



THE LUPUS LIGHTHOUSE

30th Anniversary

As we look back over the past 30 years we have much to celebrate!

Winter 2007/2008
Volume 29 * Number 4

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BCLS History

✿ The first meeting of the Lupus Erythematosus Group (LEG) was held on November 17, 1977. On February 4, 1978, LEG elected its first president, Sandra Tong.

✿ The first issue of our newsletter, The Lupus Lighthouse, was published in November 1979.

✿ The board expanded its reach in 1998 when Penny Bradshaw, from Prince George, joined the board for four years. We added a second regional board member in 2000 when Catherine Boeckner, from Lake Cowichan joined the board for two years.

Lupus Awareness

✿ 1995 was the beginning of a new campaign: "Loonies for Lupus". This was ideal for our provincial volunteers sitting at October Lupus Awareness tables in local shopping malls. The decals were brightly coloured and the slogan says it all. Numerous communities around the province participated. The campaign lasted 5 years.

✿ Thank you to BCLS president, Shelley Crawford, for making a Leadership Vancouver connection that brought new awareness in October 1996. Canada Safeway sponsored a lupus panel on their 2% milk containers in stores in BC, Alberta and Manitoba. This campaign ran for 2 years.

✿ In 2001, the BC Lupus Society had an opportunity to be involved with two Backstreet Boys concerts. Volunteers decked out in BC Lupus "conquering lupus" t-shirts educated fans while handing out thousands of brochures and manning an information booth at GM Place.

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BC LUPUS SOCIETY MISSION STATEMENT

To provide education and support to people affected by lupus; to create awareness of lupus and to support advances in treatment and research.



***WE INVITE
YOUR
COMMENTS!***

If you have any suggestions, comments, questions or general feedback for us, we would like to hear from you.

You can reach the BCLS office by email:
info@bclupus.org
or

by phone:
604-714-5564
1-866-585-8787
(toll free in BC & Yukon)

or
by mail:
BC Lupus Society
200-1645 West 7th Ave
Vancouver, BC
V6J 1S4

***We look forward to
hearing from
you!***



President's Notes

After shoveling snow from my driveway, walkways and sidewalks for the umpteenth time, the arrival of Spring seemed years away. It was a great shock, when looking forward in my calendar, to realize that World Lupus Day is just three months away!

The 8th International Congress on SLE was held in Shanghai China in May of 2007. The Lupus Canada delegate attending the Congress discovered that lupus organizations around the world share the same difficulties and challenges that the BC Lupus Society encounters; financial restrictions, limited support from government representatives and little public awareness about lupus.

World Lupus Day activities in 2007 included Argentina's 34th annual medical symposium, Belgium's balloon release event with the distribution of pamphlets, Indonesia's candlelight celebration, Malaysia's walkathon with special "WLD" umbrellas, Spain's national lupus congress, US community outreach and awareness events and United Kingdom's awareness campaigns in public schools.

One initiative resulting from the International Congress on SLE is to increase the publicity of World Lupus Day by coordinating events and activities around the world – there is power in numbers. It is for that reason that the Canadian Walk A Block for lupus event will now be held in conjunction with World Lupus Day, on May 10th.

As a result of the efforts made by BC Lupus Society members, public awareness of lupus and people living with lupus was significantly increased in 2007. Radio ads for the Surrey Walk A Block event, a terrific spot with Dr. Rhonda Low on the television evening news and a great segment with Dr. Art Hister on his syndicated radio show helped to make the general public aware of the seriousness of the disease and the difficulties faced by people living with lupus.

Financial benefits from the Walk A Block events are also significant. Lupus Canada set a goal of \$300,000 to be raised by the 2007 Walk A Block event. Congratulations! Only by the hard work of many volunteers and the generosity of our many donors and sponsors, the goal was exceeded. A total of \$340,000 was raised. In British Columbia we raised approximately \$45,000. We can do better!

You can make a difference. Ask your family and friends to join you and Walk A Block for lupus. Create your own neighborhood walk or join a community walk. A greater number of walks and walkers will create more publicity, more public awareness and more funding for lupus. There is power in numbers.

Mike Hinman
President

WINTER 2007

The Importance of Fatigue in Lupus

By: J. Antonio Avina MD, MSc. PhD candidate

Presented at the BC Lupus Society Symposium on November 3, 2007

Fatigue is a very common problem that has been ignored because we as rheumatologists, and you as patients, are often more concerned about other major (organ) involvements than worrying about fatigue. But fatigue is a very important component from the overall symptoms that patients suffer.

Prevalence of fatigue in SLE

Research has shown that fatigue will affect 80-100% of patients with SLE. As a presenting symptom, it is an important clue in making a diagnosis as it is the most frequent symptom in SLE. Fatigue is present in 80-90% at disease onset. In 30-50% of lupus patients fatigue is the most debilitating symptom interfering with physical, social and emotional functions. However, it is usually assumed as “benign” in the context of other lupus manifestations and there is often nothing that the physician can offer. Very often you, the patient, are more concerned about other manifestations from your disease than fatigue.

Factors associated with fatigue in SLE

The cause of fatigue is unknown but there are several factors that contribute to fatigue. Fatigue is an important component of other diseases, i.e. cancer, diabetes and especially chronic disorders. Is there an association between fatigue and disease activity? Some people believe there is and some people believe there is not.

First, we need to understand what it means in research to say there is a correlation. Correlation values vary between zero to one. A “0” means there is no correlation (factors are independent and have no relationship) and “1” means there is 100% correlation (if one factor changes then the second factor will also change in the same proportion and direction). For example a correlation of .5 means that if one factor is changed then a 50% change will occur in the second factor.

