

Lupus Courier

LUPUS SOCIETY OF ALBERTA

March 2011

Volume 12 Issue 1

Definition of
Disease Flare

Pain Management
Through Exercise

"Step Out For Lupus"

2011

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**NEW CLUE
TO LUPUS**

Childhood
Neuropsychiatric
Lupus Research

Lupus Society of Alberta

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Systemic Lupus Erythematosus (SLE) is an autoimmune disease that affects thousands of Canadians, mostly women during their child-bearing years. Symptoms vary greatly from patient to patient, and treatment is highly individualized. Lupus patients are urged to contact their physician or health professionals with any questions or concerns about their illness.

Lupus Courier is mailed quarterly to current members of the Lupus Society of Alberta. Inquirers receive one complimentary copy and are invited to join the Society. The purpose of this newsletter is to publish current, well-balanced reports on lupus and its treatment, health management and research, to serve as a supportive resource and to inform readers of the organization's actions. Articles are presented for the readers' information and do not necessarily reflect the opinions or views of the Lupus Society of Alberta.



Message from the Editor

We all seem to be winter-weary and longing for spring. The photo on this edition's cover certainly conveys what spring, and its struggle to arrive, has been like this year. With that in mind I propose that we remove spring from our vocabulary and substitute "*Sprinter*". as a more appropriate name for what passes as spring in Alberta. It seems that we always have to watch enviously as others in different parts of our vast country, enjoy a distinct and lasting transition from winter to warmth, flowers, green grass and budding trees.

Despite the interminable winter your Board has been busy with organization planning, holding the Annual General Meeting and Board elections. We send our great appreciation to Muriel Kaun and Josée Davies who served on our Board as Vice-President and Southern Director, respectively and welcome Ian Montgomerie as the new Vice-President and Nha Wong as Southern Director. During the AGM we were fortunate to hear a presentation from Shawna Curry on the subject "Exercise for Pain Management". Her remarks are included in this issue and they provide excellent advice for lupus patients.

We do have information available for you as a result of the AGM. I will be happy to send you a copy of our Annual Report and/or the Audited Financial Statements. Thanks to our loyal and new donors, the LSA has not experienced the funding shortfall that many other not-for-profits have experienced in the last 2 or 3 years. We also have had the good fortune to have volunteers across the province take leadership roles in fundraising endeavours that have had a profound and positive impact on our bottom line and thus, what we are able to do for the lupus community.

The Board is once again seeking volunteers to serve on our Standing Committees. Your location does not prevent you from participating so please give this opportunity some thought. More information is available on page 13 and you can e-mail or call me at the office if you have questions or can join us in our committee work.

"A **volunteer** is a person who is a light to others, giving witness in a mixed-up age, doing well and willingly the tasks at hand, namely, being aware of another's needs and doing something about it."



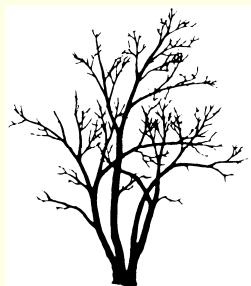
March 2011

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OUR MISSION

To provide education and support on lupus and lupus related issues and enable research to find effective treatments and cures.



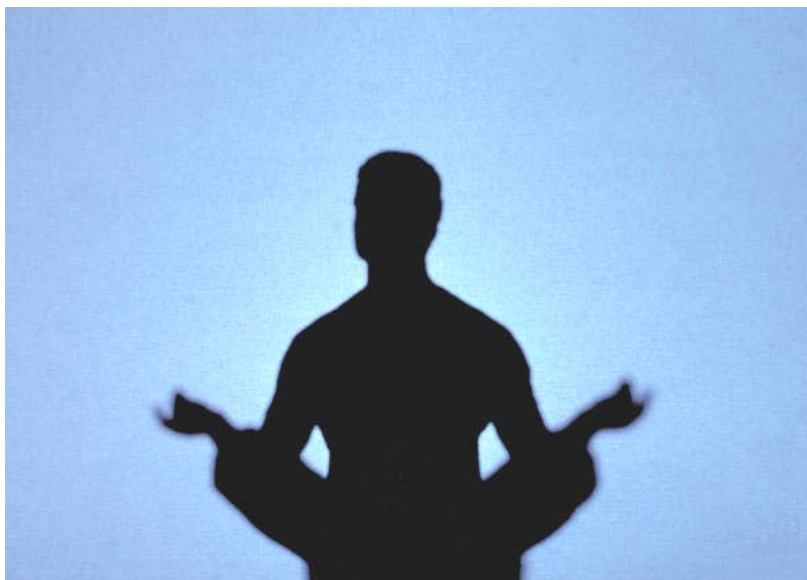
CAN YOGA BE OF BENEFIT TO LUPUS SUFFERERS?

