronic, continuous symptoms. Up to 30–40 % of European patients with Crohn's disease (CD) present with complicated disease at diagnosis and a similar proportion of patients may develop complications over the next 10–15 years of follow-up, states the result of the new ECCO study.

Hospitalization and surgery rates

The cumulative risk of hospitalization for Crohn's disease is 53 % ten years from diagnosis, with highest rates in Denmark, Ireland, Portugal and somewhat lower rates in Norway, Greece and Italy. The need for hospitalization either for Crohn's disease or ulcerative colitis not only reflects disease severity but also the need for diagnostic workup, health care and reimbursement policy. The overall cumulative surgery and re-operation rates in Crohn's disease are still high in Europe with 30–50 % of patients in need of surgical intervention and up to 20 % require a second operation within five to ten years.

Disability and economic burden of IBD in Europe

IBD not only affects the intestines but can be associated with extra intestinal manifestations in 20–40 % of patients. These include diseases of the eyes, joints, and skin. It is estimated that a patient with IBD will be off from work for three to six weeks per year and hospitalized for ten days. Approximately 20 % of patients in Norway have received disability pension at ten years. In a cross-European study 44 % of respondents said, that they had lost or had to quit a job because of IBD. This is a challenge that many individuals surmount by playing down their symptoms, keeping their condition hidden from colleagues and continuing work when other less stoical colleagues might have taken time off.

Mainly young individuals are affected

Since IBD mainly affects young individuals in their early adulthood and in all aspects of their life, IBD causes substantial direct and indirect costs to both health care systems and society. Daniel Sundstein, a 27 year old Danish physiotherapist and IBD-patient says: "It was 2007 when I ended up in hospital, lost 15 kg of weight and was diagnosed with IBD. Without my family and friends I would have never been able to manage my "new" life. From my point of view IBD should not be an excuse to young people for not living out their dreams. Still in the hospital I fixed my next goals: running a marathon, completing education and

getting a full-time-job. All my goals were accomplished in three and a half years, I kept on focusing on three things: training, education and social life."

Young patients are given medicine throughout their lives, Sundstein stresses that it should be discussed with patients how preventing more illness can be balanced against potential side effects. For him, flares are a part of IBD and therefore patients should be taught to cope better with their situation. Sundstein: "No one is the same after getting diagnosed with IBD – I chose to fight and change my life for the better."

EFCCA: Concrete measures to fight IBD

The European Federation of Crohn's and Ulcerative Colitis Associations is an umbrella organisation representing 27 national patients' associations from 26 European countries. EFCCA aims to work to improve life for people with (IBD) and give them a louder voice and higher visibility across Europe. Dr. Marco Greco, Chairperson of EFCCA: "More efforts need to be made by policy makers and other stakeholders to ensure that the quality of life of people living with IBD is improved. This does not only include fighting for better standards of care such as faster disease diagnosis, better access to IBD specialists, biological treatments and so on, but also addressing other issues that affect peoples daily lives, such as work, education or relationships".

"To achieve this, we, the patient community, have joined forces with the medical and the scientific community and other stakeholders", says Greco. It has opened up infinite possibilities for mutual cooperation. One concrete outcome of working together has been the "World Symposium on patient funded IBD Research" that EFCCA organised in October last year. Another milestone has been the "World IBD Day event" that was organised in the European Parliament to directly address European policy makers. Greco: "This might be the first step of a legislative process able to fill the lack of harmonization and to eradicate the discriminations on IBD in the territory of the European Union. Health policy and healthcare issues should be included within the wider spectrum of social, economic, cultural and environmental policies under the WHO and EC label "Health in all policies".

Join The Fight against IBD has been made possible by the generous contribution of over 50 different supporters, from personal donations to industry from all sectors of society. EFCCA and ECCO are grateful for this generosity and will continue its work to reduce the burden of disease in young people.

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Press information:
Welldone Marketing- und Kommunikationsberatungsges.m.b.H. Wien
Mag. (FH) Maria Weidinger-Moser I Public Relations
Tel.: +43/(0)1/402 13 41-47 I Email: pr@welldone.at

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SPEAKERS

Univ.-Prof. Dr. Walter Reinisch
Vienna General Hospital – Medical University Vienna

Dr. Tine Jess
National Health Surveillance and Research,
Statens Serum Institut, Denmark

Daniel Sundstein
Physiotherapist, IBD patient, Denmark

Dr. Marco Greco
Chairperson of EFCCA

Presenter:

Dr. Severine Vermeire
ECCO President-Elect

European Crohn's and Colitis Organisation

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Environmental factors as major triggers of chronic inflammatory diseases

Univ.-Prof. Dr. Walter Reinisch, Vienna General Hospital – Medical University Vienna

Over the last five decades the number of chronic inflammatory diseases has increased by ten to 15 times in highly developed countries. Even more alarming is the fact that children and adolescents are increasingly affected. Chronic inflammatory diseases include asthma, diabetes mellitus type 1, multiple sclerosis and inflammatory bowel disease (IBD), subsuming the main entities Crohn's disease and ulcerative colitis. The genetic dispositions do only explain a small amount of these diseases. The major triggers of chronic inflammatory diseases seem to be environmental factors.

An unbalanced diet, drugs like antibiotics, smoking, stress, the lifestyle and living environment in cities and increased hygiene seem to be reasons which could promote the development of chronic inflammatory diseases. Chronic inflammatory disorders are associated with genetic polymorphisms which are partly shared among them, for example for IBD over 150 genetic polymorphisms have been described, partly shared with rheumatoid arthritis or psoriasis. Whereas these genetic polymorphisms may exist already for decennia or rather millenia and may have provided a benefit for its carriers in the past, they confer a risk of chronic inflammatory disorders in our present environment. Results are lacking which might help to explain on how environmental risk factors could add to the existing genetic dispositions. It might be epigenetic modifications, which could foster an additional layer of "weakness" on the somatic level. In addition, these risk factors might also modulate our second genome, which is the microbial flora populating our bodies.

