Features

- **IAS Inaugural Meeting/Minisymposium (p7)**
- **Adhesions Tapes (p10)**
- **Adhesions Ribbon Competition (p3)**
- **A Patient's Guide to Adhesions.(p11)**

Columns

Connections

The Newsletter of the International Adhesions Society
Vol 1 Issue 1, 2001

INTERNATIONAL Adhesions Society

Inaugural Issue!!

A milestone in the growth of the International Adhesions Society

Welcome

Our inaugural issue of 'Connections' marks a milestone in the history of the IAS and our fight against Adhesion Related Disorder (ARD). From our informal beginnings in 1996 we have grown in leaps and bounds. TWO web sites, Internet chats, local chapters, an Inaugural Meeting, a MEN's section and tons of support - these are all things that none of us would have dreamed possible. All of this grew from one article on the Internet - " A Patient's Guide to Adhesions," abridged and updated here on page 11.

There are now hundreds of members around the world supporting each other - practically as well as emotionally. We have arranged for previously refused medical coverage, we have arranged for members to travel to Germany to receive the latest products available to reduce adhesions and we have been able to assist in obtaining disability coverage for ARD patients.

The hundreds of requests we receive from doctors as well as patients serves to highlight the need for greater awareness about the…….

#1 COMPLICATION of SURGERY:

Some attendees of our inaugural meeting

ADHESIONS!!

We are therefore delighted to publish this inaugural issue that will be available in doctors' offices as well as on the Internet. We hope that this newsletter will be an effective weapon in the fight to increase awareness about ARD as well as for its prevention.

Finally I would like to thank all those volunteers who make the IAS work daily, as well as our sponsors who are described later in this newsletter.

Sincerely

David Wiseman, PhD, MRPharmS,

Founder, IAS.

WHY IAS? WHY ADHESIONS!!

Hospital admissions for Adhesion Related Disorder RIVALS the number of:

- hip replacements, or
- heart bypass operations, or
- appendix operations

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.

Everyone has heard of heart, hip and appendix operations, but why not ADHESION operations!

- Adhesions are the #1 complication of surgery.
- Adhesions are internal scars that connect organs not normally connected.
- Adhesions can cause pain, bowel obstruction, infertility.

INTERNATIONAL ADHESIONS SOCIETY (IAS)

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

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Sticky Questions and Mailbag

Here are some recent questions. Answers here have been typified for illustration.

Q: I am overwhelmed with joy in seeing that there is a website for adhesion sufferers. I live in CA - have been unable to work for the last three years. I have an extremely compassionate doctor, yet there is no hope for relief for me. Do you know of any support groups or physicians in my neighborhood? I am desperate.

A: We have several IAS volunteers in CA (see list p6). Also here are some names of physicians who been recommended as having experience treating ARD patients. There are no guarantees, so please check these doctors yourself. It is important that you get a proper diagnosis to determine the cause of your pain.

Q: Dear Dr. Wiseman. I have heard about adhesion barriers. What are they?

A: Adhesion barriers are devices that are placed at the site of surgery to reduce the formation of adhesions by preventing organs from sticking to one another. There are two barriers available in the USA: INTERCEED (Ethicon) and Seprafilm (Genzyme). In other countries, there are products which have related actions: INTERGEL (Ethicon) and ADEPT (ML Laboratories). PRECLUDE, made of Gore-Tex is used by some doctors, but is not indicated for adhesion reduction.

Q: Dear Dr. Wiseman. I have had over 30 laparotomies/ laparoscopies for ovarian cysts/tumors over the last 12 years. After a complete hysterectomy in 1993, I am now plagued with chronic adhesions. I am now having surgery to remove them at least every 4-6 months, and they keep returning - worse and more frequently than the ones before. They wrap around my intestines and emergency surgery becomes a necessity. I am desperate for help and am physically and emotionally exhausted from so many surgeries. I need help!

A: Unfortunately you are not alone. I am sure your doctors are as frustrated as you are. One of our tapes has a list of techniques that surgeons are using to prevent adhesions. After a full consideration of all the risks and benefits, your doctor may decide to recommend some of these to you.

Q: Why does it seem from everything I read on the IAS web site, that women are more prone to adhesions than men? Is this a hormone thing?

A: There have been suggestions that hormones can affect adhesions. However you must remember that due to anatomic differences, women have more opportunities than men for diseases and invasive procedures of the abdomen. Also the Internet behaviour of women is different from men, which makes it seems like there are more of them with adhesion problems.

The International Adhesions Society

Although adhesion formation occurs after almost every surgical operation, the problems that adhesions cause - medical, psychological and social - are poorly understood by health providers and patients alike. The number of hospital readmissions for adhesion related complications rival the number of operations for heart bypass, hip replacements or appendix operations. Over a third, 35%, of women undergoing open gynecological surgery will be readmitted for adhesion related complications in the following 10 years an average of 1.9 times.

Patients suffering from Adhesion Related Disorders (ARD) are often sentenced to the frustrating ordeal of having to find experienced and accessible healthcare for their condition. In addition they are often mislabeled as "psychiatric" cases and are isolated from family and friends.

Why the IAS?
Only recently have medical professionals begun to realize the extent of ARD and the devastation caused not only by the condition itself, but also by misunderstandings about it within the medical community.

The IAS was formed around 1996 as the result of the large email correspondence received by Dr. David Wiseman, an expert in the area of post-operative adhesions. Together with a group of ARD patients, some of whom had undergone over 20 operations for adhesions, the founders realized that a significant effort must be made to make both patients and doctors aware of the problem of ARD.

It was decided to establish a web site. Since then thousands of patients around the world have been accessing our information pages, or sending messages of support and hope to fellow sufferers.

In addition we have volunteers who are able to assist needy cases in obtaining qualified medical care. We also have a database of doctors around the world who are knowledgeable about adhesions and sympathetic to the needs of the adhesions patient.