By Rob Juson

Group Organiser, Northamptonshire Lupus Group

I was a person who was always fit and active. I played a lot of sport; squash, tennis, orienteering, golf and often at the gym or out running. Holidays were always packed full of walking, cycling, playing ball games with the children, swimming and all the other things that you do on a good, active holiday. That was until the dreaded lupus came along and stopped me from doing all of the activities that I really enjoyed, especially golf. As with a lot of other lupus sufferers I am unable to walk very far and some days hardly at all.

Strenuous exercise is impossible for both medical reasons and because I am simply unable to do it. Consequently I was desperate to find some sort of exercise that I could do and would hopefully be of benefit. During a conversation with my daughter she suggested that I try Yoga, something she has done on and off over the years and found antenatal yoga to be very good for her. I am a very cynical person and when I looked at the claims as including, "good for the body, mind and soul," my response was, shall we say, not positive.



It was therefore under pressure from my daughter to "try it and see" that I reluctantly went on to the Internet and discovered The British Wheel of Yoga.

(continued on page 6)

New Combination of Antibodies May Better Predict Childhood Neuropsychiatric Lupus

Reprinted from
Lupus Foundation of America www.lupus.org

The role of measurement of serum autoantibodies in prediction of pediatric neuropsychiatric systemic lupus erythematosus. Authors: Mostafa GA, Ibrahim DH, Shehab AA, and Mohammed AK. (2010). *Journal of Neuroimmunology* 227: 195-201.



What is the topic?

Neuropsychiatric lupus (NPSLE) is difficult to diagnose and can be present when disease activity in other organs cannot be identified. Gangliosides are fats on the outer covering of cells and are found throughout the brain. Some people can make antibodies (immune proteins) that target one of these fats, called ganglioside M1.

What did the researchers hope to learn?

The researchers hoped to learn whether antibodies to ganglioside M1 could predict childhood NPSLE any better than standard laboratory measures currently in use.

Who was studied?

The researchers studied 30 children with lupus (24 girls and 6 boys) between the ages of 8 and 16. For purposes of comparison, 30 healthy children with no immune or neuropsychiatric disorders were also included. Children who clearly had NPSLE at the start of the study were not included since the idea was to see if the test for antibodies would predict the onset of NPSLE.

How was the study conducted?

All of the children with lupus were given the steroid treatment prednisolone (0.5 mg/kg/day), either alone or along with other immune-suppressing drugs such as intravenous cyclophosphamide. The children were tested for symptoms of NPSLE and overall lupus disease activity. Blood was drawn from each study participant to assess anti-ganglioside and anti-ribosomal P

antibodies. Patients were then examined and tested for brain function (neuropsychological tests) every month for one year.

What did the researchers find?

12 of the 30 children with lupus developed some clinical evidence of NPSLE during follow-up. Children with NPSLE had significantly higher anti-ganglioside and anti-ribosomal P antibodies than did healthy children or children with lupus that did not develop NPSLE. At the time of initial evaluation (and before NPSLE developed), 83% and 50% of children who later developed NPSLE had anti-ganglioside M1 and anti-ribosomal P antibodies, respectively. Both antibodies were found together in 33% of those patients. All patients who developed NPSLE during the study follow-up had at least one of the antibodies. None of the 18 patients who did not develop NPSLE had either one of these antibodies.

Children with higher levels of anti-ganglioside M1 antibodies seemed to have weaker results on brain (neuropsychological) tests. A similar trend was observed for children with higher levels of anti-ribosomal P antibodies, but this finding was not statistically confirmed.

In children with lupus, overall disease activity level was not statistically related to levels of either anti-ganglioside or anti-ribosomal P antibodies. Levels of anti-nuclear antibodies or antibodies to double-stranded DNA were not statistically related to clinical evidence for NPSLE.

What were the limitations of the study?

This small, preliminary study suggests that children with lupus may have anti-ganglioside M1 and anti-ribosomal P antibodies before developing NPSLE. This does not prove cause and effect and should be confirmed in a large group of children with lupus.

What do the results mean for you?

This study found that anti-ganglioside M1 antibodies might help to predict NPSLE in children with lupus, especially when paired with anti-ribosomal P antibodies.

Failed Autoimmune Suppression Mechanism New Clue To Lupus

Date: February 2, 2011

Reprinted from
The Jackson Laboratory www.jax.org

Bar Harbor, Maine — Researchers at Dana-Farber Cancer Institute in Cambridge, Mass., in collaboration with Jackson Laboratory scientists, have identified a regulatory defect that drives lupus.

Correcting the defect “may represent an effective therapeutic approach to systemic lupus erythematosus-like autoimmune disease,” the researchers state in their research paper, published in the *Proceedings of the National Academy of Sciences*. The research team was led by Harvey Cantor, M.D., chair of the department of cancer immunology and AIDS at Dana-Farber, in collaboration with the laboratory of Jackson Professor Derry Roopenian, Ph.D.

Autoimmune diseases develop when the immune system, which is supposed to identify and vanquish potentially dangerous infectious agents, instead attacks the individual's own body. Most autoimmune diseases strike specific organs, such as the pancreas in type 1 diabetes. Lupus, however, is a systemic disease in which abnormal antibodies are produced throughout the body, inflaming a variety of tissues and organs, including the skin, heart, lungs, kidneys and brain.