Attacks on the largest external surface of our body

The intestinal tract is the largest external surface of our body and therefore prone to exposures from the environment. It has been shown that smoking, antibiotics or the composition of our diets are impacting the intestinal microbiome, which is the composition of our gut flora with microbial agents, potentially in an irreversible manner. The intestinal microbiome is also skewed in patients with inflammatory bowel disease and more recently associations between the intake of antibiotics during childhood and the risk of Crohn's disease has been reproducibly reported. Inflammatory bowel disease may represent only the tip of the iceberg, on how the intestinal microbiome might be turned to its lower end of diversity and richness. Changes in the gut flora have also been associated with other chronic inflammatory disorders such as rheumatoid arthritis or multiple sclerosis.

Thus, evidence is accumulating that the intestinal tract is a major centre of a homeostatic balance of the body in the avoidance of chronic inflammatory disorders.

Inflammatory Bowel Diseases – a disease in the taboo zone

Abdominal pain, diarrhoea lasting for weeks and months, incontinence, loss of weight, fatigue, and sometimes fever: if such symptoms keep occurring in intervals this could be an indication for IBD. It is an enormous constraint if a patient has to use the toilet up to 20 unforeseen times a day. At times patients and doctors report that social contacts are abruptly ended as IBD has such an impact on their social lives.

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Crohn's disease and ulcerative colitis are chronic diseases which could affect patients throughout their whole lives. Both can occur throughout all age groups, however, the statistical peak of manifestation is between the ages of 20 and 30. There is an alarming increase in the number of children being affected with IBD. The number of paediatric inpatients has doubled in Austria during the last 15 years.

Due to insufficient knowledge about symptoms and alarm signals it can take months to years from the occurrence of first symptoms to actual diagnosis of Crohn's disease, hampered by the fact that some functional disorders of the gastrointestinal tract could present with similar symptoms. An IBD-check has been developed in Austria, aimed to expedite the diagnostic process by targeted questions. However, as there is no explicit proof for the diagnosis of IBD from symptoms and laboratory examinations an ileocolonoscopiy is mandatory. Due to state-of-the-art therapies, IBD is adequately treatable intended to achieve a normal quality of life, although there is still no actual cure despite intensive research. An increased mortality rate needs to be acknowledged particularly among young patients with IBD.

Call for attention and collective action

European Crohn's and Colitis Organisation (ECCO), the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) and United European Gastroenterology (UEG) call for attention and collective action. The jointly engagement of ECCO and EFCCA as exempflied by this activity is aimed to lift the awareness on IBD among European decision makers. This might have various implications from the implementation of specialized medical services for our patients, to the eradication of inequalities in social and professional life when being affected by IBD. Furthermore, the instalment of funds is essential, dedicated to support scientific approaches to unravel the riddle of IBD on a population-based level and not only in studies with mice.

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The new ECCO-EpiCom Study: The Burden of Inflammatory Bowel Disease in Europe

Dr. Tine Jess, National Health Surveillance and Research, Statens Serum Institut, Denmark

Inflammatory Bowel Diseases (IBD) are chronic disabling gastrointestinal disorders impacting every aspect of the affected individual's life and account for substantial costs to the health care system and society. The disease cannot be cured. New epidemiological data suggests that the incidence and prevalence of the diseases are increasing and medical therapy and disease management have changed significantly in the last decade. The incidence of ulcerative colitis and Crohn's disease in Danish children has increased by almost 50% in just nine years, which is matched by data from Scotland, Ireland and Spain, where the incidence of Crohn's disease in children has trebled since 1996. An estimated 2.5–3 million people in Europe are affected by IBD, with direct healthcare cost of 4.6–5.6 bn € per year.

In the Epidemiological Committee of ECCO we felt that a comprehensive literature review was needed to provide accurate information to European patients, doctors and politicians on the burden of IBD in Europe, including data on disease course, risk for surgery and hospitalization, mortality and cancer risks, as well as the economic aspects, patients' disability and work impairment.

The occurrence of IBD (Crohn's disease and ulcerative colitis) is subject to considerable variation, both between and within geographic regions. The highest occurrence of IBD is found in developed countries, and within Europe, especially in Northern Europe, but in Southern and Eastern Europe occurrence is also increasing. An estimated 0.3% of the European population suffers from IBD equalling 2.5–3 million persons. The majority of patients with inflammatory diseases in Europe experience a relapsing disease course with 20–25% of patients experiencing chronic continuous symptoms. Up to 30–40% of European patients with Crohn's disease (CD) present with complicated disease phenotype at diagnosis and a similar proportion of patients may develop complications over the next 10–15 years of follow-up.

Hospitalization and surgery rates

The cumulative risk of hospitalization for Crohn's disease is 52.7% at ten years from diagnosis, with highest rates in Denmark, Ireland, Portugal and somewhat lower rates in Norway, Greece and Italy. Need for hospitalization both for Crohn's disease and ulcerative colitis not only reflects disease severity but also the need for diagnostic workup, health care/reimbursement policy and ethnic differences. Furthermore, the bar for hospitalization may be different in expert centers versus community settings.

Hospitalization rates are high, but slowly decreasing in patients with Crohn's disease. The overall cumulative surgery and reoperation rates in Crohn's disease are still high in Europe with 30–50% of patients needing a surgical intervention and up to 20% needing a reoperation within 5–10 years.