International Adhesions Society

Mission

Our Mission is to:

1. Provide information on ARD, its treatment and prevention, to patients, doctors and other professionals.

2. Provide support to patients suffering from ARD (we do not diagnose or treat health problems).

3. Promote awareness and research in the prevention and treatment of ARD.

4. Serve as a forum for public education; to raise the level of awareness among doctors, healthcare providers, government, and the public at large to promote comprehensive and integrated care for adhesion sufferers.

The International Adhesions Society offers:

* Worldwide database of doctors knowledgeable about adhesions.

* Support to patients and doctors through message boards, email, and telephone contact

* Local IAS Chapters

United Kingdom Adhesions Society - www.adhesions.org.uk

We are pleased to announce the launch of the UKAS web site, founded by Kath Findlay in 1998. With aims identical to the IAS, the UKAS has a network of local volunteers to ARD patient in the UK. The UKAS, like the IAS, is compiling a list of national resources, doctors and other professionals who can assist the ARD patient.

Adhesions Ribbon: Competition Open

To boost awareness of adhesions and ARD we would like to produce the "Adhesions Ribbon" (Adhesions Knot?) to be worn and displayed everywhere. We are holding a competition for the best design. The winning design will be attractive, original, practical and economical to make. The winning designer will be receive $100 and a free set of IAS tapes. Please submit designs to Bev at BNB@new.rr.com by June 30 2001.

IN THE NEWS

Product Approvals

ADEPT ™ (ML Labs) was launched recently in Europe for reducing adhesions. This glucose polymer acts by maintaining high volumes of abdominal fluid, causing organs to "float" and preventing them from sticking.

SEPRAMESH ™ (Genzyme) is a mesh used to repair hernias. Unlike conventional meshes, it is coated with a substance that reduces the formation of adhesions to the plastic mesh.

Waiting for Approval

INTERGEL™ (LifeCore), although available around the world, is awaiting approval in the United States and is the subject of a dispute between the company and FDA. The matter will come before a Dispute Resolution Panel of the FDA on June 4th 2001.

Clinical Trials

Gliatech are completing their US clinical trials for ADCON solutions. Submissions for approval may take place in 2001. The company has suffered manufacturing and FDA setbacks that they are working to overcome. Confluent have begun SprayGel trials in Europe and in the US, as are Chitogenics and Fziomed.

Other Products

Patients undergoing laparoscopy often experience pain and loss of body temperature. The cold, dry gases that inflate the abdomen create a wind-chill. INSUFLOW is a new device that warms and humidifies the gases. Patients experience less post-operative pain and more rapid recovery. Although the makers, (Lexion) do not claim this, it is our opinion that this device is likely to contribute to a reduction of adhesions.

Another device with the potential to reduce adhesions and other surgical complications is PROTRACTOR, made by Dexterity Surgical. This device reduces damage caused in conventional operations by holding the wound open in a circular fashion, and keeping the abdominal tissues moist.

Latex and Powder Free Gloves

Regent Medical has added the Biogel Skinsense N nonlatex glove to its range of Biogel powder-free surgical gloves, providing two safety features for patients and surgeons. These latex-free gloves can be used by surgeons and in patients, with latex sensitivity. The lack of powder used in traditional gloves, avoids the complications associated with powder such as adhesions, allergy, contamination and foreign body reactions.

Upcoming Research

It appears that there may be reasons why some patients suffer from adhesions more than others. The IAS would like to determine what these reasons are. This research will lead to a better understanding of ARD, its treatment and prevention. We are soliciting contributions to enable us to conduct this work.

Physiotherapy and Relief of Adhesions

We have received a number of reports from members and therapists about the benefits of certain forms of physiotherapy in ARD patients. This benefit may even extend to adhesion-related infertility. We look forward to hearing about more definitive studies that will confirm these findings. If you would like to explore this avenue please contact us.

Delivery of Seprafilm

Synechion/Tilton JV are developing instruments that will allow Seprafilm to be used in laparoscopic procedures.

Business News

Genzyme Surgical, Biomatrix and Genzyme Tissue Repair have merged to form Genzyme Biosurgery, hoping to be a leader in adhesions research.

Dr. Korell, Duisburg, Germany

Our thanks to Dr. Korell for his incredible hospitality. For 12 of our members and some husbands, he arranged accommodations, sightseeing and entertainment during their treatment in Germany.

ACHIEVEMENTS: BEV

We asked our tireless IAS volunteer Bev Doucette to list our top achievements for the IAS (many of these are due to Bev!!).

1. Allowing ARD sufferers and families around the world to share their problems via the IAS, with the message "YOU ARE NOT ALONE".

2. Securing effective treatment and disability pay for a veteran in the VA system in Montana. A similar success story occurred in Texas. We have other examples of securing SS disability assistance for ARD patients.

3. Upgrading the medical discharge of a young female Lieut. from the Air Force in Nevada due to her suffering ARD.

4. Presentations about the IAS at an FDA meeting on adhesions.

5. We helped an 86 year old lady in Wisconsin receive a proper diagnosis of ARD. This allowed her to receive adequate pain medication for the first time in 50 years!!

6. Obtaining private and Canadian government funds to allow a patient to receive help in Germany.

7. Organizing two trips for IAS members to receive treatment for ARD in Duisburg, Germany.

8. Putting patients in touch with doctors all around the world who can help with ARD.

FREQUENTLY ASKED QUESTIONS ABOUT ADHESIONS

Q: *What are adhesions?*

A: Adhesions are scars that occur internally after surgery, or other trauma such as infection or endometriosis. They connect and disturb internal organs that are not normally attached.

Q: *What problems do adhesions cause?*

A: Adhesions cause pelvic or abdominal pain, infertility or bowel obstruction. Since these things may have other causes, it is important that you consult with your doctor.