Follicular T helper (TFH) cells fuel B cells to produce antibodies, which can be useful in fighting infections. But in lupus, TFH fuel B cells that produce dangerous antibodies that attack normal tissues (autoantibodies). CD8+ T cells (“killer T cells”), on the other hand, normally attack and destroy only infected cells. Cantor and colleagues discovered that a small, but critically important, population of CD8+ T cells (less than 5 percent), plays a specialized role in protecting from lupus. These so-called CD8+ T regulatory, or Treg, cells are specially equipped to destroy TFH cells, and by doing so, prevent lupus from developing.

Using a mouse model for systemic lupus erythematosus in humans that was originally discovered 30 years ago by Edwin Murphy at The Jackson Laboratory, the Dana-Farber researchers, working with Roopenian’s laboratory, found defects in CD8+ Treg activity.

The new paper, Roopenian explains, is the first to demonstrate the potential breakdown of this suppression mechanism in lupus. “Overcoming this defect,” he says, “offers a potential approach to prevent lupus.”

Cantor receives funding from the **Lupus Research Institute**. Cantor notes, “Our LRI funds allowed us to carry out the early experiments that led to the definition of the CD8 suppressor cells.”

The **Jackson Laboratory** is a nonprofit biomedical research institution based in Bar Harbor, Maine. Its mission is to discover the genetic basis for preventing, treating and curing human diseases, and to enable research and education for the global biomedical community.



CAN YOGA BE OF BENEFIT TO LUPUS SUFFERERS? *(continued from page 3)*



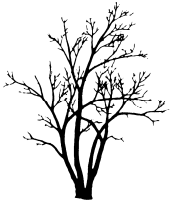
Having found that there were quite a few teachers fairly close to my home I printed the list and decided to telephone a few and see what they had to say about their ability to help someone with lupus. I have to say that I gained the impression that a lot of Yoga teachers only want to teach healthy people. However I did find a lady, in a village only a few miles from mine, she was very positive, and did some research before coming back to me confident that she could help.

I started with a number of 'one to one' sessions with the teacher, which definitely improved my flexibility and I reached a standard whereby she was happy that I could attend her regular class. The routines were tailored to suit me and despite being in a class of others she still has me following a slightly different programme to the rest. I attend her class once a week and have my own 30-minute programme that I do twice a week at home. Yoga is not a method of becoming ultra fit or to lose lots of weight, it is meant to improve your flexibility and balance, improve your breathing and reinforce your core strength. After a couple of months of regular practice I have to admit that my daughter was right, I really do feel substantially better in myself and do move with more ease. I owe my daughter and my teacher, a very large thank you.

I would heartily recommend other lupus sufferers to try it but please be sure that you go to a qualified teacher.

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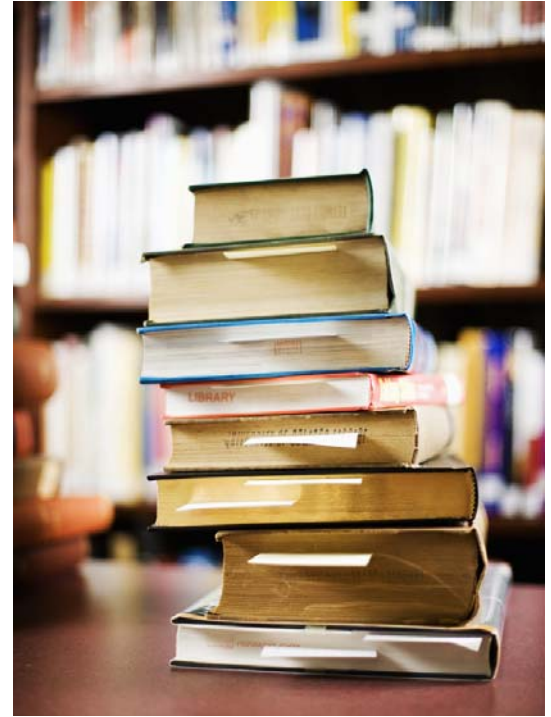




LUPUS SOCIETY OF ALBERTA LENDING LIBRARY

March 2011

LSA Members can borrow any of our books (maximum of 3 books at one time). Books must be returned at the end of 3 weeks. You can pick your selection up at the office or we can mail them out to you.