In ulcerative colitis (UC) hospitalization rates have remained stable over time and reflect disease severity and risk for colectomy. The risk of colectomy in ulcerative colitis is approximately 10% after 10 years from the diagnosis. An earlier unexplained geographic variation in surgery rates within Europe has diminished in recent years.

Disability and economic burden of IBD in Europe

IBD not only affects the intestines but is also associated with extra intestinal manifestations in 20–40% of patients. These include diseases of the eyes, joints, and skin. The overall disability rate among European

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IBD patients is 34 % but varies between countries probably due to differences in disease severity, local socioeconomic and societal factors, and insurance policies.

It is estimated that an IBD patient will be sick about 4 weeks per year, off from work for 3 to 6 weeks per year and hospitalized for 10 days. Median days lost from "household and recreational activities" are approximately 20 days per 6 months. Approximately 20 % of patients in Norway have received disability pension at 10 years. In a cross-European study, about half of the patients responded that their life was significantly affected by IBD during their most recent flare-up and 44 % of respondents said that they had lost or had to quit a job because of IBD.

The most significant facts: 10 % of IBD patients experience unemployment, patients have 3–6 weeks of sick leave per year, and permanent work disability is 2-fold increased. It is difficult to measure the economic burden of the disease across Europe due to large variation in direct and indirect costs and significant differences in health care policies. Based on data from the late 1990s, when expensive biologic treatment was not available yet, the direct economic burden associated with IBD can be estimated as high as a total of 4,681–5,596 million Euro direct costs per year in Europe. Updated cost estimation models based on new treatment algorithms incorporating the biological therapies are urgently awaited.

Cancer and mortality

The relative risk of small bowel cancer in IBD is 27-fold increased and the risk of colorectal cancer is 2-fold increased as compared to the risk in non-IBD individuals of same age and gender.

Fortunately, the absolute risk of colorectal cancer is only 1–2.5 % at 20 years and Scandinavian studies suggest a decrease in risk in recent years. The overall risk of extra-intestinal cancer is not markedly increased in European patients with IBD despite an increased risk of cancer of the upper gastrointestinal tract, lung, skin and urinary bladder in Crohn's disease and an increased risk of biliary-liver cancer and leukemia in ulcerative colitis. This is counterweighted by a decreased risk of lung cancer, which may reflect that Crohn's disease patients tend to be smokers, whereas ulcerative colitis patients tend to be non-smokers. Treatment with certain medications, such as thiopurines, may increase the risk of lymphoid tissue cancer and non-melanoma skin cancer. Mortality is up to 40 % increased in European patients with Crohn's disease as compared to the general population, whereas mortality is not increased in European patients with ulcerative colitis as compared to the general population.

Mainly young individuals are affected

Since IBD affects mainly young individuals in their early adulthood and impacts all aspects of the affected individual's life they account for substantial direct and indirect costs to both health care system and society. About half of the patients have frequent relapses or continuous active disease and may develop extra intestinal manifestations. In addition up to 2/3rd of the patients with Crohn's disease still develop complications requiring hospitalization and/or surgery. Unfortunately, still app. 20 % of the IBD patients in Europe will end up with disability pension. 10 % have to face unemployment and 25 % part time employment problems. In addition sick leave is affecting up to half of the patients and even direct health care costs may be as high as 2000–3000 € per year in average.

Further Pan-European epidemiological and follow-up studies as well as strategic disease modifying trials are needed to investigate the role of tight control and early patient profile stratification in the disease management hopefully leading to superior long-term outcomes, improved quality of life, decreased disability rates and ultimately a normal life.

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Young, sick and ready to fight

Mr. Daniel Sundstein, Physiotherapist, 27 years old IBD patient, Denmark

It was in the middle of May 2007 when I was put to bed with what I first thought was a food poisoning, a salmonella infection or something similar to that. I was at the end of the first year of my training as a physiotherapist and the exams were coming up.

Two weeks later I had lost a lot of weight and had severe anaemia. I was admitted urgently to hospital and the doctors could begin their investigation of what was wrong with me. One week later I was diagnosed with ulcerative colitis and was in a heavy intravenous treatment with cortisone. Although it helped to get control of my condition, I was still very ill and the doctors had only biological medicine left before they would remove my colon. I had lost about 15–16 kg and was as pale as a ghost because of the anaemia. I still remember the day the doctor came and gave me the "ultimatum": Either the medicine works or we will have to remove your colon.

So they tried biological medicine, I got a lot better very quickly and one week later I was released from hospital and could go home with my life changed in a way I had never imagined.

How to live my life in the best possible way?

While I was in hospital I began to think about the future. What could I do to live my life in the best possible way? What goals did I want to achieve? Basically: Who should I be? Big questions, but when your health and life is put to extremes, you should start wondering about what you can do to help yourself in the best possible way – and my mind was set on exercising! As Edward Stanley once said: "Those who think they have no time for bodily exercise will sooner or later have to find time for illness".

Back then I did not know what impact IBD would have on my life. I had my own thoughts, I had the doctors telling me what I could expect and I could read on the Internet how other people with IBD were living their lives. I very quickly stopped reading – it was not good for me to read about all these lives. I focused on the negative stories, it demotivated me and I began to feel sorry for myself. I then took a decision: having IBD is like having a flue once in a while – just more often. Sometimes I will get sick and be put into bed by this. But most of the time I will be just like everybody else – healthy and happy.

My next goals: running a marathon, completing the education and a full-time-job

Therefore, I began already in the last week of my hospitalization the training towards my new personal goal: to run a marathon. I also had another aim: to complete my education as planned in January 2010 and being able to get a full-time job afterwards.

