

# Adacolumn® Newsletter

In this issue of the Adacolumn® Newsletter registered nurse and PhD Lena Oxelmark from the IBD-unit at Sophiahemmet has contributed with a summary of the 4 topics in her thesis on aspects on inventions and unconventional treatments. You also have the opportunity to order copies of the short report (related to topic no. 3) that will soon be published in the Scandinavian Journal of Gastroenterology. To order your copy please complete and send the enclosed form.

We would like to thank everyone who applied for the Adacolum Travel Grants and the names of those lucky enough to be selected by the Scholarship Committee are announced on page 3.

Now we are looking forward to the two big events that will take place this autumn, the UEGW October 23-25 in Berlin (Otsuka booth: 15.1/38) and the FESPIBD November 23-25 in Rome. We hope to see you at our booth at these events.

Finally we would like to wish you all a nice autumn with a lot of ideas and inspiration. Enclosed a small gift that will get your mind set on solving problems.

**By guest editor - RN PhD Lena Oxelmark**  
IBD-unit, Sophiahemmet, Karolinska  
Institutet, Stockholm

*Quality of Life in Inflammatory Bowel  
Diseases- aspects on interventions and  
unconventional treatments*

#### **Paper # 1**

**An International Survey of the Use and Attitudes Regarding Alternative Medicine by Patients With Inflammatory Bowel Disease (IBD).**

*Rawsthorne P, Shanahan F, Cronin N, Anton P, Löfberg R, Bohman L, Bernstein C.*

*Am. Journal of Gastroenterol.:1999;94, 1298-1303*

**Background:** There is an increasing interest in complementary and alternative medicine by patients with chronic illnesses. IBD-patients may seek alternative medicine for symptomatic relief and as a novel approach when conventional medicine has incompletely satisfied their health care needs or failed to provide them with some sense of control over their illness. For some it may reflect their disgruntlement with their physicians or with conventional medicine in general, as it may be seen as too complex and technologically oriented, impersonal, costly, inconvenient, unavailable or inaccessible. The aim of this study was to determine the extent of alternative medicine usage and the attitudes towards it, among patients with IBD, in four different countries (Canada, US, Ireland and Sweden).

**Methods:** A self-administered anonymous questionnaire was used including the patients demographic data, employment status, annual income, urban versus rural residence, kind of IBD, health status, no of visits to practitioner of conventional medicine last year, no of sick days in home or hospital. A list of alternative medicines was given and the patients were asked to indicate the alternative therapy and the reason, as well as condition or symptom for which they sought alternative medicine. Additionally the questionnaire included 22 questions regarding respondents' attitudes towards conventional medicine and alternative medicine. **Results:** 51% percent of the 289 patients used some form of alternative medicine. The usage was higher in North America than in Europe. Cork 31% (n = 58), Los Angeles 68% (n = 114), Stockholm 32% (n = 56), Winnipeg 57% (n = 61). The six most commonly used therapies were: exercise (28 %), prayer (18 %) counseling (13 %), massage (11 %) chiropractic (11 %) and relaxation (10 %). Only 7 % used acupuncture or homeopathy and 5 % used herbal medicine. The attitude section showed that the patients were more likely to use alternative medicine if they were not satisfied with the conventional therapy and respondents from Cork to be more likely to respond positively toward alternative medicine and negatively towards conventional medicine compared to the other centres.



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### Paper # 2

#### **Anxiety, Functional Health Status and Coping Ability in Patients with Ulcerative Colitis undergoing Colonoscopic Surveillance.**

*Oxelmark L, Nordström G, Sjöqvist U, Löfberg R. Inflammatory Bowel Diseases 2004; 10: 612-617.*

**Background:** Patients with longstanding extensive ulcerative colitis (UC) have an increased risk of developing colorectal cancer (CRC). High risk UC-patients are nowadays enrolled in surveillance programs in order to decrease CRC-incidence and mortality, although little is known about patients' concerns and anxiety when subjected to colonoscopic surveillance. The aims of this study were to evaluate functional health status, general state of health, anxiety and coping ability in patients with UC taking part in such a program in a university hospital setting.

**Methods:** Forty-one patients with longstanding, extensive/total UC in remission (median disease duration: 21.0 yrs) undergoing surveillance comprised the study group. Twenty patients with extensive disease but with shorter disease duration (median 8.0 yrs) and 19 patients with only distal involvement UC acted as controls. Four different self-administered questionnaires (SAQ) were used. The SAQ assessments were made twice in the study group and once in the controls.

**Results:** No statistically significant differences were found in any of the SAQ assessments. The median scores obtained were well within the ranges seen in normal healthy subjects.

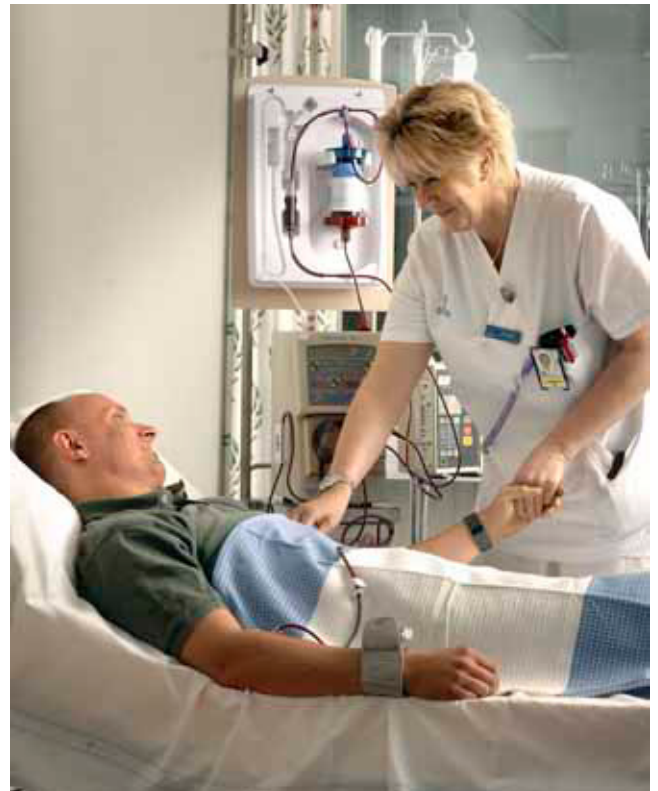
**Conclusions:** Colonoscopic surveillance in longstanding UC does not seem to generate increased anxiety or impairment of functional or general health status among participating patients. Rather, UC patients in clinical remission seem to cope just as well as healthy individuals irrespective of the CRC-risk or surveillance procedures.