Q: *Will I get adhesions if I have surgery?*

A: Chances are that you will. Almost everyone who has surgery will form adhesions?

Q: *How big of a problem is adhesions?*

A: Adhesions Related Disorder (ARD) is the most common complication of surgery. Hospital admissions for ARD rival those for heart bypass, appendix and other well-known operations. A third of all women having gynecologic surgery will have nearly 2 admissions in the next 10 years for adhesion problems!!!

Q: *Will I have adhesion-related problems?*

A: Many people go their entire lives without problems, but the complications of adhesions can strike at any time, even 50 years after your operation!!

Q: *What other problems might I encounter?*

A: Pain may become so extreme and obstruction so frequent, that severely affected patients are unable to work. Obtaining health care or disability is difficult. Finding a doctor who will be able to care for these patients is an exercise in frustration. Family life is destroyed and patients often report that nobody believes that they are really sick. These problems magnify the basic problem to the point of suicide.

Q: *How do I know if I have adhesions?*

A: If you have had an abdominal or pelvic operation and experience chronic pain, bowel obstruction or infertility, then adhesions may be one of the main causes. It is important that you seek proper medical advice to determine the exact cause of your problems.

Q: *Can I take a test for adhesions?*

A: Currently there is no test, X ray, ultrasound or MRI that detects abdominal adhesions. The only way to know for sure is to have an exploratory operation.

Q: *Can my surgeon cut the adhesions?*

A: Yes, but even if adhesions are cut, they can reform, and new ones may also occur.

Q: *What can I do to prevent adhesions?*

A: Ask your doctor about medical products (adhesion barriers) which are used at the time of surgery to reduce the chances of adhesions. None are 100% effective or appropriate in all types of surgery. For other methods you can discuss with your doctor, please contact us.

Q: *How can I get rid of my adhesions?*

A: Other than surgery, there are no proven ways of reducing adhesions. "Alternative" treatments may help to alleviate the pain, but none of these have been scientifically proven.

Q: *What should I do?*

1. Find a doctor who will help you understand your medical condition.
2. Establish a network of friends who are experiencing the same suffering.
3. Be knowledge about adhesions, the problems that they cause and how to reduce them.
4. Start an IAS Chapter in your city.

YOU ARE NOT ALONE!!

In Memorium

We remember Marian Lewis of Odessa, FL, who died 7/26/00 after many years of suffering, starting with a burst appendix in 1958. We send condolences to her family and many friends, and our special wishes to Mr. Lewis who recently assisted IAS members on their trip to Germany. We also remember others who died from complications related to their adhesions: Christina Buelteman, died January 2000, Menominee, Michigan, Cindy McAleer (Nov 13 1962 - June 11 2000), and Susan Stransky, of Florida, who died 2/14/00, after suffering for seven years with ARD.

LOCAL IAS RESOURCES

The following have kindly agreed to act as IAS coordinators in their respective areas. Please contact them for more details about local resources for ARD patients. Please contact the IAS of you are having trouble reaching these people, or to volunteer in your city.

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IAS MEN'S Section

Please see page 10 for more details
Jim jlynch@UDel.Edu

Suggested Local Activities

* Monthly meetings

* Compile local resources for ARD patients: doctors, pain clinics, other therapists.

* Compile information regarding local health insurance coverage and how to ensure proper access to care.

* Compile local procedures for obtaining disability or family services.

* Invite local physicians and other health providers to speak about adhesions and their treatment.

* Establish a local support network of members willing to talk with others - just to talk!! A problem shared is a problem halved.

PLEASE NOTE:
The IAS, its local groups and representatives, Synechion, or Dr. Wiseman cannot provide medical assistance or medical advice. All patients should be advised to seek the care of a qualified medical professional.

SPECIAL SUPPLEMENT: IAS Inaugural Meeting &Adhesion Minisymposium

The inaugural meeting of the IAS at Wayne State University on March 12th proved to be an enormous success. As an added bonus before our meeting, several IAS members were able to attend an academic minisymposium on adhesions organized by Dr. Michael Diamond, Professor of Gynecology at Wayne State University.

Gus Sisler from New York (left) and Bev Doucette (Marinette, Wisconsin).

"*This meeting gave us all renewed hope because it is difficult to have hope with this disease. If we are to help others with fears, we need meetings like this to help us know what is out there so we can spread the word*," beamed Gus Sisler.

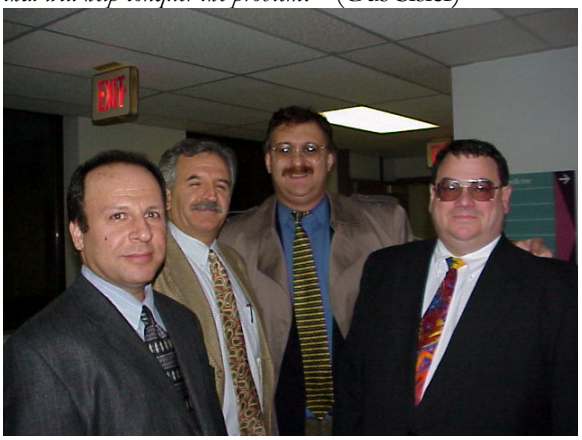
Some of the participants at the IAS Inaugural Meeting (from left) Jim and Beth Butler (Flint, MI), Dr. Michael Diamond, Dr. David Wiseman, Dr. Lena Holmdahl, Margaret Holmes (CEO, Dept. Obgyn, Wayne State University), Gus Sisler and Bev Doucette.

Meeting Highlights: Adhesion Minisymposium, Wayne State University.

This unique symposium featured some of the world's experts in adhesions. Kicking off the program was its organizer Dr. Michael Diamond, Professor of Gynecology at Wayne State University. A member of the IAS Advisory Board, Dr. Diamond has been conducting research into adhesions for nearly 20 years and has worked on a number of anti-adhesion agents, including INTERCEED, Seprafilm, Sepracoat and ADCON.

