Features

- IAS Attends PAX Congress in Amsterdam
- Groundbreaking Research on Bowel Obstruction
- IAS Initiates Discussion with U.S. Surgeon General
- IAS plays key role in new ICD9 CM code

STOP PRESS!!

IAS to hold first European Meeting in Amsterdam, April 10/11 2003



Connections

Newsletter of the International Adhesions Society April 2003 Issue No. 2

Welcome

Welcome to a new edition of **Connections**, the newsletter of the International Adhesions Society. We are especially pleased to announce the interim findings of our two patient surveys. In addition to the findings themselves, they highlight the unique role the IAS can play in conducting serious research into the problems of Adhesions Related Disorder (ARD).

Our findings were deemed of sufficient scientific quality to be presented at the VIth International Symposium on Peritoneum in Amsterdam (<u>PAX Congress</u>), April 10-12, 2003.

Through this unique approach to defining and characterizing ARD, we can look forward to uncovering better ways of helping to prevent and treat ARD in all its aspects - surgical, medical, nutritional, psychological, financial and social. Our research will also serve to highlight to plight of the ARD as we campaign for better adhesion disclosure of related complications to patients undergoing surgery. Please continue to support this research by participating in upcoming studies.

Sincerely

David Wiseman, PhD, MRPharmS.

Founder, IAS.

Tracy Joslin, Administrator

IAS in Europe, India, Canada, Russia

We are delighted to welcome a number of new IAS support contacts around the world: Netherlands, Russia, Canada and India as well as a number of states in the USA. Please see our web site for details.

IAS Initiates Talks with U.S. Surgeon General

23 January 2003: Today, the International Adhesions Society (IAS) discussions with Vice Admiral Dr. Richard Carmona (right), the Surgeon General of the United States, concerning public health issues related to post-surgical adhesions. Dr. David Wiseman (left), Founder of the International Adhesions Society met with the Surgeon General as well as with two of his aides. "Having been a paramedic, nurse and a surgeon, Dr. Carmona knew immediately from several perspectives what we were talking about." "I think he was certainly sympathetic with our case and will be



supportive in the future," said Dr. Wiseman. Our thanks go to Beverly Doucette of Wisconsin for laying the groundwork for this landmark meeting.

NIH Recognizes Adhesions

We are delighted to see that the problem of ARD is coming to the fore in research. Researchers at the National Institutes of Health contacted the International Adhesions Society recently to enlist our help in recruiting patients to take part in a research study to assess the effects of a drug RALOXIFENE on endometriosis, pain and adhesions in women. To learn

more about the study, please visit the <u>WHAT's NEW</u> section of our Web site.

Groundbreaking Patient Research

Our research has revealed a number of important findings that we hope will advance the treatment and prevention of ARD. <u>Full results</u> are shown on the next page, but the highlights are:

- ARD patients have a bowel obstruction on average once a year.
- 85% ARD patients suffer from chronic pain. Pain medication often makes their bowel problems worse.
- 48% of patients are unable to work, and 46% of these could not obtain benefits.
- 32% of those who tried physical or massage therapy reported a benefit.

With regard to the information given to patients prior to surgery:

- Information about adhesions was given to patients in 54% of adhesiolysis procedures, but in only 10% of other abdominal or pelvic procedures
- In procedures not involving cutting of adhesions, patients were told of adhesion barriers in only 6% of cases

ICD9 CM Code for Adhesion Barrier

The <u>Centers for Medicare & Medicaid Services</u> approved the addition of an <u>ICD-9-CM code</u> for the "Application of an Adhesion Barrier for Prevention of Adhesions" in the USA. IAS members and health professionals around the world played a pivotal part in ensuring that our voice was heard as to the necessity of this code! This new code will enable the US government, as well as researchers, to understand the magnitude of the problem, the need for use of adhesion barriers and increased funding for research in the prevent and treatment of ARD.

INTERNATIONAL ADHESIONS SOCIETY (IAS)

The IAS is a volunteer organisation for the promotion of awareness and research into Adhesion Related Disease, as well as the support of patients and families afflicted with ARD.