Running a marathon was the first thing I wanted to do after getting IBD. In my mind this was the best thing I could do to myself. I wanted to prove that IBD wouldn't have influence on my dreams and goals – in short: I wanted to retake the control over my own life and by this prove to my family, my friends and myself that everything you want to do is possible.

All my goals were accomplished within three and a half years – this despite several setbacks. But every flare up told me one single lesson: to contact my specialist as soon as I feel any symptoms of IBD! My motivation was amplified through my social network and my family.

A part of my new social life was joining the EFCCA Youth Group in 2009 and in 2012 to become the leader of the group. Being a member of this international community means that I have a strong sense of fighting for a common cause. Without my family and friends I had never been able to manage my "new" life. Therefore I kept on focusing on three things: training, education and social life.

My change of life

From my point of view IBD should not be an excuse to young people for not living out their dreams. Since young patients are given medicine all through their lives we should discuss how to consult them in preventing more ill from the side effects. Flare-ups are also a part of IBD and this is why we should discuss how to teach them to cope better with their situation.

No one is the same after getting diagnosed with IBD – I chose to fight and change my life for the better. What do you choose?

EFCCA: The patient community join forces together

Dr. Marco Greco I Chairperson of EFCCA

Last year's "Join the Fight" press conference that we co-organised with ECCO in Barcelona was a huge success. Over 150 people from all over the world worked together to raise international awareness about IBD and its impact on the quality of life for the estimated three million citizens suffering from IBD in Europe. It has shown us what can happen when the medical/scientific and the patient community join forces! It has opened up infinite possibilities of mutual cooperation giving people from all over the world a new sense and hope in their fight against IBD.

One concrete outcome of working together has been the World Symposium on patient funded IBD Research that EFCCA has organised in october last year. This Symposium provided a platform for patients and the scientific community to establish connections, to find new strategies together and to engage in open and honest discussion. To see so many people with a common purpose, working with such goodwill and delivering what is more than a message of hope: delivering a project that justifies hope.

A milestone: addressing European policy makers

Another milestone for us has been last year's World IBD Day event that EFCCA organised in the European Parliament allowing us to directly address European policy makers. Together we are working to gain recognition of the difficulties faced by people living with IBD. The support that EFCCA is receiving from the members of the European Parliament is not only a symbolic action but also a clear statement in favour of IBD people and patients in general. This might be the first step of a legislative process able to fill the lack of harmonization and to eradicate the discriminations on IBD in the territory of the European Union.

But let us not forget that one year later, the message emerging from the IMPACT survey remains the same: more efforts need to be made by policy makers and other stakeholders to ensure that the quality of life for people living with IBD is improved.

Recommendations

Following last year's IMPACT study of over 6000 IBD patients, EFCCA has elaborated the following recommendations:

Early diagnosis of IBD:

- Maintain good access to IBD specialists, especially in the face of financial cuts to health services.
- Review diagnostic protocols for those who wait over a year for diagnosis, to reduce this divergence with otherwise good standards.
- Investigate and find methods to prevent presentation to emergency care, experienced by a majority, before diagnosis.
- Work with emergency care colleagues to raise awareness that the majority of people with IBD are treated in this department.

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For health care and treatment:

- Maintain and develop good IBD health service standards, in line with published guidelines.
- High hospital admission represents a poor patient experience, an urgent opportunity for improvement, and significant morbidity. Reducing this burden may somewhat counterbalance the costs of new IBD treatments – it may pay to treat with innovative therapies.
- Ensure that use of corticosteroids is in line with ECCO Guidelines, and that the full range of treatment options are considered, according to comparative risk-benefit profiles.

For health services:

- Improve access as well as provision, of specialist IBD healthcare professionals.
- Increase the duration and frequency of specialist consultations.
- Improve consultation techniques (for both parties), to ensure depth and coverage of issues, so that no important information is omitted.

For relationships:

- The impact of IBD on relationships should be considered by healthcare professionals.
- Healthcare professionals should actively sign-post patients to national IBD associations.

For daily life:

- Management plans should include assessment and management of the key three symptoms: fatigue, urgency, and pain.
- Success criteria should focus on effective management of symptoms, as well as IBD as the root cause.
- Management plans should include assessment of the wider symptomatic impact of IBD on everyday life, as well as the clinical context.

For work and education:

- Good management of IBD supports employment. The cost of new innovative treatments for IBD may be counterbalanced by improved employment and reduced social costs.
- Effective medical consultation should address the patient's full life context – including work.
- A patient's employment and educational aspirations should be regarded as goals and success criteria.
- Flexible, supportive, and non-discriminatory work practices are required. Those who face discrimination must be supported in challenging this.

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United We Stand: About EFCCA

The European Federation of Crohn's & Ulcerative Colitis Associations is an umbrella organisation representing 27 national patients' associations from 26 European countries. EFCCA aims to work to improve life for people with inflammatory bowel disease (IBD) and give them a louder voice and higher visibility across Europe.

It does this by encouraging and facilitating the exchange of information and the promotion of cross-border activities and by raising public awareness of IBD, the European patients' concerns and EFCCA with the European Commission, the European Parliament and the WHO. EFCCA encourages scientific, social and other research into the causes, diagnosis and treatment of IBD and ensures that health policy and health-care issues are included within the wider spectrum of social, economic, cultural and environmental policies under the WHO and EC label "Health in all policies". It promotes health equalities for all and empowers patients' associations including them in the decision making processes both at national and EU level.

