



LUPINE NEWS

THE OFFICIAL NEWSLETTER OF THE LUPUS SOCIETY OF NOVA SCOTIA



SPRING 2008

SPRING 2008

President's Message *By Josephine Fromm*

Hi everyone,

How have you enjoyed the winter and now ready for spring? I have always loved the snow but, believe me, we've had all the snow I want to see for a while!

The LSNS has had two executive teleconferences to take care of some bills & to discuss my health problems. My doctor has said that I need to reduce my stress level so I have decided to try to handle being the president of the LSNS while having someone else handle our business with Lupus Canada. Iris Scallen has agreed to take on this duty as of May 1st. I will work with her as long as she needs me.

Lupus Canada has decided to change the date of the Canada wide "Walk a Block for Lupus" from October to May. Lupus Canada is holding this year's W.A.B. on Saturday May 10th to correspond with World Lupus Day.

The date for World Lupus Day is the same every year and we will not be moving out walk to May. This being said, we will not be able to call our walk "Walk a Block", as it will not be Canada wide, nor will we be able to use any of the "Walk a Block" materials for our event.

The LSNS has decided to continue holding a walk in October, even if it cannot be called "Walk a Block". This was decided on for several reasons:

1. May 10th interferes with our annual "5K Walk, 10K Run" for Lupus Research in Baddeck.
2. There are already several other charity fundraisers in the Halifax area in May.
3. The park where we hold the Cumberland County walk is too wet and dirty in May.
4. It is harder to get donations so soon after our last walk with

little notice.

5. AND October is, of course, still Lupus Awareness Month.

Please REMEMBER that the "5K Walk, 10K Run" is coming up on **May 10th** and the Quilt Raffle tickets should be out by June. Please try to sell as many tickets as possible and take part in the Baddeck Run / Walk, if you are able. These are our two main fundraisers.

Remember our motto: "**Working together to conquer lupus.**"



LSNS President, Jo Fromm

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LUPUS AWARENESS BEGINS WITH YOU!

BECOME A MEMBER OF THE LSNS, LET US ALL BE COUNTED

LUPUS CANADA REPORT

Lupus Canada has moved the date of the nation-wide Walk a Block event this year to coincide with World Lupus Day on May 10th. The Lupus Society of Nova Scotia has, of course, decided against this move for the 2008 walk for a variety of reasons. The issue will be revisited in the summer and a decision on the 2009 walk will be made before the LSNS Walk for Lupus event in October. This will be done to ensure that participants, donors and corporate partners have plenty of notice of a potential date change.

Other news from Lupus Canada:

Lupus Canada and the Canadian Network for Improved Outcomes in Systemic Lupus (CaNIOS) present the 2008 Health Sym-

posium, "Pathways to Good Health". This year's symposium will be held May 31st at the Delta Montreal in downtown Montreal, Quebec.

The symposium features several keynote addresses, some of those topics this year include: Kidney Disease & lupus, Healthy Eating with lupus, Neurological Complications and Lupus, updates on research being conducted across Canada and much, much more.

For the latest news on the 2008 Health Symposium in Montreal or for more general information and the scoop on what's happening with Lupus Canada visit their website at www.lupuscanada.org.

LSNS ANNUAL 10K RUN / 5K IN BADDECK TO BE HELD MAY 10TH This year's event to coincide with World Lupus Day

Once again, the Lupus Society of Nova Scotia is proud to be a part of the Annual 10k Run / 5k Walk in Baddeck for Lupus research.

This year's event will be held on May 10th, which just so happens to be WORLD LUPUS DAY!

The race will start at the Middle River Community Hall, Victoria County, Cape Breton

- Registration opens at 9:00am.
- Race Starts at 10:00am.
- Pledge sheets are available in advance.

All participants are timed. There will be loads of great prizes, refreshments and good cheer! This event is open to everyone, please support a great cause and keep fit by doing so.

For more information on this year's 10k Run / 5k Walk in Baddeck, contact Linda at 1-902-295-2271 (Daytime) or 902-295-2631 (Evening).

For even more on this or any other LSNS event, email the society at lupusociety@ns.sympatico.ca

Editor's Message - by Brian Gunn

Another issue of Lupine News, another set of challenges to conquer. First off, I offer my apologies for the delay in this issue reaching your mailbox. I was in the midst of a move for April 1 and it ate up much more of my time (before & after the move) than I had hoped or figured it would.