To determine the best way to measure fatigue, Dr. Matthew Liang organized through the American College of Rheumatology, an ad hoc committee to develop a systematic review on measuring fatigue. As co-chair of the ad hoc



committee I am presenting the data today and this paper will be published in December.

We identified 34 studies that have

been published in the last 40 years. Ten of these studies evaluated correlations between fatigue and disease activity. Eight studies found a significant correlation with a range between 0.26 and 0.53. There were many different instruments to measure disease activity in these studies, i.e. SLAM, SLEDAI, ECLAM, DAI. The SLAM is the most sensitive and the only instrument that showed a positive correlation between fatigue and disease activity. This suggests that disease activity is correlated to fatigue but the correlation depends on what instrument is used to measure disease activity.

Nine of these 34 studies evaluated the association between fatigue and depression. Eight studies found a significant correlation between the two (0.22 - 0.61). This means that if you get more depressed you will have more fatigue. Again, the range in correlations is due to the instruments used to measure depression.

Four of the 34 studies evaluated the association between fatigue and pain. Three studies found significant correlations (0.47 - 0.74).

Four studies evaluated the association between fatigue and sleep and two found significant correlation (0.46 - 0.47).

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Ten Reasons to Join the BC Lupus Society

1. Join the fight against lupus.
2. Learn about lupus.
3. Receive quarterly issues of *The Lupus Lighthouse*.
4. Support research.
5. Learn to live with lupus by learning coping skills.
6. Help the BCLS help others.
7. Make new friends with a common bond.
8. Gain emotional support.
9. Receive new research information.
10. Show that you care about the cause of lupus.

Fatigue continued from page 3

Only one study evaluated the relationship between fatigue and anemia. There was no significant correlation (-0.24). You can see here a negative sign. A negative correlation means that they are negatively correlated. In other words the two variables will go in opposite directions. Thus, if one factor increases its value the other factor will decrease its values.

How to measure fatigue?

We did a search on how many studies have been published about fatigue in general. There were less than 25 from 1975-1979 and over 900 from 2000-2004. Eighty percent were published in the last decade. Altogether there were 2,285 papers on fatigue using 252 different ways of measuring fatigue. One hundred and fifty of these instruments were only used once; 156 were multi-symptom scales, meaning they used fatigue as only one of many measured symptoms (non specific for fatigue). Seventy-one instruments were developed specifically to measure fatigue. Many were designed for specific diseases, including lupus.

As I mentioned, an ad hoc committee on SLE response criteria for fatigue was formed to perform a systematic review on the measurement of fatigue in SLE. We wanted to answer these questions: Do we have valid and reliable instruments available? Do we need another instrument to measure fatigue in lupus? How have we been measuring fatigue in SLE in the last 30 years?

We searched MEDLINE and EMBASE databases, as well as clinical experts, and books from 1966 to 2006. We evaluated the psychometric properties of each instrument. This is an advanced way of measuring if an instrument really measures what it's supposed to measure, its reliability, its ability to discriminate (fatigue from non fatigue) and its ability to respond to change.

The whole process happened in three steps: First a working group summarized the existing literature; this group presented to a larger panel of experts who met in Germany and who then presented to a larger expert panel. Many of the people who have been doing lupus research were involved. It was very important for the group to evaluate responsiveness of the instruments (i.e., be able to detect change in fatigue levels after treatment).

We identified 15 fatigue instruments that were used in the 34 studies. I will focus on instruments that have been used specifically in lupus patients:

1. FSS (Fatigue Severity Scale) was developed for patients with Multiple Sclerosis and lupus. This instrument was used in 19 studies. This was the most frequently used instrument.
2. MAC-FS – developed by Dr. Matthew Liang for a clinical trial in 1995 was used in 3 studies.
3. FAI, a version of FSS, is a multi-dimensional scale (measures fatigue in different dimensions, i.e. mental fatigue, physical fatigue, depression associated fatigue, etc) was used in 1 study.
4. SBPI (The Sjogren Based Psychometric Instrument) was also used in 1 study.

Remember that we set responsiveness as an important criterion for the evaluation of fatigue instruments (ability to detect change in fatigue levels). Only three of the 34 instruments evaluated had been tested for responsiveness in SLE: These instruments were FSS, MAC-FS, and MFI-20. The FSS has been translated to French, Spanish, German, Portuguese and Chinese, suggesting a great acceptance in the world. This also allows comparison of fatigue levels across different countries since they are using the same instrument. This instrument was the only one that tested for correlation for disease activity, depression, pain, sleep disorders and anemia.

Impact of fatigue on quality of life

The SF-36 is an instrument used to measure quality of life in many dimensions including general health, bodily pain, vitality, physical functioning, mental functioning, social functioning, and physical and emotional roles. FSS (fatigue severity scale) had a good correlation with all dimensions measured by the SF-36.

Management of fatigue in SLE

Only six studies in the last 40 years (290 patients) world-wide have looked at treatment for fatigue. Not a single study evaluated drug treatment for fatigue. One study evaluated group self-management that included a two hour session per week per six weeks. This study showed improvement using this technique. Four studies measured the effect of exercise on fatigue. There has been scientific evidence to support that

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Music X'PO 2007 Vol 3

The Inlet Theatre in Port Moody was rocking on Saturday October 20! The capacity crowd was not disappointed. From Elvis and Johnny Cash tribute entertainers to a magician and ENSIEME (a new tenor trio) – just to mention a few – there was something for everyone and everyone left with a smile. Of course we can't forget our own Neil Tolentino, singing and dancing his way to our hearts with "Fly Me to the Moon". We are pleased to report that over \$7,000 was raised for the BC Lupus Society. Bigger plans are being discussed for next year. If you would like to be involved please give the BCLS office a call.