For more information please visit our website at: www.efcca.org

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CURRICULUM VITAE

Univ.-Prof. Dr. Walter REINISCH

MedUni Wien I Chair Steering Committee "Join the fight against IBD" I The tip of the iceberg – Searching causes for the increase of Chronic Inflammatory Diseases

Education

1970–74	Primary School Maria Enzersdorf, Südstadt / Niederösterreich
1974–82	Secondary School Mödling, Franz Keim Gasse
16. 6. 82	Graduation

Academic career

1982–89	Study of Medicine at the University of Vienna and Medical Doctors Degree
1/90–3/90	Postdoctoral Fellow at the Institute of Specific Prophylaxis and Tropical Medicine in Vienna
1/90–9/91	Postdoctoral Fellow at the Laboratory of Experimental Hematology at the University of Vienna
10/91–2/92	Postdoctoral Fellow at the Laboratory for Biochemical Physiology / National Cancer Institute, Frederick, USA
3/92–5/92	Postdoctoral Fellow at the Clinic of Internal Medicine IV, Dept. Gastroenterology and Hepatology
5/92–2/99	Assistant Doctor at the Clinic of Internal Medicine IV, Dept. Gastroenterology and Hepatology
Since 28. 2. 99	Medical specialist for Internal Medicine
11/93	Course GCP – Good Clinical Practice
Since 96	Principal Investigator of several clinical trials in IBD patients, lastly approximately 10 trials/ year including the design, conduct and publication of investigator-driven clinical studies.
01	Cofounder of ECCO
3/01–6/05	Treasurer and Member of the Governing Board of the European Crohn's Colitis Organization (ECCO)
11/03	Graduation to Professor in Internal Medicine
9/04–2/08	Member of the Scientific Committee of ECCO
9/04	Member of the Ethics Committee of the Medical University Vienna
11/04–11/08	Scientific Officer of ECCO within United European Gastroenterology Federation (UEGF) responsible for the program on IBD at United European Gastroenterology Week (UEGW)

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10/05	Panelist at the Fonds National Suisse de la Recherche Scientifique
Since 10/06	Head of Austrian IBD Study Group
Since 02/07	Section Editor Journal of Crohn and Colitis
02/08–02/10	Secretary of European Crohn and Colitis Organisation
05/09	Opponent Medical University of Helsinki
09/09	Certificate as Emergency Doctor
12/09-	Member of Public Affairs Committee of UEGF
02/10	Honorary Member of European Crohn and Colitis Organisation
Since 02/11	Member of the Clinical Committee of ECCO
11/11	Co-Founder of DARM+
12/11	Winner Austrian Event Awards in category social/charity events for IBD toilet race Vienna

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CURRICULUM VITAE

Dr. Tine JESS

National Center for Health Data and Disease Control, Copenhagen/Denmark I Presentation of study results: The burden of Chronic Inflammatory Bowel Diseases in Europe

Education/Training

06/2002	University of Copenhagen, Denmark; M.D. / Medicine
2002–2004	Herlev University Hospital, Denmark; Residency / Internal Medicine
04/2008	University of Copenhagen, Denmark; D.Sc. / Medical Science
2009	National Board of Health; Consultant / Clinical Epidemiology

Positions (including maternity leaves in year 2005 and 2010)

2002–2004	Residency (Internal Medicine, Surgery), Herlev University Hospital, Copenhagen, Denmark
2004–2005	Research Fellow, Dept. of Gastroenterology, Mayo Clinic, MN, and Herlev University Hospital, Copenhagen, Denmark
2005–2007	Clinical Epidemiologist (with medical responsibility for the creation of the Dept. of Epidemiology), Novo Nordisk, Copenhagen, Denmark
2007–2010	Senior Clinical Epidemiologist, Institute of Preventive Medicine, Copenhagen, Denmark
2010– present	Head of Gastroenterology Research, Dept. of Epidemiology Research, National Health; Surveillance and Research, Statens Serum Institute (under the Danish Ministry of Health)

Honors and Awards

1999	Scholarship from the Danish Cancer Society
2004	Rising Star in Europe (Danish Society of Gastroenterology)
2006	Youngest Publishing Researcher Award and High Impact Awards (n=2), Herlev University Hospital
2007	High Impact Journal Awards (n=2), Herlev University Hospital
2008	High Impact Journal Awards (n=2), Herlev University Hospital
2009	Female Research Leader Award (670,000 USD) – Danish Council of Independent Research
2012	Medal of Honor – Danish Society of Theoretical and Applied Medicines
2012	Elected for the Young Academy of the Royal Danish Academy of Sciences
2013	For Women in Science Award from HRH Princess Marie of Denmark on behalf of L'Oreal and UNESCO

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CURRICULUM VITAE

Daniel SUNDSTEIN

IBD patient, Denmark I A patient's everyday life

Mr. Daniel Sundstein is 27 years old; his parents are Faroese and Danish. Mr. Sundstein lives in Copenhagen.

2012	Leader, EFCCA Youth Group
2011	Studying MSc. in Osteopathy
2010	Physical therapist, self-employed in a private clinic
2009	Group Member, EFCCA Youth Group
2004	Campaign Manager for several Danish politicians
2002–2010	Swim Coach

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CURRICULUM VITAE

Dr. Marco GRECO

EFCCA president I Joining forces: What is already done in the fight against IBD and which duties have decision makers in health care?

Marco Greco is chairman of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) since 2008. He has also been the founder of the EFCCA Youth Group, and was its leader from 2003 till 2007.

Currently he is working as an attorney at law at "bi-g.it", focusing on litigation, commerce and consumers' protection legislation.

He has a Ph. D in Law and Religion, Religious Freedom and Discrimination and a degree in Canon law at Università Cattolica del Sacro Cuore in Milano, where he works, after a period of research spent at George Washington University School of Law, in Washington D.C. (USA). His main area of research focuses on the relationship between law and religion in the healthcare system.

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FACTS

What is ECCO?