Dr. Diamond outlined the way adhesions form, their clinical significance and the properties of an ideal adhesion barrier. In particular Dr. Diamond highlighted the importance of good surgical technique in adhesion prevention and reviewed the status of laparoscopy and adhesions. When laparoscopy started to develop in the 1990's there were great hopes that it would serve to reduce adhesion formation.

"*Meeting the researchers was exciting because they are the ones that will help conquer the problem.*" (Gus Sisler)



(From left): Drs. Ghassan Saed, Nasser Chegini, David Wiseman, Michael Diamond.

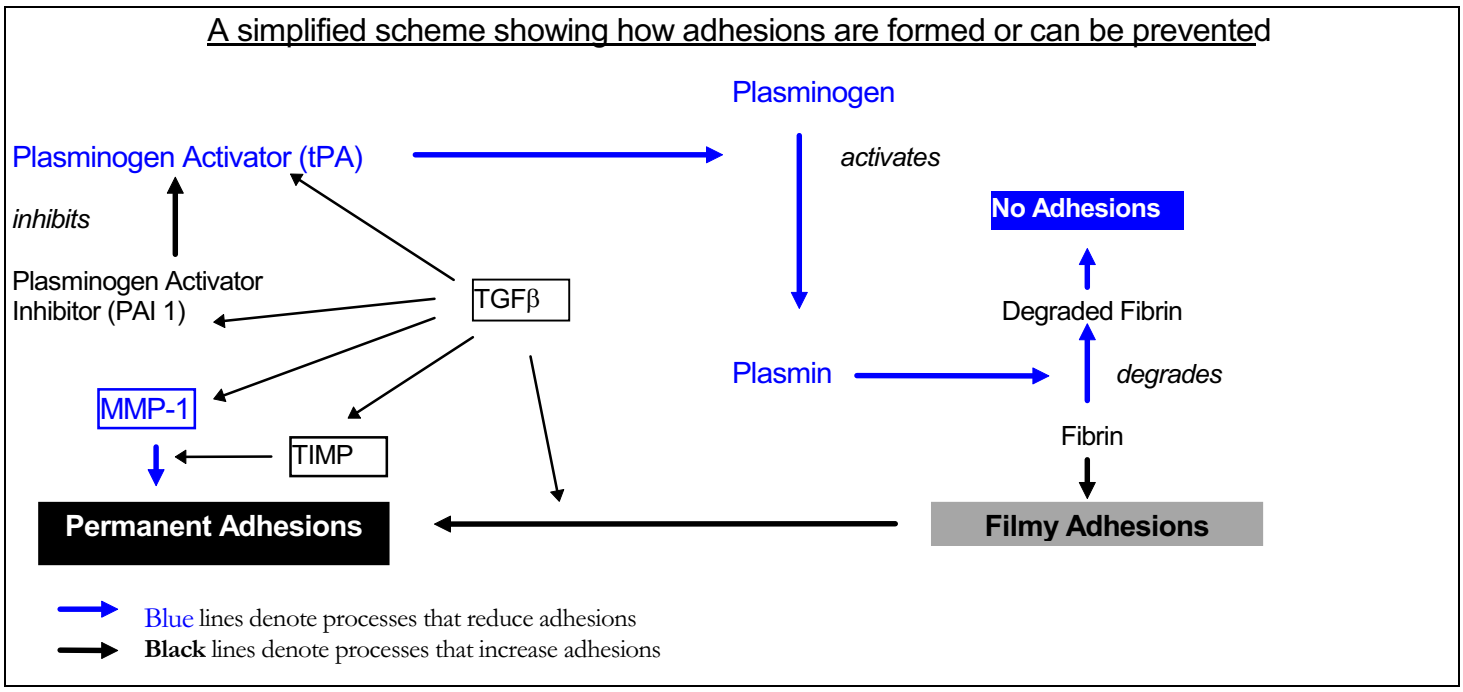
While laparoscopy has many advantages over conventional surgery, adhesion prevention does not appear to be one of them. Some reasons for this may include the fact that arid and cold gases are used to inflate the abdomen. These gases may dry and cool tissues, compromising their ability to resist adhesions.

Dr. Diamond affirmed the IAS view that despite the prevalence of Adhesion Related Disorder, there is little public awareness of its devastating effects and consequently little funding available for research.

Next to bat was Dr. Lena Holmdahl, Professor of Surgery at Gothenburg University in Sweden. A general surgeon by training, colo-rectal specialist, and a member of the IAS Advisory Board, Dr. Holmdahl reminded us of her motivation for her research: the startling statistic that the chances of small bowel obstruction can be as high as 25% within 10 years, depending on the procedure. Dr. Holmdahl then reviewed some of her work over the last ten years and presented some exciting new work on the role of the plasmin system in adhesion formation.

The plasmin system consists of a series of enzymes and inhibitors that regulate the activity of plasmin, an enzyme which degrades fibrin. Fibrin is the sticky substance derived from blood that is what adhesions are made of before they "take root". But the more plasmin available, the more chance that adhesions will be dissolved before they have a chance to "take root".

Plasminogen activator (the most common one is called tPA) activates plasminogen to become plasmin, which degrades fibrin, removing fledgling adhesions. There is a catch though - and that is something called PAI-1 (Plasminogen Activator Inhibitor) - this is a molecule that inhibits tPA. The more PAI-1, the more fibrin and the more chance for adhesions.



So the big question that has engaged Dr. Holmdahl and her group is what factors increase or decrease the levels of tPA, or its inhibitor PAI-1 in peritoneal tissue? The answer seems simply to be the trauma due to surgery. Whether it is the use of retractors, the act of wounding, the lack of oxygen or even the effect of inflating the abdomen in laparoscopy, these are all factors that change the balance of tPA and PAI in favor of the formation of adhesions. Of even more interest is the observation that in the levels of PAI-1 are higher in adhesions themselves (possibly explaining why adhesions that cut regrow with a vengeance!) and in patients classified as "severe adhesion formers".