To borrow any of the following books contact:

Lupus Society of Alberta:

#200, 1301 – 8 Street SW Calgary, AB T2R 1B7

Telephone: Calgary and area (403) 228-7956

Toll Free 1-888-242-9182

Fax: (403) 228-7853

Email: lupuslsa@shaw.ca or lsaservices@shaw.ca

Title	Author	Publisher	Date	Pages
After Shock <i>What To Do When The Doctor Gives You – Or Someone You Love – A Devastating Diagnosis</i>	Jessie Gruman, Ph.D.	Walker & Company, NY	2007	259
Are You Tired Again? I Understand <i>Activity Book for Children</i>	Marilyn Weisberg Deutsch	Mari-Sue Productions	1995	42
Arthritis Foundation's Guide to Alternative Therapies	Judith Horstman	Arthritis Foundation	1999	284
Arthritis Helpbook	Kate Lorig & James F. Fries	Addison-Wesley	1995 4 ed.	218
Autoimmune Diseases and Their Environmental Triggers	Elaine A. Moore	McFarland & Co. Inc.	2002	227
Canada Pension Plan: A guide to Disability Benefits	Elena Sacluti	MS Society of Canada	2000	36
Caregiver Helpbook: Powerful Tools for Caregiving	Vicki L. Schmall, Marilyn Cleland, and Marilynn Sturdevant	Legacy Health System	2000	309
Celebrate Life: New Attitudes for Living with Chronic Illness	Kathleen Lewis	Arthritis Foundation	1999	232
Challenges of Lupus: Insights & Hope	Henrietta Aladjem	Avery Publishing Group	1999	238
Chicken Soup for the Christian Soul: 101 Stories to Open the Heart and Rekindle the Spirit	Jack Canfield, Mark Victor Hansen, Parry Aubery, and Nancy Mitchell	Health Communications, Inc.	1997	401

LIBRARY ORDER FORM

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YOUR NAME: _____ TELEPHONE _____

POSTAL ADDRESS _____

E-MAIL _____ Are You a Member? _____

**If you want to become a member please see application form
on the last page of the *Courier*.**

Title	Author	Publisher	Date	Pages
Chicken Soup for the Surviving Soul: 101 Healing Stories of Courage and Inspiration	Jack Canfield, Mark Victor Hansen, Patty Aubery and Nancy Mitchell	Health Communications, Inc.	1996	359
Conquering Rheumatoid Arthritis	William Bensen & Wynn Bensen	Empowering Press	1996	90
Control Your Pain (2 c)	Robert H. Phillips	Balance Enterprises, Inc.	1996	48
Coping with Depression in Chronic Illness	Sean Hogan-Downey		1995	14
Coping with Kidney Failure: A Guide to Living with Kidney Failure for you and your Family (2 c)	Robert H. Phillips	Avery Publishing Group	1987	309
Coping with Prednisone (*and other cortisone-related medicines)	Eugenia Zukerman and Julie R. Ingelfinger, M.D.	St. Martin's Press	2007	236
Coping With Lupus (2 c)	Robert H. Phillips	Avery Publishing Group, Inc.	1991 (4 c.)	276
Delicate Balance: Living Successfully with Chronic illness	Susan Milstrey Wells	Perseus Books	2000	289
Despite Lupus <i>How to Live Well With A Chronic Illness</i>	Sara Gorman	Four-Legged Press	2009	207
Fibromyalgia, An Essential Guide for Patients & Their Families	Daniel J. Wallace & Janice Brock Wallace	Oxford University Press	Oxford University Press	2003

Title	Author	Publisher	Date	Pages
Get To Sleep: How to Sleep Well... Despite Lupus	Robert H. Phillips	Balance Enterprises, Inc.	1995	17
God Rides a Yamaha: Musings on pain, poetry, and pop culture	Kathy Shaidle	Northstone Publishing	1998	143
How to Help Children Through a Parent's Serious Illness	Kathleen McCue, M.A., C.C.L.S. With Ron Bonn	St. Martin's Griffin	1996	221
Help Yourself: Recipes and Resources From the Arthritis Foundation	Arthritis Foundation		1995	159
How Doctors Think	Jerome Groopman, MD	Houghton Mifflin Company	2007	307
Hughes Syndrome: A Patients Guide to the Antiphospholipid Syndrome	Dr. Graham Hughes	Lupus UK	1997	21
In Search of the Sun: a woman's courageous victory over lupus	Henrietta Abadjem & Peter H. Schur M.D.	Macmillan Publishing	1988	264
It's Not Just Growing Pains	Thomas J.A. Lehman, MD, FAAP, FACR	Oxford University Press, Inc.	2004	416
Life Disrupted <i>Getting Real About Chronic Illness In Your Twenties and Thirties</i>	Laurie Edwards	Walker & Company, NY	2008	272
Living a Healthy Life With Chronic Conditions: Self- Management:	Kate Lorig, Halsted Holman David Sobel, Diana Laurent, Virginia Gonzalez, Marian Minor	Bull Publishing Company	2000	330
Living Well...Despite Lupus (3 c)	Robert H. Phillips	Balance Enterprises Inc.	1996	50
Living With Lupus <i>All the Knowledge You Need to Help Yourself REVISED</i>	Sheldon Paul Blau, MD with Dodi Schultz	Perseus Books	1993	264
Lupus: A GP Guide to Diagnosis	Compiled by Yvonne Norton	Lupus UK	2000	118
Lupus Book (The): Revised and Expanded Fourth Edition	Dr. Daniel J. Wallace	Oxford University Press	2009	258
Lupus Erythematosus: A Patient Guide	Wallace, Hann & Quismorio	Lupus Foundation of America	2000	36
Lupus: Everything You Need to Know	Robert G. Lahita, M.D., Robert H. Phillips, PH.D.	Avery	1998	224
Lupus: Living with it: Why you don't have to be healthy to be happy.	Suzy Szasz	Prometheus Books	1995	243
Lupus Q & A <i>Everything You Need to Know</i>	Robert G. Lahita, M.D., Robert H. Phillips, PH.D.	Avery	1998	240
Lupus the facts	Dr. Graham Hughes	Oxford Medical Publications	127	
Lupus: The First Year An Essential Guide for the Newly Diagnosed	Nancy C. Hanger	Marlowe & Company	244	