That being said, I have tried to adjust the timing of the publication of each newsletter from here on out to better reflect and coincide with major LSNS events such as: World Lupus Day, The annual 10K run, 5K walk in Baddeck, the LSNS AGM & Health Symposium, the walk for lupus in October, as well as all of the other happenings within the LSNS throughout the year.

Within this issue you will find an important update on the walk for lupus / Walk a Block in Jo Fromm's message (pg. 1) and the Lupus Canada Update (pg. 2). Also, there is a great story on a young woman who will be participating in the Blue-nose International Marathon in honour of her mother and her battle with lupus (pg. 8). Speaking of running, check out the updates on the 10K

Run / 5K Walk in Baddeck on May 10th— aka: World Lupus Day. Plus there is much more information within this edition of Lupine News to keep you abreast of everything that is new (and old) with the Lupus Society of Nova Scotia.

The call is still out there for anyone within the society to submit their favourite recipes, story ideas or news from a fundraiser that someone has planned to benefit the LSNS.

I would also like to hear from the membership regarding opinions on this edition of Lupine News. Do you have an idea that can make this newsletter better? Please, let me know.

I am working with LSNS Secretary, Iris Scallen to have our website updated more often and more consistently. We will keep you posted on those developments.

Thank you for taking the time to read this column and this edition of Lupine News, remember — this is *your* newsletter, reflecting *your* society.

Email: lupussocietyns@ns.sympatico.ca

DISCLAIMER

Please note that information included in the articles published by LUPINE NEWS are not necessarily endorsed by the Lupus Society of Nova Scotia.

The articles in this publication are provided for your information only and should be researched, by you, before adhering to any suggestions or advice they may provide.

Should you have further questions, we recommend that you contact your physician.

MEMBERSHIPS!

THE LUPUS SOCIETY OF NOVA SCOTIA'S CALENDAR YEAR RUNS FROM SEPTEMBER 1ST THROUGH AUGUST 31ST

MEMBERSHIP FEES REMAIN CONSTANT AT \$20.00 FOR SINGLE & \$30.00 FOR MEMBER PLUS SPOUSE

THANK YOU TO THOSE MEMBERS THAT HAVE ALREADY RENEWED FOR 2007-2008.

MOVING ???????



**PLEASE REMEMBER TO SEND YOUR
NEW ADDRESS TO OUR OFFICE.**

**THE LUPUS SOCIETY OF NOVA SCOTIA
P.O. BOX 38038
DARTMOUTH, NS
B3B 1X2**

This will ensure that you are up to date with the latest news
& information from the Lupus Society of Nova Scotia.

SPECIAL THANKS

THE LUPUS SOCIETY OF NOVA
SCOTIA EXTENDS A VERY SPECIAL
'THANK YOU' TO OUR FRIENDS AT

**PARK PLACE RAMADA
PLAZA HOTEL**

FOR THEIR CONTINUED SUPPORT!



"FOOD FOR THOUGHT"

A good laugh makes us a better friend to ourselves and to everybody around us.

- Author unknown

LSNS MISSION STATEMENT

The aim of the Lupus Society of Nova Scotia (LSNS) is to educate patients, their families and the general public, including medical personnel, about LUPUS. We also provide a support network for patients and their families who have been diagnosed with the disease.

We have both a 1-800 number and a local number for messages. We publish a quarterly newsletter and send information packets to new members and those seeking information on Lupus. We promote lupus Awareness and raising funds for lupus Research.

DONATIONS & MEMORIALS

Thank you to our many donors over the past few months for their generous support of the
Lupus Society of Nova Scotia.

Cardiovascular Disease activity in lupus -- even in remission?

Lupus is a disease that has periods of obvious activity and apparent remission. However, even during what seems like quiet periods when there are no clear-cut symptoms, it is possible that changes are occurring below the surface that can cause complications later.

What did the researchers hope to learn?

Lupus patients are at increased risk for cardiovascular disease (CVD), which involves hardening of the arteries and can lead to heart attacks or strokes

later in life. The bone marrow makes special cells that help repair damaged blood vessels (endothelial progenitor cells, EPCs); people with CVD may have fewer of these repair cells in their blood stream, and this may contribute to the damage of the blood vessel walls, increasing the risk for cardiovascular disease. This group of researchers wanted to learn if lupus patients had lower levels of these helper cells, even when they were in remission.

Who was studied?

(Continued on page 9)

SPECIAL THANKS

The Lupus Society of Nova Scotia would like to acknowledge **Dymaxion** and their employees for their generous donation from their casual day fund.