Extending this work was Dr. Nasser Chegini, Professor of Cell Biology at the University of Florida, who has characterized the role of TGFβ (Transforming Growth Factor β), Matrix Metalloproteinases (MMP's) and their inhibitors (TIMP - Tissue Inhibitor of Metalloproteinases) in adhesion formation and their interaction with the plasmin system. MMP's degrade collagen - the substance that makes up the bulk of permanent adhesions. The more MMP, the less collagen, and the fewer adhesions. TGFβ and TIMP inhibit MMP production or activity. Dr. Chegini's exhaustive work describes how the delicate balance of these molecules, as well as how this balance is tipped within different organs may explain why some organs (eg ovary) appear more prone to adhesion formation than others. Furthermore the levels of these molecules within adhesions themselves may also account for the particular problems of adhesion reformation.

Using a very interesting test-tube (*in vitro*) method, Dr. Ghassan Saed, Assistant Professor, Wayne State University described his studies of fibroblasts, the cells responsible for the production of collagen as well as TGFβ, MMP's and TIMP. These cells can also produce PAI-1. Dr. Saed showed how levels of these molecules in fibroblasts taken from normal as well as adhesion tissue are tipped in favor of adhesion formation when they are deprived of oxygen. These effects are more dramatic, and appear not be reversible, in fibroblasts taken from adhesions. This again, showing how adhesion tissue is predisposed to further adhesion formation. Finally Dr. Saed showed how two other molecules - Interferon gamma and Interleukin 10 - can help to tip the balance in the other direction, towards reduced adhesion formation.

Finally Dr. David Wiseman presented an historical view of progress that has been made in adhesion prevention, as well as the challenges and opportunities for research in adhesion prevention entitled "Adhesions: Past the Future".

Meeting Highlights: IAS Inaugural Meeting

Speaking at the IAS Inaugural Meeting were (from left): Drs. Michael Diamond (Detroit), David Wiseman (Dallas) and Lena Holmdahl (Sweden).

Our Inaugural IAS meeting featured once again Drs. Diamond and Holmdahl who gave overviews of their work and their views of the major challenges ahead. Both highlighted the importance of improving public awareness of the problem of ARD. Dr. Wiseman gave an overview of the IAS, what we have achieved and what we hope to achieve.

There were plenty of questions for Drs. Diamond, Holmdahl and Wiseman, but most importantly was the feeling that we had reached another important milestone in our history, and another step towards alleviating the suffering due to adhesions.

Cassette TAPE recordings of the lectures of Drs. Holmdahl, Diamond and Wiseman, as well as copies of Dr. Wiseman's slides can be ordered from the IAS. Please see page 10.

Thoughts of an IAS Member: Bev Doucette

My first impression from the meeting was that there simply is not enough interest in ARD within the medical community (let alone Congress) to make a difference! But I was greatly encouraged by what I saw and heard from my meeting with some of the finest researchers in the field of Adhesion Related Disorder: Drs. Wiseman, Holmdahl, Chegini, Diamond and Saed. I was uplifted to see the camaraderie of these Drs. and their cooperative interest in ARD. It was impressive to finally meet those who really do care about and are trying to impact this disease in a positive way. These Drs. actually are researching ways to reduce ARD devastating impact on people, and on society as a whole!

This research might be late in finding interventions for those of us who suffer from ARD daily, but without their collaborative efforts, we have little going for us. I am aware of other researchers, but I know of none who come together as these Drs. did and who are taking an active role in trying to make a difference in our lives with ARD! I applaud their efforts, compassion, awareness, and persistence.

Don't get me wrong, but this slow and tedious work is being conducted by only a handful of researchers. It is not hopeless, not at all, but we have to start to take action, real action. Hopefully Congress will take notice, and we will be able to secure research grants for those who are willing to look for answers for ARD.

If anything can have an immediate and positive impact in the eradication of ARD, I believe it is us, ARD patients, through the International Adhesions Society - it offers the ARD sufferer the shortest route to things that might make a difference in their suffering - education, support, direction, and at times, intervention by an advocate.

But the reality right now is what you see here. It is what we have and that is a lot actually. We have the best surgeons, the IAS and each other. Now as long as we have all this, the only direction from here is…UP!!

COULD'NT come to DETROIT? Let Detroit come to you! Tapes and notes available!

Couldn't make it to Detroit for the IAS Inaugural meeting? Don't worry because now you can order a set of tapes containing the following lectures:

Dr. Michael Diamond	The significance of adhesions
Dr. Lena Holmdahl	Advances in the understanding of adhesions
Dr. David Wiseman	International Adhesions Society: Patient perspectives, why adhesions form and challenges ahead.

As well as the following additional lectures:

Dr. David Wiseman	The use of crystalloid (salt) solutions for adhesion prevention
Dr. David Wiseman	"TEN (and more) WAYS YOUR DOCTOR CAN HELP TO REDUCE or ALLEVIATE ADHESIONS"

Members joining at the suggested level of $50 will receive a free set. Or to order your set, please send a check for $35 (add $5 for outside USA), with you name and address to: Synechion, Inc. PMB 238, 6757 Arapaho Rd., Suite 711, Dallas, TX 75248

IAS Men's Section

We are pleased to announce the formation of the IAS Men's section. So many of our members are women. However there are a significant number of men who have the same kinds of problems due to adhesions. Their access to informed medical care for their ARD tends to be even more limited than it is for women. Accordingly we have established the IAS Men's Section to be coordinated by Jim Lynch of Delaware.