Title	Author	Publisher	Date	Pages
Many Shades of Lupus: Info. For Multicultural Communities. (2c.)	NIAMS	NIAMS		27
Meeting the Challenge: A Young Person's Guide to Living With Lupus (8 c)	Amy J. Neil	Arthritis Foundation	1990	50
Monster Under The Bed: Child Rearing When A Parent is Chronically Ill	Barbara Butler	LFA	1989	30
My Lupus: What I Need to Know	Jenny Tekano	Mary Pack Arthritis Program, Vancouver	1998 June	30
New Hope for People with Lupus	Theresa Foy DiGeronimo, M.Ed	Prima Publishing	2002	283
Official Patient's Sourcebook on Cataracts (Directory for the Internet Age – Revised)	James N. Parker, M.D. and Philip M. Parker, PH.D.	ICON Health	2002	245
Official Patient's Sourcebook on lupus Nephritis (Directory for the Internet Age – Revised)	James N. Parker, M.D. and Philip M. Parker, PH.D.	ICON Health	2002	190
Prednisone User's Exercise Manual	Carol Z. Congedo, Jane Brandenstein	LFA	2002	30
Questions and Answers About... Sjogren's Syndrome	National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS)	US Department of Health and Human Services, Public Health Service, National Institutes of Health	January 2001	
Scott's Story About a Disease Called Lupus	A collaboration with Lupus Foundation of America	LFA	2002	34
Self-Advocacy Guide	Written and Compiled by Elena Sacluti	MS-Multiple Sclerosis Society of Canada, Alberta	August 2000	28
Sick and Tired of Feeling Sick And Tired (2 c)	Paul J. Donoghue & Mary E. Siegel	W.W. Norton & Company	1992	284
Silver Linings	Edited by Shaena Engle	Prometheus Books	1997	270
Taking the Lead: Dancing with Chronic Illness	Louise Giroux	Northstone	1998	188
The New Arthritis Breakthrough	H. Scammell	Evans & Co.	1998	330
The New Sjogren's Syndrome Handbook	Sjogren's Syndrome Foundation, Edited by S. Carsons, M.D. & Elaine K. Harris	Oxford University Press	1998	230
The Osteoporosis Book, A Guide for Patients & Their Families	Nancy E. Lane, M.D.	Oxford University Press	1999	206
The Scleroderma Book, A Guide for Patients & Families	Maureen D. Mayes, M.D.	Oxford University Press	1999	182
Understanding Lupus	Dr. Graham Hughes	JSC Consultants Ltd.	1990	100
Understanding Lupus	Henrietta Aladjem	Macmillan Publishing	1985	247
When Mom Gets Sick (2 c.)	Rebecca Samuels	LFA	1985	27
Why Me? The Courage to Live	Debra Kent	Pocket Books	2001	194
Women, Work and Autoimmune Disease (Keep Working Girlfriend!)	Rosalind Joffe and Joan Friedlander	Demos HEALTH	2008	222

International Consensus for a Definition of Disease Flare in Lupus

LFA LUPUS RESEARCH UPDATE

Authors: Ruperto N, Hanrahan L, Alarcón G, Belmont H, Brey R, Brunetta P, Buyon J, Costner M, Cronin M, Dooley M, Filocamo G, Fiorentino D, Fortin P, Franks A Jr, Gilkeson G, Ginzler E, Gordon C, Grossman J, Isenberg D, Kalunian K, Petri M, Sammaritano L, Sánchez-Guerrero J, Sontheimer R, Strand V, Urowitz M, von Feldt J, Werth V, and Merrill J. (2010).

What is the topic?

Lupus is a chronic autoimmune disorder characterized by unpredictable disease flares and remissions. However, there has never been community-wide agreement on how to define clinical flares in lupus patients. Various clinical trials have used different definitions of flare, making it hard to compare results or interpret outcomes. Specific problems were identified with current flare measurements, including the fact that minor worsening could cross thresholds defining severe disease and that patients with significant worsening of disease might not be treated as aggressively as the definitions required. To address this problem, the Lupus Foundation of America convened an international working group to obtain a consensus definition of disease flare in lupus to facilitate new drug development and help physicians characterize lupus with standard, agreed-upon language.