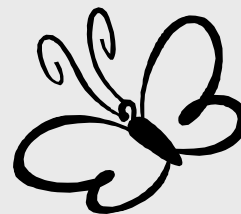
LUPUS SOCIETY OF NOVA SCOTIA'S BOARD OF DIRECTORS 2007—2008

Directors

Jo Fromm	President
Vacant	Vice-President
Kerrie Murphy	Treasurer
Kerrie Murphy	Past - President
Iris Scallen	Secretary
Sharon Moody	Membership Chair
Megan Trenholm	Youth Representative
Brian Gunn	Newsletter Editor
Danny Brownlow	Honorary Director
Lynda Cavanagh	Speaker
Dr. John Hanly (QEII)	Medical Advisor

Committees

June Broyden	Tape Saver Program Chair
Vacant	Walk a Block Coordinator
Vacant	PR Chair



ANNOUNCING SYMPOSIUM 2008

Lupus Canada
&
Canadian Network for Improved Outcomes in Systemic Lupus (CaNIOS)

“Pathways to Good Health “

7th Annual National Lupus Patient Symposium

◆ Saturday, May 31, 2008 ◆ Montreal Quebec ◆ Delta Montreal

SESSION TOPICS INCLUDE:



- ◆ *Kidney Disease and Lupus*
- ◆ *Youth to Adulthood – the Transition Years Lupus*
- ◆ *Research in Canada*
- ◆ *Healthy Eating and Lupus*
- ◆ *Neurological complications and Lupus*
- ◆ *“Keeping Well around the Clock”*



For more information or to register call 1-800-661-1468 or visit: www.lupuscanada.org

CALENDAR OF EVENTS

MAY

- May 10 *WORLD LUPUS DAY* — for more information visit www.lupuscanada.org
- May 10 10k Run, 5k Walk for Lupus Research in Baddeck, NS
- May 10 Walk a Block 2008 - Canada-wide (except Nova Scotia)
- May 23-27 8th International SLE Congress, Shanghai, China
- May 31 Lupus Canada's Annual Conference and Health Symposium, Montreal, QC.

JUNE

LSNS Annual Quilt Raffle kicks off — Tickets go on Sale!

OCTOBER

OCTOBER IS LUPUS AWARENESS MONTH!

- Oct. Walk for Lupus - NS Province-wide
- Oct. 04 LSNS AGM, Annual Health Symposium and Volunteer Recognition Luncheon, Dartmouth
- Oct. 04 2008 Quilt Raffle prize winners are drawn!

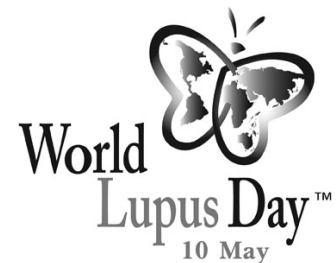
WORLD LUPUS DAY VOLUNTEERS WANTED

Do you or someone you know have the time & energy to volunteer by setting up a table or information booth at the local grocery store, school lobby or community centre?

May 10, 2008, World Lupus Day is quickly approaching. World Lupus Day is a great opportunity to promote awareness and the great work of the Lupus Society of Nova Scotia.

For more information, please contact the LSNS at lupusocietyns@ns.sympatico.ca or call 1-800-394-0125

Working together to conquer



SOBEYS GROCERY TAPES

The Tape Saver Committee looks forward receiving your Sobeys grocery tape receipts via our P.O. Box and processing them for return. **Only grocery tape receipts from Sobeys qualify for our program.**

Thank you to those of you who have sent in their Sobeys grocery tapes. Funds from the grocery tape program help the LSNS continue to carry out its mission.

Besides, it 's one of the easiest fundraisers we have!

RUNNING WITH A PURPOSE

Manda Watt plans to “Giv’er” for lupus

Manda Watt, who hails from Truro but now calls Halifax home, is preparing for her first marathon.

Manda’s mom passed away from complications of lupus when Manda was only ten years old. Though Manda was very young she has fond memories of her loving mother who showed great strength in coping with her illness over many years. Throughout her mom’s illness and in the years following her death Manda had the loving support of family and friends.

Early on, Manda, an employee with Popeye’s Nutritional Supplements, has wanted to do something for lupus in honour of her mother. This year Manda has entered the half marathon of the Bluenose International Marathon being held in Halifax on May 18th. Watt is taking this opportunity to raise awareness and funds for the Lupus Society of Nova Scotia.