Just in case you missed this wonderful show, you can purchase a Music X'PO DVD for \$20 (shipping included) from the BCLS office.



l-r: Susan Milliken and Mary-Jane Mehlenbacher

Arbonne Lupus Promotion

Mary-Jane Mehlenbacher, Arbonne International independent consultant, donated her proceeds from a lupus sales promotion held in September and October to the BC Lupus Society. At the symposium she presented BCLS Board Member Susan Milliken with a cheque for \$938.05. She also participated in the marketplace at the symposium and many of us were able to buy lovely hostess gifts and stocking stuffers. All together we raised over \$1,000! Thank you Mary Jane – your generosity towards the lupus cause is heartfelt and gratefully received.

Walk A Block for Lupus

Walk A Block for Lupus began as a community fundraiser in Ontario in 2002. It was then adopted as a national campaign. Our first walk in 2003 raised \$4,869 in BC. Each year we have grown and we are very excited about the potential of this event.

Highlights from walks held in 2007 in communities around the province follow in this newsletter beginning on page 7.

This year Walk A Block for Lupus is being held to coincide with World Lupus Day on May 10.

If you would like more information please visit the Lupus Canada website (www.lupuscanada.org) or call the BCLS office.

Step by step we are walking together to conquer lupus!



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exercise helps with fatigue. Two of the studies showed improvement. All four studies used a randomized control trial, which is the best way to show if a therapy works. The last study used telephone counseling, and this was also some benefit.

Some of these studies used more than one instrument to measure fatigue.

Future directions for fatigue in SLE

We still need to identify the most important contributors for fatigue in lupus, i.e. depression, pain, sleep disorders, disease activity as well as other non studied contributors including gender, age, culture, and disease duration on a patient's perception of fatigue. We also need to address other dimensions of fatigue. Also the impact of medications on fatigue has not been evaluated properly (Does prednisone improve fatigue?). Since there is no gold standard to measure fatigue in lupus, the committee decided to recommend the use of FSS to measure fatigue and we hope that future clinical trials will use this instrument. We also need to include patient's perspective on fatigue. Thus, how much improvement does a patient need to feel before we can say that treatment worked? A recent study from our group found that a 10% change in the FSS will be considered significant from the patient's perspective. This study needs further confirmation by other scientists.

Conclusion

Fatigue is the most prevalent symptom in lupus. Up to 50% of people with lupus feel it is the most disabling symptom. Fatigue correlates with depression, sleep disorders, and pain. It also correlates with disease activity only if the SLAM is used to measure disease activity. Fatigue measured with the FSS correlates with quality of life. No pharmacologic therapies have been evaluated for fatigue. Exercise and psychosocial interventions seem to be effective in the management of fatigue.

We suggest that the FSS is the best available instrument to measure fatigue in SLE in future studies based on its validated psychometric properties, the fact that it is the most commonly used instrument until today, and it has been used and validated in several languages. Future research areas of interest are longitudinal studies of fatigue in early lupus, identification of clinical and psychosocial factors as determinants of fatigue in diverse patient populations.

Dr. Avina is a Clinical Fellow, Division of Rheumatology, Department of Medicine, UBC; Research Associate, Arthritis Research Centre of Canada

This article has been edited by Dr. Avina and is printed with his permission.

Communities Around the Province Walk for Lupus

Surrey

Despite the heavy rain, this year's Walk A Block for Lupus at Bear Creek Park was a huge success!

The activity tents included the BCLS information booth, the Kid's Tent with face painting and crafts and a 9-hole mini golf. The RCMP were back for their 3rd year with the Child Identification Team, Auxiliary unit, Bike patrol team and, of course, the Safety Bear. The baseball radar cage, new this year, was a big hit. Starbucks coffee and PaddleWheeler Pub brought in great food and service! The Surrey Fire Department was out in full force with two fire trucks and hats for the kids along with their mascot Sparky. JRFm radio provided great music and onsite reporting. The Silent Auction brought in just over \$2,000 and Glamour by Gwen mobile Spa was onsite with hand and foot massages.



Our Special guest this year was the official mascot of the Vancouver Canucks "FIN". The much loved Orca was handing out his autographed posters to the kids and posed for many pictures with fans of all ages!

With all the activity, we raised just over \$36,000! This brought us into the top fundraisers in the country.

Thank you to all our sponsors and all the members of the Surrey-Vancouver Lupus group, team leaders and their families, who once again provided great support making this event such a huge success!



• *Team leader, Leisa Cadotte (front right), with members of her team: Susan Milliken, Renuka Senaratne, Gwen McDonald and Jen Hayes.*

• This year a 5km run, sponsored by the Running Room, was added to our event and 60 participants received medals at the finish line. One hundred percent of the proceeds were donated to Walk A Block for Lupus by the Running Room. This run was the first of its kind for lupus anywhere in Canada! We are pleased to let you know that the Running Room will sponsor the run again in 2008.



• *Communities walk continues on page 9*

Focus on Lupus in Children and Teens: Growing Up with Lupus



Dr. Lori Tucker, MD, is the Director of Research, Division of Pediatric Rheumatology and is on faculty at the Centre for Community Child Health Research at BC Children's Hospital. She gave an informative presentation lupus in children and teens at the Symposium on November 6, 2007. The following excerpts are taken from her presentation.

Facts about lupus

How common is lupus in children?

It is uncommon but not rare. Lupus is diagnosed at a rate of .5 per 100,000 children per year. This is less than the adult population in which approximately 5 per 100,000 new cases are diagnosed each year.

Is lupus more prevalent in female children?

Yes, but the female to male ratio is different from that in adults with lupus. In young children (before puberty), the ratio is 3-4:1 girls to boys; it increases to 9:1 in adolescents. We don't really know why this is, but it is suggested that hormones that become active at puberty likely have some role in developing lupus.