Jim's problems started in January 1998 about 3 years after a colon resection for diverticulitis. Shortly thereafter he developed sharp abdominal pain and complete obstruction due to adhesions that were lysed. After a failed attempt to repair an abdominal hernia from this second operation, Jim had a myofascial flap advancement, with adhesiolysis in October 1999. Since then Jim has had a number of procedures and interventions for partial bowel obstruction and had endured sustained abdominal pain. Jim is about to undergo an abdominal adhesiolysis.

We would like to gather as much information about the experience of men with ARD, as well as to identify resources for men with ARD. Please look out for the Men's Section on our web site and also contact Jim at jlynch@UDel.Edu to sign up for this list.

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A PATIENT'S GUIDE TO ADHESIONS and RELATED PAIN

or…

YOU ARE NOT ALONE(updated and abridged 5.10.01)

by David M. Wiseman, PhD., MRPharmS, Founder, International Adhesions Society

[This article first appeared on the Internet in 1998. For the purposes of this newsletter it has been abridged and several minor updates made. The article references a number of other pages which are part of the article itself, or where information can be found. For the complete article, please visit our web site www.adhesions.org, and follow the link to "A Patient's Guide to Adhesions").

SUMMARY

Chronic pelvic pain and/or associated intestinal disturbance are a major cause of misery for thousands of patients. Often in constant pain, the patient experiences loneliness, hopelessness, frustration and desperation with thoughts of suicide, straining family and work relationships to the limit. Although ADHESIONS are often (but not always) the cause of this pain, treatment for adhesions is not performed either because the surgeon does not believe that adhesions can cause the problem, or because lysis (cutting) of adhesions is considered too difficult or futile.

Adhesions are an almost inevitable outcome of surgery, and the problems (ADHESION RELATED DISORDER - ARD) that they cause are sometimes severe. Adhesions are probably the single most common and costly problem related to surgery, and yet most people have never heard the term. This lack of awareness means that doctors are unable or unwilling to tackle adhesions, insurance companies are unwilling to pay for treatment and patients are left in misery.

This paper describes adhesions, their treatment and relationship to pain and bowel obstruction. Further, patient's stories illustrate how ARD affects their daily lives and how they cope with a sometimes insurmountable problem.

A key lesson and source of comfort for ARD patients is that they are not alone. The importance of mutual support among patients cannot be underestimated. There are no easy answers. In drawing attention to the human side of this problem, we hope to educate patients and doctors about medical, surgical or psychological treatments available.

Introduction

Subj: PLEASE HELP ME. I AM AT A LOSS!!!! Date: 98-03-25
This e-mail I am hoping against all hope gets to Dr. Wiseman. I am a 38 year old woman. Here is a little about my history:
1976--Appendix Surgery
1978--Perforated Ulcer Surgery
1981--C-Section Surgery
1981--Bowel Obstruction Surgery
1982--Kidney Stone Surgery
1984--Gallbladder Surgery
1985--C-Section Surgery
1986--Perforated Ulcer Surgery (Again)
1986--Ovarian Cyst Surgery
1987--Gastric Resection Surgery
1987--Hysterectomy Surgery
1989--Bowel Obstruction Surgery
1992--Bowel Obstruction Surgery
I am now in Pain all the time and have massive amounts of ADHESIONS and all the doctors tell me there is NOTHING that can be done. The doctors tell me to chew my food better and to eat less often. I weigh 125 pounds and am in pain all the time. I hate to eat that is the worst pain of all. My husband and two children would like their mom and wife to be in some kind of a comfort zone. can you PLEASE help me. I am getting at my wits end. I am still young and would like to be able to live my life. My work, my family and I am all suffering. PLEASE

Unfortunately, this email is typical of the many we receive from patients who are desperate to be relieved of their suffering due to ARD. Another typical story was posted on one of the many Internet message boards.

Subj: ADHESIONS/pelvic pain Date: 96-11-04
I am about to face my fourth surgery for pelvic ADHESIONS. The first one, 9 years ago was a clean-up laparotomy for endometriosis. This was followed by continued pain and an eventual complete hysterectomy 3 years ago. Then pain free for a few months. Then back to the same old pain. Another surgery 11 months later for severe ADHESIONS. (Bladder adhered to stomach wall, colon, bowel, etc. all stuck together-apparently quite a mess) That was 13 months ago and now after severe pain has returned a CT Scan has revealed a cyst (or

> something) the size of a softball. I am due to have surgery in a few weeks to remove it. Has anyone else had similar problems? What can be done to prevent these ADHESIONS from re-occurring? My body can not continue to have surgery year after year…..If anyone has any suggestions please e-mail me or post here on this board. Thanks.

Permeating my email as well as message board postings are feelings of desperation:

> "I am at the end of my rope…...I am tired of living my life in pain"
> "I almost don't want to bother with additional tests; there seems to be no hope for me and I am at the end of my rope, barely hanging on by a thread. I need HELP - is there ANYTHING I can do to have a life that has quality?? How can I get relief? PLEASE - any info you can give me would be extremely valuable. I need to know that I don't have to live the rest of my life this way. thank you."

and sometimes suicide:

> "For the suicidal thoughts I have thought of them but have come to realize that suicide is not the escape"

Patients often report that they are told that their pain is a figment of the imagination:

> "I have been told I'm a wimp, it's all in my head"
> "Doctors are taught A+B=C. Any diversion from this is in the patients head'"

Thoughts about the medical profession range from quiet resignation:

> "There are no doctors who can really help me."

to cynicism:

> "It seems that every time a member of the medical profession gets their hands on me, I come away with less and less"

to open hostility and mistrust:

> "My doctor would rather have me suffer in pain. Most doctors don't understand pain, and refuse to treat it. Why must we suffer? Pain should be treated with strong pain medication. I have spent far too much time laying on heating pads, in bed, suffering excruciating pain. Why should people suffering in pain go to Jack Kervorkian to end their pain forever. Doctors are irresponsible, and insensitive."

especially towards male doctors:

> "Find a female GYN with a brain who will understand what you mean when you say 'pain'. If men can't feel it -- they don't 'get it'."