Anyone wishing to support Manda’s efforts can make a donation to the Lupus Society of Nova Scotia, PO Box 38038, Dartmouth, NS, B3B 1X2.

Just like the marathon’s slogan suggests, on May 18th Manda plans on to “Giv’er” in memory of her mother.

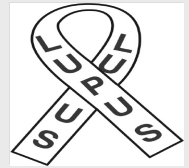


Manda Watt will run in memory of her mom on May 18.

LSNS ANNUAL 10K RUN / 5K WALK

MAY 10TH —WORLD LUPUS DAY

Middle River, NOVA SCOTIA



**Everyone
is
Welcome!**

**Tons of
Great Prizes!**

Be a winner and help a great cause...

THE LUPUS SOCIETY OF NOVA SCOTIA!

For further details or to register, please contact
902-295-2271 or email the LSNS -
lupussocietyns@ns.sympatico.ca

(Continued from page 5)

Fifteen women with lupus and 15 healthy women of the same age and similar smoking histories were recruited for this study. The lupus patients all were in remission for at least one year, and used low doses of prednisone or hydroxychloroquine alone or in combination with other lupus medications.

How was the study conducted?

The researchers took blood samples from all of the study participants and measured the EPCs and other cells that help produce them, called hematopoietic stem cells (HSCs). They compared the levels of EPCs and HSCs in the lupus patients and the healthy controls, and they also looked for relationships between the levels of these repair cells and other factors. To see whether the patients were developing CVD, the researchers measured the "stiffness" of the patients' arteries with tests for blood pressure and blood flow.

What did the researchers find?

The levels of the EPC and HSC repair cells were lower in the lupus patients than in the controls. There was no correlation between the levels of these cells and measures of active lupus such as anti-dsDNA antibodies or antiphospholipid antibodies. Prednisone use did not appear to affect the number of the EPCs or HSCs, but hydroxychloroquine use did -- higher doses of this medication were associated with increased numbers of EPCs. Also, lupus patients who used hydroxychloroquine tended to have lower stiffness scores for their arteries than other lupus patients, which the researchers took as a sign that their blood vessels were staying healthier than others. All of these findings led the researchers to conclude that for some lupus patients, the ability to repair damaged blood vessels may be impaired, even if the patients are in remission and on medication, and it might be that con-

tinuing to take hydroxychloroquine even when otherwise well could help to protect the arteries from future risk.

What were the limitations of the study?

The size of the study population was very small, which makes it difficult for these preliminary findings to be thought of as proven. The researchers didn't examine past use of medications, which may have had an impact on the lupus patients' status when the study was conducted. Also, the lupus patients as a group had more traditional CVD risk factors than the controls, such as higher cholesterol, and it is possible that these other risk factors could have been affecting the levels of EPCs rather than lupus -- as could other things going on in the blood vessels and elsewhere they didn't account

What do the results mean for you?

This study suggests the possibility that lupus might be contributing to future blood vessel damage even when there is no visible sign of the disease. At the same time, it suggests that finding a way to boost levels of EPCs and the HSCs might help prevent CVD from occurring in some lupus patients. It also offered further evidence suggesting that hydroxychloroquine might be useful in preventing CVD in lupus patients. It would be helpful to have a "before and after" study to see whether hydroxychloroquine raises EPCs in patients after it is given, compared to what is found in the same patients before it is given.

Reprinted with permission

Haematopoietic and endothelial progenitor cells are deficient in quiescent systemic lupus erythematosus

Annals of the Rheumatic Diseases, Volume 66, Number 7, July 2007, pp. 865-870

SUMMING UP AGM 2007 *By Iris Scallen*

October 13th, 2007 was a beautiful fall day. The LSNS observed its Annual General Meeting and Health Symposium at the Ramada Plaza Hotel in Dartmouth. The day began with registration and a coffee meet and greet. Many friendships were renewed and new ones formed.

The meeting opened with a warm welcome from our President Josephine Fromm who then introduced our first speaker of the day, Ms. Maureen MacDonald, MLA for Halifax Needham. Ms. MacDonald, the former Health Critic for the NDP, spoke on the present health situation of the province and how it is affecting Nova Scotians. Maureen also has personal knowledge of lupus and its effects on the lupus sufferers, their family life and friends. She was warmly received and answered questions at the end of her talk.