Are certain racial groups more prone to getting lupus?

Yes, quite similar to adults with lupus. Lupus is more common in Asian, First Nations, African (African American and Afro-Caribbean), East Indian, and Hispanic children than in Caucasian children.

Is lupus more severe in children than adults?

Our research shows that this seems to be true. Children are more likely to have kidney or CNS disease. They tend to have higher disease activity scores, and they accumulate disease damage faster than adults.

BC Children's Hospital Lupus Program (Division of Pediatric Rheumatology)

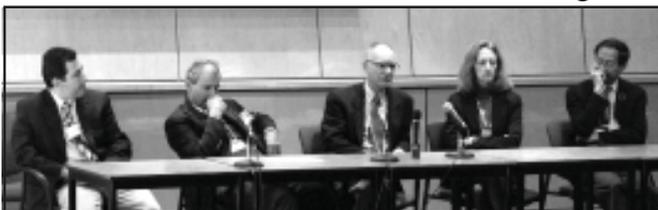
What program does the Division of Pediatric Rheumatology at the BC Children's Hospital have for children and teens with lupus?

The Pediatric lupus clinical program is a coordinated clinical care program which provides medication, education and social support for children with lupus and their families. A multidisciplinary health team of 5 pediatric rheumatologists, a social worker, a nurse, physiotherapist, and occupational

therapist work with children and families. Patients are seen by a variety of care providers at each clinic visit; the pediatric nephrologists at BC Children's Hospital also coordinate their care with the pediatric rheumatologists such that patients can be seen by both teams on the same day and clinical care decisions are made together.

Lupus in children continues on page 10

The ever popular Q&A panel was back. Participants included (l-r): Dr. Antonio Avina, Dr. Erik Yeo, Dr. John Esdaile, Dr. Lori Tucker and Dr. Matthew Liang. Portions of this Q&A panel will be included in a future issue of The Lupus Lighthouse.



Communities walk continued from page 7

Chetwynd

Towards the end of September, we received an email from Lupus Canada saying that **Trina Gayse**, who lives on Vancouver Island, would like to organize a Walk A Block for Lupus in her hometown of Chetwynd on Thanksgiving weekend. Team Trina quickly moved into action. They spread the word to family and friends and announced the walk in the local newspaper. Together they raised \$1,700 and are looking forward to next year's walk. Congratulations on your quick and efficient organization, your great turnout and successful result!



Port Alberni

This was **Lil Davidson**'s second year for Walk A Block for Lupus in Port Alberni. Last year they had 12 people participate and she was pleased to report that this year they almost doubled that number. The weather was not bad—cool, with sprinkles of rain. The heavier rain (fortunately) came later in the day. Through the combined efforts of her family and friends they collected \$1,295. Next year they hope to entice others with lupus in Port Alberni to join them!



British Columbia Girls Choir

In 2004 the **British Columbia Girls Choir** adopted the Walk A Block for Lupus as a joint fundraiser and marked the beginning of an ongoing relationship. This year the British Columbia Girls Choir walked with family and friends in New Westminster on Saturday October 20. They were pleased to announce that they raised \$980 for each of the organizations!



Port Coquitlam

Judy and Steph Leadbeater organized a Walk A Block for Lupus in Lions Park, Port Coquitlam on Sunday October 21. This was their 5th walk! Fifty two walkers participated - an excellent result given the very rainy day. This year they included a small raffle and in total they raised \$3,500. Thank you for your ongoing commitment to the Walk A Block for Lupus campaign.



Communities walk continues on page 13

Arthritis Resource Guide for BC

Looking for a support resource in BC? The Arthritis Resource Guide for BC (ARGBC) website has been developed for people with arthritis and their health care providers. It offers you the ability to find resources in your area that can help meet your needs. Such as, contact information for:

- provincial and federal financial programs aimed at helping people with temporary or permanent disabilities;
- medical equipment and assistive devices on loan, rental or custom-made;
- multi-lingual resources and services;
- transportation services if you are unable to use the public transit system or have mobility issues
- and much more!

To find out more visit:
www.argbc.ca

Lupus in children continued from page 8

Parents and children receive the *Loop* newsletter and *Pediatric Rheumatology Research News*, as well as a variety of other educational materials about pediatric lupus and treatments. Many of the pediatric lupus patients attend the summer pediatric rheumatology camp experience at Camp Capilano, where kids can meet other kids with lupus and other rheumatic diseases. The Pediatric Rheumatology team also has a special approach towards transition, the process of helping teens to become increasingly responsible for their own health care, culminating in the Young Adults with Rheumatic Diseases clinic at The Mary Pack Arthritis Centre, where young adults continue to be followed and supported through about age 22 yrs.

How is the medical approach different for children and teens?

- The child's medical approach needs to take into consideration the family, and be family-centered and inclusive.
- Active lupus, and/or the treatments for lupus, can affect growth and development. Thus children's growth, physical and psychosocial development needs to be closely monitored.
- The usual pediatric vaccination schedule must be modified depending on the patient's medications.
- The same medications given to adults with lupus are used, but the dosages are adjusted for the weight of the children. Nearly all children require corticosteroids (prednisone) at some point and the majority of children will receive an immunosuppressive medication as well.
- Special attention needs to be paid to teens because they are more likely to not follow their treatment regime.

Research at BC Children's Hospital Lupus Clinic

Does the pediatric lupus clinical program undertake research?

Yes, the program integrates research with clinical care. The researchers are the Doctors in the clinic and the pediatric rheumatology team. *Our pediatric rheumatologists are undertaking Vancouver-based projects and are recognized as leaders in the emerging Canadian and North American pediatric lupus research networks!*

What lupus research is happening at BC Children's Hospital?