The European Crohn's and Colitis Organisation (ECCO) is a fast growing and highly active non-profit association focusing on Inflammatory Bowel Disease (IBD). ECCO acts mainly in Europe and encourages collaboration beyond Europe's borders allowing anyone around the globe interested in IBD to benefit from our programme and services.

Mission

ECCO's mission is to improve the care of patients with IBD in all aspects through international guidelines for practice, education, research and collaboration in the area of IBD.

Aims

A key goal of ECCO is to promote, sponsor and steer national and international IBD research efforts. ECCO successfully influences IBD management through the development, publication, dissemination and teaching of IBD guidelines and other educational materials such as workshops and the e-CCO learning platform. ECCO facilitates and promotes the education of healthcare professionals in the field of IBD. It enhances the quality of research in the field of IBD, both in basic and clinical science.

ECCO takes a political voice in Europe and collaborates with organisations sharing an interest in IBD, including medical societies, patient organisations and industries. Furthermore ECCO participates in the activities of the United European Gastroenterology (UEG) and in the organisation of the annual United European Gastroenterology Week (UEGW).

Country Members

Since the foundation in 2001, ECCO has embraced 31 Country Members who are the driving force and are considered as ambassadors spreading the ECCO Spirit, such as Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, The Netherlands, Turkey, Ukraine, United Kingdom.

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History

ECCO was founded in Vienna, Austria, in 2001 as an umbrella organization for national Inflammatory Bowel Diseases (IBD) study groups in Europe. It expanded from an organisation with 14 Country Members to an association comprising 31 affiliated countries in 2008.

More information: http://www.ecco-ibd.eu

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FACTS

What is EFCCA

The European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) was founded in 1990 as a not for profit organisation. Registered in Belgium (1996) it is a Europe-wide umbrella federation of national patients associations.

The member associations work within their countries to help people with Crohn's disease and Ulcerative Colitis, collectively known as Inflammatory Bowel Diseases (IBD). EFCCA has developed a wide range of projects, introduced new members, sought funds, encouraged research and worked towards becoming an effective international organisation. EFCCA represents 27 national patients´s associations, with more than 100,000 members with IBD. Through their effort, they have been able to reflect the growth of IBD diagnosis, the increasing visibility of the benefits of self-help associations and their increasing roles.

Mission

Their main objective is to improve the well-being of people with IBD. And give them a louder voice and higher visibility across Europe.

Aims

Within their objectives, EFCCA makes an important effort to encourage and facilitate the exchange of information and the promotion of cross-frontier activities, to raise public awareness both of IBD, the European patients' concerns and EFCCA with the European Commission, the European Parliament and the WHO, to encourage scientific, social and other research into the causes, diagnosis and treatment of Inflammatory Bowel Disease, to ensure that health policy and healthcare issues are included within the wider spectrum of social, economic, cultural and environmental policies under the WHO and EC label "Health in all policies", to promote health equalities for all and to empowere patients' associations and including them in the decision making processes both at national and EU level.

Country Members

EFCCA is spread across Europe: Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, Luxemburg, Malta, The Netherlands, Norway, Poland, Portugal, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland and United Kingdom. It has two associate members in Israel and Argentina.

History

EFCCA was born in 1990 when a number of national associations met to found the European Federation of Crohn's & Ulcerative Colitis Associations. It was formally established in Strasbourg in 1993 and was registered by Brussels in 1996.

More information: http://www.efcca.org/

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Umweltfaktoren als Hauptursache:

Massiver Anstieg von chronisch entzündlichen Erkrankungen bei Kindern und Jugendlichen

In den vergangenen fünf Jahrzehnten sind chronisch entzündliche Erkrankungen in den Industriestaaten um das zehn- bis 15fache angestiegen. Noch erschreckender ist die Tatsache, dass vor allem Kinder und Jugendliche verstärkt betroffen sind. Zu den chronisch entzündlichen Erkrankungen zählen unter anderem Asthma, Diabetes Mellitus Type 1, Multiple Sklerose sowie die Gruppe der chronisch entzündlichen Darmerkrankungen (CED). Die European Crohn's and Colitis Organisation (ECCO) und die European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) fordern ein verstärktes Wahrnehmen dieser besorgniserregenden Entwicklung und rufen zum gemeinsamen Gegensteuern auf. Aus diesem Grunde wurden am 13. und 14. Februar 2013, im Vorfeld des jährlichen, internationalen ECCO-Kongresses in Wien, eine Reihe von Presseaktivitäten zum Schwerpunktthema chronisch entzündliche Erkrankungen durchgeführt.

„Nur ein geringer Teil der Erkrankungen kann auf eine genetische Veranlagung zurückgeführt werden. Die Hauptursachen für chronisch entzündliche Erkrankungen scheinen in belastenden Umweltfaktoren zu liegen", warnt Univ.-Prof. Dr. Walter Reinisch vom Allgemeinen Krankenhaus der Stadt Wien (AKH) – Medizinische Universität Wien. Unausgewogene Ernährung, Medikamente wie Antibiotika, Rauchen, Stress, Lebensstil und Lebensumfeld in den Städten sowie übertriebene Hygiene scheinen jene Faktoren zu sein, welche die Entwicklung von chronisch entzündlichen Erkrankungen fördern können.

Reinisch: „Den chronisch entzündlichen Erkrankungen liegt zumeist eine genetische Anlage, in Form von genetischen Varianten (Polymorphismen) zugrunde. Bei chronisch entzündlichen Darmerkrankungen wurden beispielsweise über 150 verschiedene genetische Polymorphismen beschrieben, die teilweise auch bei rheumatischer Arthritis oder bei Schuppenflechte beschrieben werden. Diese genetischen Polymorphismen bestehen wahrscheinlich seit Jahrhunderten oder bereits seit Jahrtausenden und es ist anzunehmen, dass sie in der Vergangenheit für ihre Träger gesundheitliche Vorteile mit sich brachten. Doch in Verbindung mit unseren gegenwärtigen Umweltfaktoren tragen diese auch das Risiko für chronisch entzündliche Erkrankungen."