Many report the human cost of their ADHESIONS or suspected ADHESIONS:

> "A lot of relationships have also been ruined simply because I was unable to be there because of [my] extreme pain. Adhesions DO CAUSE PAIN!! It has been a 28 year ordeal for me. and it is still not over. My faith in doctors has been shattered."

> "My Husband is so understanding that I feel guilty often for depriving him of intimate times (because of pain). It is so hard on him because he knows that if there is any activity below the belly button and above the knees that it will usually make me bed ridden the following day in pain."

The frustration with the lack of a treatment for ARD and the agony of their affliction is tempered by the camaraderie of fellow sufferers, as in this message board posting:

> "Subj: Scar tissue and adhesions Date: 97-04-07
> I have been suffering from this for 10 years now and I am happy that I am not alone (well not happy but you know!) I have been put through the mill with the testing and Dr.'s and all the famous diagnosis' and I still have not found a solution. Why is this? They can put an artificial heart into a human but they can't get rid of ADHESIONS! Pain meds are taking there toll on me and I still have not found any relief. If anyone can offer any advise for me please do so."

This brings us to the reason for this article:

- What treatments are currently available?
- Is there something more we can do for ARD sufferers?

Before we attempt to answer these questions, let's make sure we understand something about ADHESIONS.

What are ADHESIONS?

Adhesions are scars that form abnormal connections between two parts of the body. Adhesions can cause severe problems including infertility, dyspareunia (painful intercourse), debilitating pelvic pain and bowel obstruction. Adhesions may cause

problems elsewhere such as around the heart, spine and in the hand. Adhesions are a response to injury, which can be from surgery, endometriosis, infection, chemotherapy, radiation and cancer.

THE MAGNITUDE of the PROBLEM of ADHESIONS

The rate of adhesion formation is surprisingly high given the lack of knowledge about ADHESIONS. Various studies estimate that 55-100% of patients having surgery will form adhesions, the incidence being the highest after major or multiple procedures. 1% of all laparotomies developed obstruction due to adhesions within a year of surgery with 3% leading to obstruction at some time. 60-70% of small bowel obstructions involve adhesions (Ellis, 1997). Readmissions for adhesion related complications rival the number of heart bypass, appendix or hip replacement operations (Ellis et al, 1999). 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 (Lower et al, 2000). In USA 347,000 operations for lysis of peritoneal adhesions were performed in 1993 (Graves, 1995), of which about 100,000 involved intestinal adhesions. Another report gives 446,000 procedures to lyse abdominopelvic adhesions (HCIA, 1994). In 1988, there were about 280,000 hospitalizations for adhesions, the cost of which was estimated conservatively as $1.2 billion per year (Fox Ray et al, 1993).

ADHESIONS and CHRONIC PELVIC PAIN (CPP)

ADHESIONS are believed to cause pelvic pain by tethering organs and tissues, causing traction on nerves. Nerve endings may become entrapped within an adhesion. If the bowel becomes obstructed, distention will cause pain. Patients in whom chronic pelvic pain has lasted more than 6 months may develop "Chronic Pelvic Pain Syndrome." In addition to the chronic pain, emotional and behavioral changes appear due to the duration of the pain and its associated stress.

> "We have all been taught from infancy to avoid pain. However, when pain is persistent and there seems to be no remedy, it creates tremendous tension. Most of us think of pain as being a symptom of tissue injury. However, in chronic pelvic pain almost always the tissue injury has ceased but the pain continues. This leads to a very important distinction between chronic pelvic pain and episodes of other pain that we might experience during our life: usually pain is a symptom, but in chronic pelvic pain, pain becomes the disease." (International Pelvic Pain Society)

Chronic pelvic pain is estimated to affect nearly 15% of US women between 18 and 50 (Mathias et al, 1996) with direct medical costs for outpatient visits for chronic pelvic pain estimated at $881.5 million per year. 15% of patients reported losing time from paid work and 45% reported reduced work productivity.

Not all ADHESIONS cause pain, and not all pain is caused by ADHESIONS: Not all surgeons agree that ADHESIONS cause pain. Part of the problem is that adhesions cannot be seen with MRI, CT or X ray. Several studies describe the relationship between pain and adhesions and estimate that 25 to 57% of patients with CPP have adhesions, with or without endometriosis (Rosenthal et al, 1984; Kresch et al, 1984; Howard, 1993). In 75% of patients with a physical source of pain, emotional factors contribute greatly to the perception of pain and the ability to cope with it.

TREATMENT of ADHESIONS

Despite doubts as to the relationship between ADHESIONS and pain, several studies show that lysis (cutting, adhesiolysis) of ADHESIONS provides some relief. In a German study (Frey et al, 1994) with female and male patients with chronic abdominal pain, adhesions were lysed by laparoscopy. Up to 30 months later there was a complete remission of pain in 45% of the patients, with 35% of patients reporting a substantial improvement. Other improvements were reported in Switzerland (Mueller et al, 1995), USA (Steege & Stout, 1991; Daniell, 1989) and Netherlands (Peters et al., 1992). If there is an underlying cause of adhesions, such as endometriosis or infection, this must be treated.