There are five projects underway or recently completed:

- Fitness and fatigue in youth with SLE
- The 1000 Faces of SLE-Pediatric
- Weight gain due to steroids in children with rheumatic diseases
- Novel biomarkers for lupus nephritis
- SLE-D: understanding the causes of lupus and diabetes in children

Lupus in children continues on page 12

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✿ The first annual World Lupus Day was celebrated on May 10, 2004 to bring global recognition to this disease. In 2007, lupus was featured on the BCTV evening news and Susan Milliken spearheaded a World Lupus Day dinner and silent auction for 60 people at a local restaurant.

Fundraising

✿ In 1995 Karen Tompkins, a BCLS member in White Rock, wanted to combine her love of art with a way to raise money for the Society. She approached artist Chris MacClure who agreed to create a limited edition painting for us. After reading books on lupus, "The Magic Garden" was created.

✿ Early in 1997, to celebrate our 20th anniversary, the Maple Ridge Support Group was pleased to announce that their butterfly quilt (3.5 years in the making) was finished. Many people got busy selling raffle tickets and the draw was done at the annual symposium in October.

✿ In 1999 a quilt was donated to the Duncan Lupus Support Group by the Cowichan Valley Heritage Quilting Society. Ann Geoghegan, Elvina Morgan and the members of their group got busy and organized a 4-prize raffle.

✿ In 2001, Shawna Schuh provincial contact in Grand Forks, embarked on her own raffle to raise funds for the BC Lupus Society. Three prizes were donated and Shawna was pleased to present a cheque at the Prince George Regional Symposium.

✿ Walk A Block for Lupus began as a community fundraiser in Ontario in 2002. It was then adopted as a national campaign. Each year our results have grown and we are very excited about the potential of this event.

✿ Eileen Fraser and her 18-member support group in Parksville decided in September, 2003 to undertake their first raffle. Six local businesses and each group member donated generously and soon they were able to create ten fabulous gift baskets.

✿ The first BC Lupus Society Sunset Dinner Cruise was held September 1, 2004. Through sponsorship, donations, ticket sales and the Silent Auction, everyone joined together to show their support. We cruised the harbour again in 2005.

The Lupus Program

✿ The dream of a lupus clinic began to take shape in the mid-nineties. In February 1995 the Lupus Program Committee was formed to establish a plan to implement a lupus clinic proposal. The proposal was completed in partnership with the Arthritis Society in response to the needs identified by people with lupus through the 1992 provincial lupus survey. On Thursday, May 21, 1998 the dream was realized. The Lupus Program opened its doors at the Mary Pack Arthritis Centre. The goals were to provide patient medical care for people with high risk, complicated lupus, assist patients and family learn about the disease and develop and maintain a database for storage of clinical data. Thank you to team members, Dr. Stephanie Ensworth, Rheumatologist, and Cheryl Magnusson, Clinical Resource Nurse, for their years of dedication and support.

Lupus Support and Education

✿ Over the past 30 years there have been many education events hosted by the BCLS with medical professionals speaking on topics of interest to people living with lupus. We are delighted that international lupus experts including Dr. Daniel Wallace, Dr. Robert Phillips and Dr. Susan Manzi have spoken at these events. In 2007 everyone agreed that the group of speakers at the annual Symposium was one of the best yet!

✿ In November 1996, a Support Group for Chinese speaking lupus patients and their families was formed. During the time that they were active, they had lupus literature translated and

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Lupus in children continued from page 10

A. Fitness and fatigue in youth with SLE

Who was involved in the Fitness and Fatigue in Youth with SLE study?

Fifteen youth, aged 12-19 years, underwent treadmill exercise testing and a 6 minute walk test. Oxygen volumes were used to determine their levels of fitness.

What were the findings?

All teens had moderate impairment in aerobic fitness and 67% had significant self-reported fatigue. However, the low fitness did not correlate with fatigue or disease measures. These results indicate that teens with lupus need closer attention to their physical activity, and we need to provide 'exercise' prescriptions to help our patients regain normal fitness levels.

B. The 1000 Faces of SLE-pediatric

How and why is this research being undertaken?

The goal of this Canadian research project (main centre Winnipeg) is to look at ethnic differences and outcomes in 1000 Canadian adults and kids with SLE. In the pediatric section of the study, there are 138 children and teens enrolled in 4 pediatric centres; Vancouver, Toronto, Montreal and Halifax. All eligible patients are enrolled and followed annually, looking at various facets of disease activity and damage, impact of the disease on family, school attendance, and quality of life, and access to care.

When are the findings going to be available?

We have presented the initial data at the American College of Rheumatology meeting in Boston in November 2007, and this initial data will be written up for publication. Further results will be available as we study these patients over the next years.

C. Weight gain due to steroids in children with rheumatic diseases

Why was this research undertaken?

The research was undertaken because weight gain due to steroids is a very disturbing side effect for all children treated with this medication. Children put on high dose steroids gain an average of 11 kgs (24 pounds) by 6 months of treatment and most do not completely lose the weight when doses are decreased.

What was the research model?

Twenty children who were put on high dose steroids received intensive nutritional counseling and support from the first visit with the pediatric nurse, J. Tekano and a pediatric dietician, P. Khattria. At every clinic visit, ongoing nutritional consultation occurred as well as weight and growth measurements.

What were the findings?

We were delighted to see that the children in this study gained less weight than children in the past who were not given nutritional counseling. We hope to use this information to advocate for nutrition services for our patients.