Jo Fromm then talked about our accomplishments over the 2006 – 2007 year and what to expect in the coming twelve months.

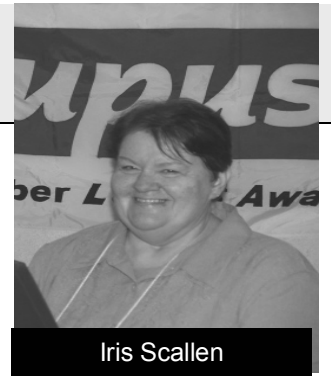
The meeting followed with a presentation of our financial statement and entertained all questions. We remain on the positive side of the ledger raising funds for research and the general operating account.

The next to speak was our Membership Chair, Sharon Moody, who was pleased to announce that we are continuing to grow with new memberships. Sharon also thanked the membership for the highest renewal rate to date, explaining how important it is to be a member in good standing and supporting the Society in raising awareness of lupus.

Next up, Jo discussed our present situation with Lupus Canada. At present the new governance has come to a halt and needs to be reformed. We have maintained our independence and a member of Lupus Canada.

Nominations were held for the LSNS Board of Directors for the year 2007-2008. Brian Gunn offered to let his name stand and the directors from 2006-2007 let their names stand for another year. The membership voted and all were elected to the Board of Directors for 2007-2008. Congratulations to all.

Josephine Fromm will continue as President, Kerrie Murphy will continue as Treasurer, Iris Scallen as Secretary, Sharon Moody accepted to continue as Membership Chair, Megan Trenholm, Youth Rep., Danny Brownlow, Honorary Director and Brian Gunn is now our Newsletter Editor.



Iris Scallen

Before we adjourned, fundraising was discussed in detail, as was the importance of moving to higher goals. One way to do this is continuing the Walk A Block throughout the Province. Brian Gunn, the Team Halifax captain, spoke on the happenings in Halifax & the press coverage that the walk had received from The Chronicle Herald. The progress on the walks from Amherst and Sydney were also discussed by Jo Fromm, Team Amherst captain, and with Gloria Rolfe as Team Sydney captain.

Other avenues we are continuing to follow: Sobeys grocery tape program; coins from the fountains at Mic Mac Mall in Dartmouth & Park Lane in Halifax; coin boxes in corner stores; memorials; corporate and private donations; the Annual Quilt Raffle and the Friends of Lupus 10K Run 5K Walk in Baddeck, NS each May (the funds generated from this event and the coins go directly to lupus research) and casual day donations from different business throughout the province. New avenues such as other forms of corporate giving were discussed & will be followed up.

Jo then thanked all members, families and friends who donated their time, expertise and talents throughout the year with whom the LSNS remained so successful.

The meeting was adjourned and we all proceeded to the Mosher Room for the 7th Annual Volunteer Recognition Luncheon. Before lunch was served our President Josephine Fromm presented gifts that were donated from business from all around the province. Everyone then enjoyed a beautiful luncheon prepared by the catering staff of the Ramada Plaza Hotel. We thank the manager and staff for a wonderful and delicious luncheon.

The afternoon session in the Burnside Room began with Dr. Diane Mosher, who presented a very informative and interesting session on "Reynaud's Syndrome". Dr. Mosher used slides to convey how destructive it could be and to learn the signs of the syndrome. After her talk, Dr. Mosher entertained questions from the group. Everyone was enlightened and found the topic very interesting.

The second speaker of the afternoon was Mrs. Daphne Calhoun-Majaess, BPE, RMT, on the Benefits of Massage Therapy for lupus sufferers. Daphne brought along 10 of her senior students. The group was divided into two sections, half to listen to the lecture and the second half to receive a ten minute massage. Everyone enjoyed a wonderful relaxing ten minute massage. Some even managed a second massage. Following her talk she took questions from the group. This was a welcomed break leading into the third and final speaker of the day.

Our third guest speaker was Dr. John Hanly speaking on Research in Nova Scotia, Canada and the world. Dr. Hanly brought the group up to date on the latest research projects. He talked on the Advances in Collaborative Lupus Research: experience from the Systemic Lupus International Collaborative Clinics (SLICC). Researchers from all Lupus Clinics around the world meet and share their findings. He spoke on the cognitive study and the 1000 Faces of Lupus study presently going on in Nova Scotia. Dr. Hanley took many questions from the group. Everyone was pleased to receive the new information on the research projects in the province and Canada.