The problem with adhesiolysis is that ADHESIONS almost always reform. This is one of the main reasons why surgeons are reluctant to perform adhesiolysis, particularly in severe cases. In addition, the presence of adhesions makes surgery more hazardous, because of the risk of injury to the bowel, bladder, blood vessels and ureters. Some patients may have periods of relief from symptoms for several months, only to have the problem recur:

> "Subj: adhesions: 98-04-04
> I have come back from [Famous Hospital], the GI specialist said that they were 10 - 12 years from knowing how to treat this problem. I still run into allot of MD's who say adhesions don't cause pain, but since I have had 7 surgeries and each time adhesions are "taken down" I get about 1 years worth of pain relief. I have even showed them research studies that show a decrease in pain after surgery and they still are skeptical. Anyway, they are sending me to Dr. XXXX who supposedly specializes in this kind of pain. I'll let you know how it turns out. Keep me informed of any developments that might be helpful with my case. Thanks"

ADHESION Barriers

For over 100 years, surgeons have used drugs and other materials to prevent adhesions from developing with little success. Such materials have included animal membranes, gold foils, mineral oil, silk, rubber, Teflon and even amniotic membrane. These materials are placed at or near the site of surgery, rather like a wound dressing. Other exotic treatments have included ingesting iron

filings and then moving a magnet around on the abdomen to keep the bowel moving and prevent it from sticking. When the tissue has healed, there is no longer a danger of forming adhesions.

Scientists have now developed adhesion barriers that protect tissue and dissolve when they are no longer needed. Products approved by FDA are INTERCEED™ Barrier, (Johnson & Johnson) and Seprafilm™ (Genzyme). INTERCEED has been shown to be efficacious in gynecological surgery and Seprafilm in gynecological and general surgery. However, the use of these products is still limited for several reasons and they do not work all the time. Furthermore, neither product has been fully tested on patients with severe recurrent ADHESIONS. PRECLUDE™ (WL Gore) is not specifically approved to reduce adhesions, although it is used. It does not dissolve and requires another surgery to remove it. Many surgeons instill large volumes of crystalloid, or salt (saline) solutions into the abdomen in the belief that these will reduce adhesions. This premise is not supported by clinical data. Products available in other countries or undergoing US clinical testing include ADEPT™ (ML Laboratories), ADCON™ P (Gliatech), INTERGEL™ (LifeCore), SprayGel (Confluent Surgical) and Oxyplex (Fziomed).

Whatever product is used, it must be combined with good surgical technique in which the surgeon handles tissues as delicately as possible, attempting to avoid further damage to them. Powder-free gloves should be used whenever possible because of the association of talc (no longer used), and even starch used to lubricate the gloves, with adhesions. It is unlikely that any one product will completely prevent ADHESIONS in all situations. There thus remains a need for an improved product that works in a variety of surgical situations and works in a greater number of patients.

TREATMENT of PAIN due to ADHESIONS

PLEASE review our tape: "TEN (and more) WAYS YOUR DOCTOR CAN HELP TO REDUCE or ALLEVIATE ADHESIONS"

A full discussion of pain is beyond the scope of this article and so I recommend visiting the World Congress on Pain, International Pelvic Pain Society and the Endometriosis Society for more information. The American Society for Reproductive Medicine has an excellent booklet on pain. To determine the cause of pain your doctor will take a history, examine you and possibly conduct some tests. These tests may include a laparoscopy.

In patients whom ADHESIONS are believed to be the cause of pain, there are no easy answers. There may not be a cure for the pain, but it may be controlled to a more acceptable level. Adhesiolysis may not be the answer or even the first choice. I would certainly ask your doctor if s/he might consider an adhesiolysis. If s/he was able to use an ADHESION barrier, s/he needs to read the product label to determine whether it is appropriate. If extensive adhesiolysis surgery is required, often a general surgeon will be (and should be) asked to collaborate with the gynecological surgeon. In Conscious Pain mapping, under local anesthetic, the surgeon attempts to locate the focus of pain by prodding different areas within the pelvis. Sometimes pain is associated with adhesions or other abnormalities such as endometriosis.

You may also wish to visit a pelvic pain specialist who may suggest treatments such as trigger point injections, neuroablative procedures (where nerves from the 'source' of the pain are cut) as well as drug treatments, physical therapy, exercise and dietary changes. Where bowel function is disturbed, comprehensive nutritional support may be necessary.

> "It is very important that we have realistic expectations when dealing with chronic pelvic pain. The pain has occurred over a long period of time and will not go away in a short period of time. Your recovery will be a process. Many modes of therapy will be used over the course of your treatment" - Dr. C. Paul Perry (Int. Pelvic Pain Society)

The treatment of CPP requires a team of nurses, psychologists, physical therapists, pain specialists, anesthesiologists, urologists, gynecologists and general surgeons working together to achieve maximum benefit for the patient.

SUCCESS STORIES: ROOM FOR HOPE

One of the biggest factors in the rehabilitation of the ARD patient seems to be the removal of feelings of loneliness. Participation in support groups and other forms of psychological support are a big help. Of course they have been a number of stories where surgical or other therapeutic intervention has helped. Please visit our web site www.adhesions.org where you can read about some happy endings (or at least beginnings) we have heard about.

CONCLUSION: YOU ARE NOT ALONE

Adhesions are an inevitable outcome of surgery, causing widespread and sometimes severe problems. Adhesions may be the single most common and costly problem related to surgery, and yet most people have not even heard the term. This lack of awareness means that doctors are unable or unwilling to tackle the problems of adhesions, insurance companies are unwilling to pay for treatment and patients are left in misery. But this situation is changing. If you are suffering from the effects of adhesions, I hope that you have learned that **YOU ARE NOT ALONE**

Emotional stress plays a major role in ADHESIONS-related pain. A good support network is essential By sharing their experiences with others, by phone, support group, the Internet or the INTERNATIONAL ADHESIONS SOCIETY, patients' feelings of loneliness, abandonment and frustration have abated, engendering a healing frame of mind.

ACKNOWLEDGMENTS

It is a pleasure to thank Jill Eckman and those patients who gave permission to use their stories

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Please join us in learning more about adhesions, how to treat them, and how to prevent them. Together we can bring some relief to patients and their families, helping them lead a more normal life.

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The International Adhesions Society

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