Lupus in children continues on page 14



Dr. Matthew Liang, Professor of Medicine at Harvard Medical School, spoke on "Challenges of Testing New Treatments for SLE". Watch for this presentation in an upcoming issue of The Lupus Lighthouse.



Josie Bradley, Symposium Committee Chair, receives a bouquet of flowers as a token of appreciation for her dedication and commitment to this event.

Communities walk continued from page 9

Grand Forks

Fifteen people, including family, friends and members of the Red Hat Society, and one dog, joined **Shawna Schuh** in the Grand Forks Walk on Saturday October 20. They had a short walk downtown starting at Pharmasave and ending at the Grand Forks Public Library for a coffee/tea social. The local media, both newspaper and radio, generously promoted their event through their community announcements. They are a great support. Together they raised \$422 and Shawna was pleased to surpass her personal fundraising goal.

Kelowna

On Sunday October 21st Kelowna hosted its first annual Walk A block for Lupus. Approximately 35 people, 4 with lupus, attended the event organized by **Laura-Ann Kavanagh**. They walked 5 km along the Mission Creek Greenway displaying signs, wearing butterflies and the Lupus Canada colours. The Walk was sponsored by The Wardrobe Boutique and a generous donation of \$500 was received from Madge Contracting Ltd. Grab bags containing lupus literature, snacks and beverages were given to all participants. There were door prizes and special prizes given to Tammy Beattie for raising an impressive \$1,185 and to the lupus walker who had to dig the deepest to finish! The event received some media attention with a segment on lupus and the Walk on the morning radio news. It was a great success raising over \$2500 in just 2 weeks. Laura-Ann will be hosting another walk on May 10th 2008. They plan to have more participants and raise \$5000!



2007 Symposium

Our symposium was a great success and we would like to recognize everyone who made it possible.

Thank you to our **speakers** who so generously shared their time and expertise: **Dr. John Esdaile, Dr. Matthew Liang, Dr. Erik Yeo, Dr. Lori Tucker and Dr. Antonio Avina.**

Thank you to everyone who **donated door and raffle prizes**: Lianne Gulka, Tilley Endurables, Raybeth Enterprises, Duthies Books, Hope Unlimited, Tina Koole, Tony Jan and Gerhilde Stulken.



Thank you to our **volunteers** for their help before and during the event: Else Bardsnes, Lillian Berno, Dani Bradley, Gina Bradley, Phil Cheevers, Lori Henry, May Henry, Elizabeth Hinman, Tina Koole and Mona Lee.



Mike Hinman thanks Leisa Cadotte, Team Leader for the Surrey Walk, for the many hours she dedicated to this event and the great success of her team.

Lupus in children continued from page 12

D. Novel biomarkers for lupus nephritis

Why was this research undertaken?

The aim of the multi-centre research (main centre Cincinnati, USA) is to identify new marker for early kidney disease in pediatric lupus.

What was the research model?

Eighty-five children have been enrolled from pediatric lupus centres in US and Canada- BC, Cincinnati, Chicago, Cleveland, Hackensack, Wisconsin and Oklahoma. Every three months the biomarker NGAL (neutrophil gelatinase association lipocalin) was tested in the blood and urine of the children and clinical data was collected.

What were the findings?

NGAL appears to be a highly sensitive and specific test for lupus kidney disease in children. This study will lead to new methods of early detection of lupus nephritis, and better methods for following patients.

E. SLE-D: Understanding the causes of lupus and diabetes in children

Why is this research being undertaken?

The aim of the study is to study the basic immunologic abnormalities in pediatric autoimmune disease using lupus and diabetes as models; and to learn the causes of these diseases; and to find new and better treatments. We will be studying patients from the very beginning of their disease, before they begin treatment.

Who is funding this research?

Two million dollars has been provided over 5 years by the Canadian Institute of Health Research which is funded by the federal government.

How is this research being undertaken?

The BC Children's Hospital study is a new collaboration between patients, pediatric rheumatology, and scientists in endocrinology and basic immunology. Blood samples from participating pediatric lupus patients are taken to the labs of basic scientists Ru Tan, Jan Dutz, Stuart Turvey, Peter van den Elzen and PJ Utz at Stanford University. Clinical information will be used to help interpret the scientific results. Patients with new onset diabetes will be studied in the same way. Other pediatric rheumatology centres will be added to the study to help provide more patients in the next year.

The following are selected responses from the Symposium Panel discussion

Is the medication Cellcept used in treating children with lupus?

Yes. Cellcept is used to treat renal disease and other types of lupus. Like many treatments in lupus, some patients have had wonderful responses, and not just in renal disease, and others have not responded as well. It may work well for some people and not others. Overall, the safety profile is very good.

Lupus in children continues on page 16



Dr. John Esdaile, Scientific Director, Arthritis Research Centre of Canada spoke at the Symposium: "What is Happening in Lupus Research - A Canadian View".

Watch for the Symposium DVD containing all the presentations to be available soon.

At the end of his presentation, Dr. Esdaile announced that the **next International Congress on Lupus and Related Diseases is being planned for June 24-27, 2010 at the Convention Centre in Vancouver!**

Lupus Canada Certificates of Appreciation

Each year Lupus Canada Certificates of Appreciation are presented to a group of dedicated volunteers in recognition of their work on behalf of people living with lupus in British Columbia. The following presentations were made at the October Symposium.

Eileen Fraser became a provincial contact in Parksville/Qualicum in 1998. She put out feelers in her community to see if there was interest in forming a local support group and found that there was. Their first meeting was held in January 1999. They have been meeting monthly at local restaurants since then. Their goals are simple: have fun, offer support and have no rules! In 2003 the group organized their first raffle. Group members and local businesses donated generously and together 10 gift baskets were created. Through the years they have Walked Blocks for Lupus and this summer they hosted a very successful BBQ which raised \$1200. Eileen and her group requested that the money be used to provide travel assistance for those traveling to the symposium from outside the lower mainland. Providing funding for travel is something that we, as a board, have discussed and we were very pleased with this request. Eileen has a positive, upbeat attitude and is a delight to work with. It is my great pleasure today to present Eileen Fraser with a Lupus Canada Certificate of Appreciation.