What did the researchers hope to learn?

The researchers hoped to create an internationally agreed-upon definition of a lupus flare that would have practical applications for clinical trial designs.

Who was studied?

This study involved several surveys of an international group of experts in lupus as well as face-to-face workshops.



How was the study conducted?

With help from the Paediatric Rheumatology International Trials Organization (PRINTO), three web-based surveys were conducted, using a scientific method called the Delphi method for pulling together a range of opinions and helping a group sort through the opinions and rank the degree of agreement for each one. Participants included 120 lupus experts from 11 countries, representing universities, government agencies, and the drug development industries. The areas of expertise included rheumatology (adult and pediatric), dermatology, immunology, nephrology, neurology, pulmonology, epidemiology, and statistics.

What did the researchers find?

12 preliminary definitions were drafted during the survey process, and refined through the agreement process. During a final face-to-face workshop, majority agreement was obtained for the following definition: "A flare is a measurable increase in disease activity in one or more organ systems involving new or worse clinical signs and symptoms and/or laboratory measurements. It must be considered clinically significant by the assessor and usually there would be at least consideration of a change or an increase in treatment."

What were the limitations of the study?

Some Delphi survey response rates were below the optimal cut-off of 70% acceptance of definitions for a lupus flare.

What do the results mean for you?

This definition of lupus flare underscores the need to see a significant change in order to consider a patient to be flaring, suggesting that measurements that define flare simply by clinical thresholds are inadequate. The absolute requirement for a change of treatment in order to define a significant worsening of disease was voted down. This may have an important impact on interpreting changes in patients during clinical trials.

The Lupus Foundation of America is the foremost national nonprofit health organization dedicated to finding the causes of and cure for lupus and providing support, services and hope to all people affected by lupus.

PAIN MANAGEMENT THROUGH EXERCISE

By Shawna Curry, B. Kin

Pain can discourage us from moving even though we can reduce and in some cases eliminate discomfort.

There are two types of pain. Acute pain comes on suddenly and usually resolves itself with or without treatment in a few days to a month. Chronic pain which lasts greater than six months is often more debilitating and there is little or no relief from treatment.

Chronic pain results in limited activity which leads to tightness and stiffness. A typical response for those dealing with chronic pain is to become withdrawn, angry, anxious and depressed.

The Mental Side Of Pain

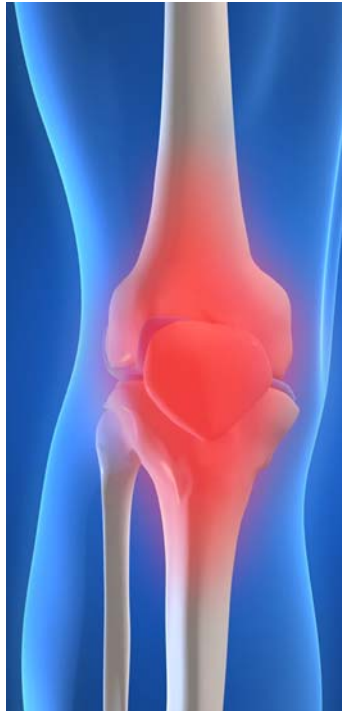
Apathy is the initial response to long term pain followed by uncertainty and fear. We can be shocked that we are having to deal with it and may go into a state of denial and minimize the situation.

The next phase can be exploration of your situation. Acceptance is important as you can then move on to productive actions to deal with your pain. Seek out information that will address your needs, set goals, timelines and limits. The purpose of your exercise program is to improve local symptoms, then improve overall health and well-being.

Before starting an exercise program consult your physician to get guidance on what you should and should not do.

Benefits of Regular Exercise

- Maintenance of bone density: Weight bearing exercises like walking with a weighted backpack or strength training can increase or stabilize bone density
- Decrease in joint pain: Joint movement delivers oxygen and nutrients to cartilage keeping it healthy and increases synovial fluid
- Increased muscle mass and strength: This reduces the load on joints
- Exercise releases endorphins: These are “feel good hormones” that offset our aches and pains and create an anti-depressant effect.
- Improved circulation and healing: Moderate exercise dilates blood vessels improving circulation and promoting healing



- Reduction of risk factors: Exercise, combined with a health diet, can reduce the risk factors and side effects of chronic pain conditions

Appropriate Exercises For Lupus

- Stretching: ROM (range of motion) and 20 to 60 seconds of stretching
- Strength Training: moderate intensity
 - Strength programs with lots of rest
 - Cardiovascular: walk, swim, bike, cross country ski

Lupus and Nutrition

Lupus is an auto-immune disease that can have a gastrointestinal component. Certain foods can be gut irritating such as gluten, dairy products, beans, legumes and lentils. Night shade vegetables, eggs and all grains may create issues for lupus patients. Consumption of a pro-inflammatory diet can lead to total-body inflammation. If you heal your gut you will also improve digestion. Supplementing with calcium, vitamin D, omega 3 and probiotics is also helpful.