### Paper # 3

#### **Quality of Life in Patients with Active Ulcerative Colitis Treated by Selective Leukocyte Apheresis.**

*Oxelmark L, Hillerås P, Dignass A, Mössner J, Schreiber S, Kruis W, Löfberg R. Scandinavian Journal of Gastroenterology, 2006. In Press*

**Background:** Disabling bowel-symptoms and troublesome side effects of medical treatment influence the health related quality of life (HRQOL) in patients with ulcerative colitis (UC). Leukocyte apheresis is a non-pharmacological but invasive, new treatment option under consideration for patients with active UC. The aim of this study was to evaluate the impact on HRQOL in patients with active steroid refractory UC treated with leukocyte apheresis and to study the correlation between QoL and disease activity.





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**Methods:** Thirty-four UC-patients participating in a prospective multi-centre study underwent weekly one hour apheresis sessions with a selective leukocyte absorptive device. HRQOL was measured by the Inflammatory Bowel Disease Questionnaire (IBDQ) before (week 1), during (week 3) and after treatment (week 6). Major outcome was assessed as changes of mean IBDQ and mean IBDQ dimensional scores, and correlations were performed between HRQOL and clinical parameters.

**Results:** The mean IBDQ increased from 138 (range 97-208) at start to 154 (95-214), at week 3,  $p=0.001$  and 163 (117-216), at week 6,  $p=0.0006$ . Three of the IBDQ dimensions (bowel, systemic and emotional) improved significantly during the study. Correlations between clinical improvement and the IBDQ were significant at week 6 in total and in all dimensional scores.

**Conclusion:** Treatment with leukocyte apheresis may improve HRQOL in patients with active UC.

## Paper # 4

### A Group-based Intervention Programme in IBD Patients - Effects on Quality of Life

*Oxelmark L, Magnusson A, Löfberg R, Hillerås P. Inflammatory Bowel Diseases, 2006. In press*

**Introduction:** Inflammatory bowel diseases (IBD) such as ulcerative colitis (UC) and Crohn's disease (CD) have great impact on patients' health related quality of life (HRQOL). The aim of this study was to develop an integrated medical and psychological/psychosocial group-based intervention program for IBD patients and to evaluate if such a programme could influence the patients' health related quality of life (HRQOL) and coping abilities.

**Method:** IBD-patients in remission or with low disease activity were randomised to intervention or control groups. The intervention comprised nine weekly sessions, alternating lectures and group therapy sessions. The Inflammatory Bowel Disease Questionnaire (IBDQ) and the Sense of Coherence scale (SOC) were used to measure HRQOL and coping ability at 0, 6 and 12 months. The interven-

tion was evaluated by a visual analogue scale (VAS) and written comments by a content analysis.

**Results:** 24 patients were included in the intervention group and 20 in the control group. The mean IBDQ score showed no statistically significant differences before (173.9) or after the intervention at month 6 (175.7), or at month 12 (171.8), or when comparing intervention and controls at month 12. Similarly, there were no statistically significant differences in mean SOC before or after intervention or when comparing groups. The VAS and the content analysis showed that the intervention was well appreciated by the patients.

**Conclusions:** The group-based intervention programme was feasible and highly appreciated. There were no statistically significant differences in average IBDQ or SOC over time or in comparison with controls, although a significant increase was seen in patients with short disease duration.

## Adacolumn® Travel Grants

We are happy to announce that the following people have been awarded the Adacolumn® Travel Grants 2006, for the purpose of visiting UEGW/FESPIBD.

R.N. Christel Nilsson	Ängelholms sjukhus
Dr. Jörgen Thostrup	Höglandssjukhuset
Dr. Anna Wickbom	Univ.sjukhuset Örebro
Dr. Lars Browaldh	Sachsska Barnsjukhuset
Dr. Gøri Perminow	Ullevåls sjukhus
Dr. Lena Grahnquist	Astrid Lindgrens barnsjh
R.N Kajsa Nyquist	Astrid Lindgrens barnsjh
Dr. Susanne Schmidt	Borås sjukhus

Congratulations!

The scholarship committee consisted of Professor Robert Löfberg from Sophiahemmet in Stockholm, Sweden and Dr. Tarja Ruuska from Tampere University Hospital in Finland.

ORDER FORM



**Short report:**  
**Quality of Life in Patients with Active Ulcerative Colitis Treated by Selective Leukocyte Apheresis.**  
*Oxelmark Lena 1 3 4, Hillerås Pernilla 2 4, Dignass Axel 5, Mössner Joachim 6, Schreiber Stefan 7, Kruis Wolfgang 8, Löfberg Robert 1 3. In press, Scandinavian Journal of Gastroenterology 2006.*

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