Cathy Imrie joined our Board in the spring of 2002. She had recently moved to Vancouver and was looking for an opportunity to be involved in her community. We welcomed Cathy, a Chartered Accountant, as our new Treasurer, a role that she held for four years. She actively participated in all the Board activities and decisions, while keeping a tight rein on our financials. We miss Cathy's perspective, insight and humour at our meetings. Though she is no longer a board member, her volunteer duties continue. She often lends a hand at proof reading our newsletter and I know that Gayle is grateful for a second pair of eyes – especially ones that were paying attention in grade school grammar class! Please join me in thanking Cathy for the great contribution she has made to the BC Lupus Society.



In 1977 a group of lupus patients and their families embarked on a quest. Among those leading this quest was **Sandra Tong**. Sandra's daughter was diagnosed with lupus at the age of 8 and Sandra was looking far and wide for information and support. Sandra met Anne Campbell, social worker at the Arthritis Society, and together they approached Drs. Stein, Price and Chalmers about forming a support group for people with lupus. The first meeting of LEG (Lupus Erythematosus Group) was held November 17, 1977 and Sandra was elected as its first president. The rest as they say is history. Sandra's interest and commitment to lupus is as strong as ever and she re-joined the BCLS board in 2003. She has a passion for patient education and programs.



Please join me in recognizing Sandra Tong as I present her with a Lupus Canada Certificate of Appreciation.

Also receiving awards but unable to join us today are:

Rena Hummel, volunteer provincial contact in Kitimat since 1995.

Rhonda Harborne, volunteer provincial contact first in Squamish, now Chilliwack, since 1995.

“The Language Of Water” is once again available!

The Language Of Water is a beautifully written story about a young woman artist who must learn how to live with the chronic disease, lupus. Paradoxically, *The Language Of Water* is also an incredible love story, a moving study of the way one family learns to support itself in new ways, and finally, a story about how some struggles carry you into a joy you might never have found otherwise.

Since its publication in 2002, *The Language of Water* has sold out its first run, has earned The Lupus Foundation of America’s Patient Education Committee Seal of Approval, and has been endorsed by the BC Lupus Society and by Lupus UK. Jude Clarke is a professional artist and art educator. She was diagnosed with lupus when she was twenty-one years old and lives in Vernon, British Columbia.

See page 19 if you wish to order a copy of this book.

Lupus in children continued from page 14

How aware are family doctors and pediatricians that children are at risk? What are we doing to make them aware?

In our experience, family doctors may be less likely to consider lupus in a child; however in general, pediatricians are well trained to recognize multi-system diseases like this or at least to consult pediatric rheumatologists! As an example, we saw a young girl in our clinic who had symptoms of lupus for a year, when she developed brown urine, the diagnosis was suspected but unfortunately by then she was quite ill. We would like this not to happen in our province, so we are trying to look at how long it takes patients to come to us in pediatric rheumatology to try to determine how we can work towards better awareness by medical students, and family practitioners about rheumatic diseases in children and teens.

What are your thoughts about the Patient Partner Program?

As a physician I would advocate for it – it is an immensely powerful tool for medical students to actually meet a patient with a disease like lupus. They won’t forget it! This might be their only opportunity to see a lupus patient and it might even be the only chance in their whole training to hear about lupus. The patient partner program is incredibly valuable!

What supports are available to help parents of children dealing with lupus?

The parents of children and teens seen in our pediatric rheumatology clinic have many opportunities for support. The children and their families are coming to see us every 3 months and at that time, they get not only to be seen by the pediatric rheumatologist, but they spend time with the clinic nurse, social worker, clinic physiotherapist and occupational therapist. Our occupation therapist spends time with the issue of school- this may be an important problem for our patients who may have either physical or neurologic problems which make school challenging. She may call the school, provide written information for teachers and counselors, or even make a school visit. Our social worker provides not only financial advice re: travel to the Vancouver clinic, tax credits, Pharmacare, etc but also counseling about coping with chronic disease for the child and parents. The children and teens who attend camp have special opportunities to make friends who have the same problems that they do, and many of them have become friends through the year. We have had family education programs with the assistance of the Arthritis Society. *I think there are many opportunities for family support through their child’s illness; we hope all children in BC with lupus are able to take advantage of our program!*

This presentation summary has been edited by Dr. Lori Tucker and is printed with her permission.

For more information on the Patient Partner Program referred to above, see page 17 of the Summer 2007 issue of The Lupus Lighthouse or contact the BCLS office.

30th anniversary continued from page 11

found newsletters and other relevant material written in Chinese. In 1997 they hosted 2 Cantonese lectures held in conjunction with the October Symposium.

Three of Kelowna’s medical specialists spoke at the Lupus Forum held in June, 1999. The Forum was organized by members of the Kelowna Support Group and attracted about 100 people from the Okanagan.

In 2001 the Prince George Lupus Chapter hosted the first regional symposium for people with lupus, their families and friends in northern BC.

The Kelowna Lupus Support Group again organized a very successful Forum at Okanagan University College in June, 2002.

The summer of 2002 saw the unveiling of our new website. In January 2004, board member Alison Stringham undertook a major website redesign and worked diligently for the next four years to keep items current and interesting. We have recently refreshed the look of our website and have ideas for new additions. Stay tuned!