What to Eat

Eat real food and avoid trends and fads. The majority of your intake should be vegetables and lean cuts of meat. Fruits, nuts and seeds are also important while you should consume as few added fats, sugars and processed foods as possible. When shopping, focus on the perimeter of the grocery store and avoid the center

aisles! When eating, take your time, chew your food and enjoy your meal. This should be a pleasant part of your day.

Tips to Stay Active

- Challenge yourself and do what you like doing
- Be gentle with yourself during flare-ups and find other forms of stress relief
- Focus on the positive: rather than thinking of what you can't do, get creative and remember there are a lot of other activities and hobbies that won't stress you out
- As time goes on recommit to physical activity and continue to set goals
- Have fun and remember laughter is a great healer

Shawna has worked in the fitness industry for 10 years as a personal trainer, triathlon coach, presenter and writer. She has a Kinesiology degree from the University of Calgary and will graduate this June with her RN degree.

Plans are "a-foot" for *Step Out For Lupus 2011*



Check Our Website For More Information www.lupus.ab.ca Brochures will also be mailed.



Volunteers are invited to join committees for Education & Support, Communications & Public Awareness and Fundraising.

You can also work on projects such as Step Out For Lupus, Education Days, etc. Call Rosemary at the office at 1-888-242-9182 or 403-228-7956 or E-mail: lupuslsa@shaw.ca

CALGARY May 1, 2011 (Sunday)
11:00 A.M. 5K & 3K run & walk
Eau Claire Market/Bow River Pathway

LETHBRIDGE Date to be Confirmed
5K & 3K run & walk
Henderson Lake Trails
& Kiwanis Picnic Shelter

BONNYVILLE Date to be Determined

LACOMBE Date to be Determined

EDMONTON September 25, 2011
(SUNDAY) 5K & 3K run & walk

The Lupus Society of Alberta is dedicated to providing education and support on lupus issues as well as enabling research to find a cure. We do this by working closely with the research and medical communities to ensure the information provided to the lupus community and to society at large is of the highest quality and consistently reliable. We provide active support to those living with lupus through a variety of programs such as those for The Newly Diagnosed, First Nations Communities, Long Term Patients, etc. The LSA plans to enhance support for research and education by creating and hosting symposiums for medical professionals on the latest lupus research.

We will continue with Education Day programs for the broader lupus community as well as the development and distribution of our highly-regarded *Courier* newsletter.

VOLUNTEER

This is a time of renewal and optimism for this society that has served the lupus community very well for almost 40 years. We have a new Board of Directors eager to build upon the Society's many successes and these volunteers realize this will require strong Committees with members who bring fresh thinking and passion to the table.

If you have that passion, aptitude and willingness to work as a volunteer contact us about serving on one of the following Standing Committees:

- **Education and Support**
- **Communications & Public Awareness**
- **Fundraising.**

Health Canada News

News Release

Government of Canada Takes Further Action to Protect Canadians under the Chemicals Management Plan



OTTAWA -- On January 8, 2011, the Honourable Peter Kent, Minister of the Environment, and the Honourable Leona Aglukkaq, Minister of Health, released draft screening assessment reports for Batch 12 of the Chemicals Management Plan's Challenge Initiative.

"We are pleased with the progress we are making in protecting Canadians from chemicals that pose a risk to the environment," said Minister Kent. "We are a world leader in chemicals management and this latest draft screening report allows us to continue our efforts in the best interest of Canadians and the environment."

"Chemicals play an important role in protecting our health and contributing to our quality of life," said Minister Aglukkaq. "Canadians want to know that the chemicals we use every day are managed properly, and that is why the Government is committed to the Chemicals Management Plan and protecting the health and environment of Canadians."

One substance from Batch 12 - Octamethyltrisiloxane or MDM - has been identified as a potential risk to the environment. MDM, which is imported into the country, is used in a variety of consumer and commercial products (e.g., cosmetics and personal care, adhesives, anti-adhesives, and in cleaner agents). The Government of Canada is considering adding this substance to Schedule 1 of the *Canadian Environmental Protection Act, 1999*. Possible measures have been proposed to manage the risks surrounding MDM substances and the potential risk it may pose to the environment. MDM has not been identified to cause harm to human health.

Notices containing summaries of the draft screening assessment reports were published in *Canada Gazette*,

Part I, on January 8, 2011. Draft screening assessment reports for twelve substances in Batch 12 and the proposed risk management scope document for MDM can be found on the Chemical Substances Website (<http://www.chemicalsubstanceschimiques.gc.ca/challenge-defi/batch-lot-12/index-eng.php>).



WANTED

Individuals with lupus or people who are close to those with lupus. If you are interested in donating your time for a photo portrait/story project of all who are affected by the disease with 1000 faces, please contact Michelle at 403-796-7708 or email: micheaujaz@shaw.ca to find out more.