At the end of the session Dr. Hanly was asked how many people suffer from lupus in the province and his answer was an estimated five hundred people. Wouldn't it be great if all were members of the Society!

The day came to a close with the draw that all had been waiting for, the Annual Quilt Raffle draw! There was also a draw for several nice door prizes that were generously donated from businesses across the province.

I wish to thank all the members of the AGM Committee with whose help this meeting was so successful, the management and staff of the Ramada Plaza Hotel for their generosity & assistance and

thank you to all of our sponsors for their generosity towards the Volunteer Recognition Awards Luncheon, Door Prizes and Quilt Raffle.

With the presentations completed everyone packed up and left for home for another year. Looking forward to seeing you all on October 4th, 2008 at the Ramada Plaza Hotel, Dartmouth, NS for this year's AGM.

For more information on next year's AGM visit our website: www.lupuscanada.org/novascotia

LSNS 2007 QUILT RAFFLE GRAND PRIZE WINNERS

Grand Prize -

Queen Size "Card Trick" Quilt:

Mr. M. Foreman (Halifax)

Second Prize -

"3 Black Cats" re-print of famous Maud Lewis painting:

Sandra Greene (Yarmouth Co.)

Third Prize -

"Swedish Weave Throw":

Mrs. J. Terry (Halifax)

Winning tickets were sold by: Quilt - Iris Scallen; Painting - Anne d'Entremont; Weave Throw - Eileen Power. The winning ticket sellers received a \$10.00 gift certificate from Sobeys.

LSNS AGM DOOR PRIZE WINNERS

- Gold Earrings (Charm Diamond) - Jo Fromm
- Bottle of White Wine (Pellar Estates) - Donna Marsh
- Set of Goat's Milk Bath Products (Lawtons Amherst) - Norah Rasley
- Bottle of Red Wine (Pellar Estates) - Eileen Power
- Denim-Blue Sweatshirt (Carter's Engraving, Amherst) - Dawn Zwicker

LUPUS SOCIETY OF NOVA SCOTIA

PO BOX 38038

Dartmouth, NS

B3B 1X2

902-425-0358

800-394-0125 (NS Only)

902-798-0772 (Fax)

lupussocietyns@ns.sympatico.ca

www.lupuscanada.org/novascotia



VOLUNTEERS NEEDED

Are you or someone that you know looking for an opportunity to volunteer and make a difference in the community?

Here's your chance!! The Lupus Society of Nova Scotia (LSNS) is looking for enthusiastic, organized and personable individuals to fill a number of needs within the organization.

The LSNS has openings in a variety of roles and would love to talk to all interested parties.

To find out how or where you could fit within the volunteers at the LSNS, contact the office by phone at 1-800-394-0125 or via email at lupussocietyns@ns.sympatico.ca

LUPUS FACT SHEETS

AVAILABLE THROUGH THE LSNS

- | | |
|---|---|
| ◆ KIDNEY DISEASE AND LUPUS | ◆ SYMPTOMS OF DRUG-INDUCED LUPUS |
| ◆ INTRODUCTION TO SKIN DISEASES | ◆ NON-STEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDs) AND COX-II INHIBITORS (COXIBs) |
| ◆ LEARNING TO LIVE WELL WITH LUPUS | |
| ◆ PREVENTATIVE COPING STRATEGIES FOR EMOTIONAL HEALTH | |
| ◆ LUPUS MEDICATIONS MEN AND LUPUS | |

TO RECEIVE ANY OF THE ABOVE MENTIONED INFO SHEETS, PLEASE CONTACT THE LSNS VIA PHONE, EMAIL OR THE MORE TRADITIONAL "SNAIL" MAIL.

ITEMS '4' SALE

BOOKSLUPUS: A GP GUIDE TO DIAGNOSIS -

\$15.00 EA. +GST

LUPUS: THE DISEASE WITH A THOUSAND FACES - \$20.00 EA. +GST

(Please add \$5.00 for shipping & handling)

LUPUS BRACELETS

\$2.00

(Please add \$3.00 for shipping & handling)

T-SHIRTS

S, M, L, XL - \$20.00

(All Proceeds from T-Shirt sales go directly to research)

(Please add \$3.00 for shipping & handling)

LUPUS ANGEL PINS & LUPUS PINS - \$10.00 ea.

The Lupus Society of Nova Scotia only accepts cheque or money order for the sale items. Please mail in your request with cheque or money order enclosed. All prices are listed in Canadian dollars.

Working together to conquer lupus