From the beginning volunteers in communities around the province wanted to be involved. Support groups formed and other volunteers were available by phone. Thank you to all our volunteer provincial contacts for the difference you make everyday. Over the years you have given thousands of hours to the BC Lupus Society. Whether it is offering a listening ear to the newly diagnosed, spending time at an information table in the local shopping mall, or spearheading events such as raffles, garage sales or the annual Walk A Block campaign, you work together towards our Society goals.

Lupus Research

CaNIOS (Canadian Network for Improved Outcomes in SLE) brings together lupus experts from across the country to improve the outcome of lupus patients through collaborative research. The BCLS provides annual funding to CaNIOS.

At the 2007 Annual General Meeting we announced that the BC Lupus Society is retaining our own Lupus Research Scholar, Dr. Antonio Avina, working out of the Arthritis

*Surrey Lupus Group
Annual Christmas Party*

On Saturday December 8, 2007 Renuka Senaratne hosted members of the Surrey Lupus Group and their friends and family for the Surrey Lupus Group’s annual Christmas party. Everyone had a chance to visit with each other, eat a delicious potluck turkey dinner, exchange gifts and share some laughs. Everyone was welcome and people came from New Westminster, Burnaby and Vancouver. The Surrey Lupus Group meets at 7 pm on the last Tuesday of the month at the Ricky’s Restaurant in the Fleetwood area. Why not make plans to join them some time?



Research Centre of Canada in Vancouver. We anticipate that lupus research momentum will rapidly increase in the next few years.

Note from the author: I have been involved with the BC Lupus Society since 1993. These are a few highlights that come to mind when I think over the past 15 years. There was much to choose from and I look forward to the next 15 years unfolding.

*Gayle Traquair
Office Manager*

BOOKS

Quantity	Description	Price / Copy
_____	"Control Your Pain" by Robert Phillips Ph.D, 144 sure-fire strategies for reducing the pain of lupus, 1996	\$ 8.00
_____	"Coping with Lupus, A guide to living with lupus for you and your family" by Robert Phillips Ph.D, 3rd edition, 2001	\$20.00
_____	"Living with Lupus, The Complete Guide" by S. Blau MD & D. Schultz, 2004	\$18.00
_____	"Lupus Q&A: Everything You Need To Know" by Drs. Lahita & Phillips, 2004	\$16.00
_____	"Lupus: The Disease with 1000 faces" Ed. by Drs. Bernatsky & Senécal 2004	\$19.95
_____	"Taking Charge of Lupus", by Maureen Pratt & David Hallegua, MD 2002	\$15.00
_____	"The Challenges of Lupus - Insights & Hope", by Henrietta Aladjem, 1999	\$18.00
_____	" The Language of Water", by Jude Clarke, 2nd edition 2007	\$20.00
_____	"The Lupus Book", by Daniel J. Wallace, MD, 2005 (hardcover, 3rd edition)	\$28.00

LUPUS PINS & WRISTBANDS

- _____ Lupus Angel of Hope Pin, \$7.95 each
- _____ Lupus Awareness Wristband, \$2.00 each , includes shipping (red with words "conquer lupus")

TO ORDER:

Name: _____

Address: _____

City: _____ Postal Code: _____

Phone Number: _____

Email Address: _____

Total cost of books:	\$ _____
Shipping fee for books only	\$ <u>5.00</u>
Total cost of brochures:	\$ _____
Total cost of Lupus Angel pins:	\$ _____
Shipping fee for pins only	\$ <u>1.00</u>
Total cost of Lupus Wristbands:	\$ _____
TOTAL ENCLOSED:	\$ _____

Payment Method: Cheque Visa MasterCard

Card # _____ Expiry Date: _____

Name on card: _____

Please mail cheque to: BC Lupus Society
200 - 1645 West 7th Avenue, Vancouver, BC V6J 1S4

BROCHURES

- What is Lupus?
- Blood Disorders in Lupus
- Lupus and Vasculitis
- Laboratory Tests used in the Diagnosis of Lupus
- The Nervous System in Systemic Lupus
- Skin Disease in Lupus Medications
- Lupus and Infections and Immunizations
- Pregnancy and Lupus
- Antiphospholipid Antibodies and SLE
- Kidney Disease & Lupus
- Depression in Lupus
- Joint and Muscle Pain in SLE
- Lupus in Men
- Cardiopulmonary Disease and Lupus
- Antimalarials in the Treatment of Lupus
- NonSteroidal Anti-Inflammatory Drugs (NSAIDS)
- Steroids in the Treatment of Lupus
- Immune Suppressants and Related Drugs
- Photosensitivity & Lupus
- Sjogren's Syndrome & SLE
- Drug-Induced Lupus Erythematosus
- Child hood Lupus
- Lupus in 'Overlap' with other Connective Tissue Diseases

Cost to purchase the brochures

\$0.75 for the first brochure,
\$0.35 for each additional.

1 brochure = \$.75

_____ brochures x .35 = \$ _____

Total cost of brochures = \$ _____

BC Lupus Society

Membership Application

The 2008 membership fee is only **\$20.00** per person
and runs from January 1 to December 31, 2008



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Name: _____ Date: _____

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Yes ___ I would like to receive event, meeting & other
related mater by email from the BC Lupus Society.

No ___ I would not like to receive BC Lupus Society
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Individual \$20.00

or Family \$25.00

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Payment method:

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The contents herein are based upon personal experiences and anecdotal reports. They are expressions of lay opinion and are not to be used for diagnostic or remedial purposes. The characteristics and severity of Systemic Lupus Erythematosus (SLE) differ markedly among individuals and therefore patients must rely upon the opinions of their treating physicians. The authors and editors disclaim liability for any errors of fact or opinion or any reliance upon the same.