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Neither the IAS, Synechion, Dr. Wiseman nor any other representative offers medical advice. This newsletter is for general information purposes only. It is not a substitute for proper medical advice. Always consult a qualified health professional before embarking on, or changing, a course of treatment.

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Ground Breaking Patient Research: Full Abstract

THE PATIENT WITH SEVERE ARD (ADHESION RELATED DISORDER); PATTERN OF BOWEL OBSTRUCTION, BOWEL DYSFUNCTION, NUTRITIONAL, SOCIAL AND PHYSICAN ISSUES

Background: Previous studies have documented the incidence and cost of adhesions in the overall population. However, to date no studies have documented the profile of patients suffering with Adhesion Related Disorder (ARD). Method: An internet-based survey was conducted among patients who visit the web site www.adhesions.org, or who have subscribed to its mailing list. Patients reporting a diagnosis of adhesions were asked to complete a survey regarding the numbers of years since diagnosis, the frequency of bowel obstruction, as well as GI disturbances, nutritional status, their ability to work and receive disability benefits and their support structure. Results: 190 patients (20 male, 170 female) completed the survey with the time since diagnosis of 7.7 + 0.5 years. 71% of patients reported having had either a full or partial obstruction, with 9.8 ± 0.92 obstructions and mean (geometric) time between obstructions of 0.93 years. 83% of respondents report suffering from chronic pain for which 77% take medication. 63% of these report that the medication worsens their bowel symptoms. 76% of patients report chronic GI disturbances, including 28% with a malabsorption problem. 48% of patients report that they are unable to work due to the problems caused by adhesions. and 46% of these report being unable to obtain disability benefits. 32% of patients reported having received physical/massage therapy and 33% of these reported receiving a benefit. 24% of patients reported that their family relationships had not suffered and that their friends and family were supportive of their condition. 28% of patients reported that their physician was able to help them somewhat, with another 31% reporting that the physician acknowledged the problem but was unable to provide any help. Only 10% of patients reported that their physician did not acknowledge the problem and was unwilling to help. Conclusion: Despite shortcomings inherent in a survey of this kind, a description of the severe ARD patient has been provided for the first time. These data will be useful in devising strategies for the medical, surgical, nutritional, social and financial support of the ARD patient.

ADHESIONS AND INFORMED CONSENT: PATIENT AWARENESS OF ADHESIONS PRIOR TO SURGERY

Background: Adhesions are a significant and common complication of surgery, and yet it appears that most patients have never heard of the term. This study set out to ascertain the information provided to patients prior to surgery regarding adhesions. Method: An internetbased survey was conducted among patients who visit the web site of the International Adhesions Society (www.adhesions.org), and/or who have subscribed to its mailing list. Patients who had abdominal or pelvic surgeries were asked to complete a questionnaire regarding the information given to them, if any, prior to surgery regarding adhesions and adhesion barriers. Results were stratified according to whether the procedure was known beforehand to include adhesiolysis. Results: 222 (20 male, 202 female) patients completed the survey adequately concerning 479 procedures. Overall patients reported being informed about adhesions prior to surgery in 25% (119/479) of the procedures they underwent. In only 50 (10.4%) of these were adhesions mentioned as part of the informed consent and in another 69 (14.4%) adhesions were discussed but not part of the consent. Patients reported being given information about adhesions in 54% of procedures involving adhesiolysis (n=161) and in 10% of procedures not involving adhesiolysis. Patients reported being provided with information about adhesion barriers, in 46% and 6% of procedures involving and not involving adhesiolysis respectively. Conclusion: Given the prevalence of adhesions, the frequency of information provided to patients about adhesions and adhesion barriers appeared remarkably low. Information was more forthcoming in adhesiolysis procedures. Despite a number of obvious caveats involved in interpreting a study of this kind, it suggests the pre-operative consultation and consent procedures may offer the ideal opportunity to educate patients about adhesions. This can only benefit both patients and doctors.

Quick Adhesions Facts

- Hospital admissions for ADHESION RELATED DISORDER (ARD) rival those for heart bypass, appendix and other well known operations. In 1996 (USA) there were 474,000 operations for removal or peritoneal adhesions.
- 35% of women having open gynecologic surgery will be readmitted 1.9 times in 10 years for operations due to adhesions, or complicated by adhesions.