Chronisch entzündliche Darmerkrankungen: Nur die Spitze des Eisbergs

Der Darmtrakt bildet die größte Oberfläche in unserem Körper und ist deshalb besonders anfällig gegenüber Umwelteinflüssen. Es wurde aufgezeigt, dass Rauchen, die Einnahme von Antibiotika oder die Zusammensetzung unserer Ernährung das Mikrobiom des Darms möglicherweise irreversibel verändern. Das Darm-Mikrobiom weist auch bei Patienten mit chronisch entzündlichen Darmerkrankungen Veränderungen auf. Kürzlich wurde wiederholt über Zusammenhänge berichtet, welche belegen, dass die Einnahme von Antibiotika während der Kindheit mit einem erhöhten Risiko, später an Morbus Crohn zu erkranken, einhergeht, sagt Reinisch.

„Chronisch entzündliche Darmerkrankungen sind wohl nur der Gipfel eines Eisberges, der uns aufzeigt, wie die Darmflora auf ein Minimum ihrer Vielfalt und Reichhaltigkeit reduziert wird. Veränderungen in der Darmflora wurden auch mit anderen chronisch entzündlichen Erkrankungen wie rheumatische Arthritis oder Multiple Sklerose in Zusammenhang gebracht", berichtet Reinisch.

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Die neue ECCO-EpiCom Studie zeigt die Belastungen durch CED in Europa

Chronisch entzündliche Darmerkrankungen (CED) wirken sich bei Patienten auf alle Lebensbereiche aus und verursachen massive Kosten für das Gesundheitssystem ebenso wie für die Gesamtgesellschaft. Die Krankheit kann nicht „geheilt" werden. Neue epidemologische Daten zeigen auf, dass die Häufigkeit und Verbreitung von CED steigen, so Dr. Tine Jess vom National Health Surveillance and Research, Statems Serum Institut, Dänemark. Die Verbreitung von CED (Colitis ulcerosa und Morbus Crohn) ist bei dänischen Kindern in den vergangenen neun Jahren um nahezu 50 Prozent angestiegen. Zahlen aus Schottland, Irland und Spanien bestätigen diesen Trend, dort hat sich die Zahl der Kinder mit Morbus Crohn seit 1996 verdreifacht. Geschätzte 2,5 bis 3 Millionen Menschen sind in Europa von CED betroffen, die direkten Gesundheitskosten dafür liegen bei 4,6 bis 5,6 Milliarden Euro pro Jahr.

Jess: „Im Epidemiologischen Komitee der ECCO erachteten wir diese Studie mit umfassenden Analysen als dringend erforderlich, um europäischen Patienten, Medizinern und Politikern fundierte Informationen über die Belastungen von CED in Europa geben zu können. Sie enthält Daten über den Krankheitsverlauf, das Risiko bezüglich Operationen und Krankenhausaufenthalten, Krebs- und Sterblichkeitsrisiken, ebenso wie die wirtschaftlichen Aspekte, die Beeinträchtigungen der Patienten im Alltag und in der Arbeitswelt."

Am häufigsten treten chronisch entzündliche Darmerkrankungen in hoch entwickelten Ländern wie z. B. in Europa auf. Vor allem Nordeuropa ist stark betroffen, doch auch in Süd- und Osteuropa sind die Erkrankungen ansteigend. Die meisten europäischen CED-Patienten erfahren einen Krankheitsverlauf mit häufigen Schüben, 20 bis 25 Prozent der Patienten leiden an ständigen, also chronischen Symptomen. Bei bis zu 30 bis 40 Prozent der europäischen Morbus Crohn Patienten sind Komplikationen, wie Darmverengungen oder Fisteln, also Verbindungen zu anderen Organen oder Hautoberfläche, bereits bei der Diagnose vorhanden. Bei einer ähnlich hohen Anzahl von Patienten entwickeln sich während der kommenden zehn bis 15 Jahre ab Diagnose Komplikationen im Krankheitsverlauf, so das Resultat der neuen ECCO-Studie.

Krankenhausaufenthalte und Operationsraten

53 Prozent aller Morbus Crohn Patienten benötigen innerhalb von zehn Jahren nach Diagnose eine stationäre Aufnahme in einem Krankenhaus. Am höchsten ist diese Rate in Dänemark, Irland, Portugal, etwas geringer in Norwegen, Griechenland und Italien. Der Hospitalisierungsbedarf für Morbus Crohn oder Colitis ulcerosa reflektiert nicht nur den Schweregrad der Erkrankung sondern auch den Bedarf nach verbesserter Diagnostik und Gesundheitsversorgung sowie eine Verbesserung im Rückerstattungssystem der Krankenkassen.

Die allgemeinen Raten bei Operationen und Mehrfachoperationen bei Morbus Crohn sind in Europa nach wie vor hoch, 30 bis 50 Prozent der Patienten benötigen operative Eingriffe und bis zu 20 Prozent erfahren einen weiteren operativen Eingriff innerhalb von fünf bis zehn Jahren.

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Arbeitsausfälle und volkswirtschaftliche Belastungen durch CED in Europa

CED betrifft nicht nur den Magen-Darm-Trakt sondern führt bei 20 bis 40 % der Patienten auch zu weiteren Krankheitsbildern, wie etwa Erkrankungen der Augen, der Gelenke oder der Haut. Es wird angenommen, dass ein Patient mit CED im Schnitt drei bis sechs Wochen pro Jahr im Krankenstand ist und etwa zehn Tage im Krankenhaus verbringt.