Alberta Provincial Stroke

Strategy report

Summary of key findings

Increased public awareness of stroke

Albertans are more aware of the symptoms of stroke because of awareness campaigns in 2007 and 2009.

Faster stroke diagnosis and treatment:

- Time between symptom onset and emergency department arrival decreased by nearly an hour for those experiencing a transient ischemic attack (TIA or warning stroke) and by 31 minutes for stroke patients.
- More TIA and stroke patients are arriving within the window when treatment can be effectively administered.
- Time between emergency department arrival and clot-busting treatment decreased by nearly 10 minutes between 2004 and 2008. (Considering that 1.9 million brain cells die per minute in an acute stroke, this decrease is substantial.)

Reduced stroke occurrence and mortality:

Emergency department and inpatient hospital visits for stroke declined 23 per cent between 2004/05 and 2008/09.

- There was a 27 per cent reduction in in-hospital mortality for ischemic stroke (resulting from a blocked blood vessel in the brain) between 2004/05 and 2008/09, and a similar reduction for hemorrhagic stroke (resulting from a burst blood vessel in the brain) in the same time period.
- The proportion of ischemic stroke and TIA survivors discharged back to their pre-stroke home increased to 80.8%. More Albertans did not require a higher level of care due to stroke compared to 2004/05.

Stroke preventive services:

- More than 13,000 TIA and stroke patients were seen in stroke prevention clinics since mid-2007.
- More than 300 patients have received urgent care through a physician's TIA hotline that provides specialist consultation, diagnostic imaging and stroke prevention.

Stroke patient satisfaction:

- Overall 94 to 95% of inpatients with stroke were moderately or very satisfied with the inpatient care they received.

Stroke in Alberta

Every year, about 5,500 people in Alberta have a stroke. Of those:

- about 3,800 are left with some form of disability, or die from their stroke.
- fewer than 2,000 are ever able to return to work; and
- about 1,300 are left with disabilities so severe they require long-term care.

The cost of stroke in Alberta is estimated to be \$200 - \$300 million annually.

Alberta Provincial Stroke Strategy (APSS)

The Alberta Provincial Stroke Strategy (APSS) was established in 2005 to improve access for all Albertans to appropriate, coordinated stroke prevention and treatment services. The first APSS evaluation report shows where improvements have been made and makes recommendations for how the strategy can continue to improve stroke services in Alberta.

The long-term goals of the Alberta Provincial Stroke Strategy are to:

- reduce stroke incidence in Alberta.
- improve stroke care by implementing best-practice standards.
- optimize recovery and quality of life for stroke survivors and their caregivers.
- reduce the financial burden of stroke in Alberta.



Wise Words

"Service to others is the rent you pay
for your room here on Earth."

--Muhammad Ali

New Address?

Name: _____
Address: _____
Telephone: _____ Fax: _____
E-mail _____

Effective Date



Or just telephone or e-mail us to pass on your new information.

Would you like to become a member of
the Lupus Society of Alberta?
Is it time to renew your membership?

Membership Application Form

A single fee of \$25 annually entitles you and the members
of your family to participate in the programs and services
of the Lupus Society of Alberta.

- I want to become a member of the Lupus Society of
Alberta
- I want to renew my membership in the Lupus Society
of Alberta

Your membership renewal date will be one year from the date
you become a member.

Name: _____

Address: _____

Telephone: _____ Fax: _____

E-mail _____

Payment method: Cheque Visa MasterCard

Card # _____

Expiry date _____

Name on Card _____

(Please Print)

Signature _____

Donation, Willow Pin, Key Chain, Purple Lupus Wrist
Band, Ribbon Lapel Pin, Magnet, T-Shirt Order Form

DONATION LSA Business # 11924 3343 RR0001

\$100.00 \$75.00 \$50.00 \$40.00 \$25.00

Other \$ _____

Tax receipts are issued for donations of more than \$10

Willow Pin/Key Chain/Wrist Band/Pin Order Form

___ Pewter Willow Pin \$10 ea. = _____

___ Limited Edition Willow Pin \$100 ea. = _____

(sterling silver & engraved gold)

___ Willow Key Chain \$10 ea. = _____

___ Purple Wrist Bands \$ 1 ea. = _____

___ Purple Ribbon Pins \$ 5 ea. = _____

___ Purple Car Magnets \$ 5 ea. = _____

___ Lupus T-Shirt \$ 15 ea. = _____

TOTAL PURCHASES \$ _____

Shipping & Handling (\$ 4.00 small pkg. Or \$ 8.00 large) \$ _____

TOTAL PAYMENT ENCLOSED \$ _____

Payment method: Cheque Visa MasterCard

Card # _____ Exp. date _____

Name on Card _____

(Please Print)

Signature _____

RETURN UNDELIVERABLE CANADIAN ADDRESSES TO: LUPUS SOCIETY OF ALBERTA Suite 200, 1301 — 8 St. SW Calgary, AB T2R 1B7