Etwa 20 % der norwegischen Patienten hatten im Zeitraum von zehn Jahren nach Erstdiagnose eine Invalidenpension zugesprochen erhalten. In einer gesamteuropäischen Studie gaben 44 % der Personen an, dass sie aufgrund von CED ihre Arbeit verloren hatten oder aufgeben mussten. Gerade die Erhebung der Situation auf dem Arbeitsmarkt ist eine Herausforderung, da viele Patienten ihre Symptome herabspielen, ihre belastete Verfassung vor Kollegen verstecken und auch dann noch weiterarbeiten, wenn andere bereits in den Krankenstand gegangen wären.

Junge Menschen sind besonders häufig betroffen

Da CED vorwiegend bei Menschen im frühen Erwachsenenalter auftritt und in alle Lebensbereiche hineinspielt, verursacht CED substantielle direkte und indirekte Kosten – sowohl für das Gesundheitssystem als auch für die Gesellschaft. Daniel Sundstein, ein 27jähriger dänischer Physiotherapeut und Betroffener berichtet: „Es war 2007, als ich mit der Diagnose CED im Krankenhaus landete. Ohne die Unterstützung von Familie und Freunden wäre ich nicht in der Lage gewesen, mein „neues Leben“ zu meistern. Dennoch sollte aus meiner Perspektive CED keine Ausrede dafür sein, dass junge Menschen ihre Träume und Ziele aufgeben. Noch während meines Krankenhausaufenthaltes setzte ich mir meine nächsten Ziele, ich wollte einen Marathon laufen, meine Ausbildung abschließen und anschließend einer Vollzeitbeschäftigung nachgehen. In dreieinhalb Jahren hatte ich alle diese Ziele erreicht, ich konzentrierte mich auf drei Dinge: sportliches Training, Ausbildung und mein gesellschaftliches Leben“, so Sundstein.

Patienten mit CED benötigen ab dem Zeitpunkt der Diagnose lebenslang Medikamente. Daher sollte mit den Patienten erörtert werden, wie das Abschwächen der Magen-Darm-Erkrankungen und die möglichen Nebenwirkungen der Medikamente gut ausbalanciert werden können. Für Sundstein sind Erkrankungsschübe ein Teil von CED, Patienten sollten geschult werden, wie sie damit am besten zurechtkommen können. Sundstein: „Niemand ist nach einer CED-Diagnose unverändert – ich entschloss mich zu kämpfen und mein Leben zum Besseren zu verändern.“

EFCCA und ECCO: Mit vereinten Kräften gegen CED

Die Europäische Morbus Crohn und Ulcerosa Colitis Vereinigung ist eine Dachorganisation und vertritt 27 nationale Patientenorganisationen aus 26 europäischen Staaten. EFCCA sieht seine Aufgabe darin, das Leben von Betroffenen zu verbessern und ihnen eine lautere Stimme und höhere Sichtbarkeit in Europa zu verschaffen. EFCCA-Vorsitzender Dr. Marco Greco: „Es ist mehr Engagement von politischer Seite und anderen relevanten Stakeholdern erforderlich, damit eine Verbesserung der Lebensqualität für Betroffene sichergestellt werden kann. Dies bedeutet einerseits das Durchsetzen von verbesserten medizinischen Standards wie beispielsweise frühere Diagnostik, verbesserter Zugang zu auf CED spezialisierten Medizinern oder die Medikation mit so genannten „Biologika“. Andererseits müssen auch Bereiche berücksichtigt werden, die den Alltag von Patienten betreffen, wie die Arbeitswelt, die Ausbildung und das soziale Umfeld der Betroffenen.

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Wir haben miterlebt, welche Möglichkeiten sich auftun, wenn die Medizin, die Wissenschaft und die Patientenvertretungen ihre Kräfte bündeln, sagt Greco. Ein konkretes Ergebnis dieser Zusammenarbeit war die Organisation des „World Symposium on patient funded IBD Research“ welches EFCCA vergangenen Oktober organisiert hatte. Ein weiterer Meilenstein war der „World IBD DAY Event“, den EFCCA direkt im Europäischen Parlament ausgetragen hat. Dadurch konnten die politischen Entscheidungsträger von Europa direkt angesprochen werden. Greco: „Dies mag der erste Schritt gewesen sein, um einen legislativen Prozess in Gang zu setzen. Es braucht in der Europäischen Union verstärkte Harmonisierung und das Zurückdrängen von CED-bedingter Diskriminierung. Gesundheitspolitik und Gesundheitsversorgung sollten in einem breiteren politischen Spektrum wahrgenommen werden. “Health in all policies“ nach dem Verständnis von WHO und EC reichen auch in die Sozial-, Wirtschafts-, Kultur- und Umweltpolitik hinein.

Die Presseaktivitäten zu „Join the fight against IBD“ wurden durch die großzügigen Beiträge von 50 verschiedenen Unterstützern aus allen gesellschaftlichen Bereichen, Privatspender ebenso wie Vertreter aus der Industrie, ermöglicht. EFCCA und ECCO sprechen dafür einen besonderen Dank aus und werden weiter daran arbeiten, gerade für junge Menschen die Belastungen der Erkrankung zu reduzieren.

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Presseinformationen:
Welldone Marketing- und Kommunikationsberatungsges.m.b.H. Wien
Mag. (FH) Maria Weidinger-Moser | Public Relations
Tel.: +43/1/402 13 41-47 | E-Mail: pr@welldone.at

Die in diesen Presseunterlagen verwendeten Personen- und Berufsbezeichnungen treten der besseren Lesbarkeit halber nur in einer Form auf, sind aber natürlich gleichwertig auf beide Geschlechter bezogen