

President's Message

By Cathy Ferren



Summer is a wonderful time to enjoy and reconnect with nature. It is also time for sunscreen, protective clothing, drinking more water and pacing ourselves.

At Lupus Ontario we are doing our best to keep you informed of association events through the electronic newsletter and social media. The office remains closed at this time.

It is important to our physical, mental and spiritual health to stay connected with others especially in this age of social distancing. Please join our online support groups and stay in touch with your family and friends as well.

I am looking forward to walks in nature, gardening and raising chickens this summer. Find something you are passionate about and start doing it.

Event: Virtual Walk for Lupus 2020

The 2020 Walk for Lupus Ontario is going Virtual!

The Lupus Ontario Virtual Walk is an opportunity to come together, anytime and anywhere to raise funds and provide hope to the millions of people living with Lupus. COVID-19 may be keeping people apart, but the Lupus Ontario Virtual Walk will prove that we are a strong and supportive community—even when we are not physically together. We have chosen **August 15, 2020** as the day for you to walk, run, cycle, dance, do yoga, ... whatever you choose to do to raise lupus awareness and funds for lupus research, support and education programs.

Find your local Walk for Lupus location:

Register for the Virtual Walk in your community or join the Lupus Ontario Virtual Walk and fundraise to help find a cure and live a Life without Lupus.

The First One 100 Registrants will Receive a Free Mask with the Lupus Ontario Logo

Keep your eye on our Social Media and this website for more information on communities as they are added and on participating in a virtual walk.

Several communities have already signed up but it would be great to increase the number of communities participating. We have tools and lots of ideas to help you out. If you are interested in being the Virtual Walk Coordinator in your community, please email info@lupusontario.org.

Pharmacy Update

Written by Sandra Williams-Reid

Is COVID-19 Causing Hydroxychloroquine Issues After All The Media Coverage?

Our social media team did a poll on Lupus Ontario Facebook page to find out if any one was having difficulties getting their Hydroxychloroquine. The respondents said no, but voiced their concerns that now the Pharmacies are dispensing only a one month supply resulting in multiple dispensing fees. Prior to Covid-19 they were able to get a three month supply.

Linda, has spoken with her local pharmacist at Shoppers Drug Mart about the 30 day prescriptions and dispensing fees. She said for those between the ages of 25 and 65 who are not on any government assisted plan that they do charge their regular dispensing fees each time. However, if this is a hardship, they should speak to the pharmacist about reducing the fees. She said it depends on each store individually if they do anything but it is worth a try if you are having trouble covering the additional fees. She said at her store they will try to make an adjustment.

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Personal Story: "We Have a Diagnosis"

Written by Betty Bellamy

"We have a diagnosis: systemic lupus erythematosus." It was New Year's Eve, Dec. 31, 1961. I had no idea what this meant but felt relief that all the symptoms of the past five years now had a name!

I was a patient at University Hospital, seven and a half months pregnant, admitted Boxing Day with fever, sore throat and ear infections. I was placed in isolation; my fear was diphtheria, scarlet fever, or other communicable disease which might harm my baby. A joint visit from my family doctor and hematologist on New Year's Eve was obviously not routine; they informed me that finally "LE cells" had been found, confirming the diagnosis, and eagerly shared their combined files re SLE with me - eight or nine pages of up to date medical information. They further suggested that I refrain from reading any dated lupus related literature and recommended that I remain in hospital until the birth of my baby in early February. I instantly felt that I was in competent hands, having two supportive doctors to whom I could turn.

For me, education became the key to understanding and has directed my life with lupus for myself as well as others. SLE was not generally known at this time; it was not something I could discuss with anyone, with the exception of my medical team and an aunt, a teacher in California, who obtained information for me from a newly formed lupus society in the Bay area.

Lupus is an individual disease, manifesting itself differently from one patient to the next, with the capability to involve most vital organs. Dr. Jean-Luc Senecal, a Canadian rheumatologist, describes it as a chronic autoimmune disease, "the disease with a thousand faces". My journey has been a long one, with arthritic problems at onset, followed by hemolytic involvement, initially anemia, in recent years thrombocytopenia, commonly known as low platelet levels, and subsequent involvement of the gastrointestinal tract and other organs. This journey began with six or seven years of disease activity, followed by a long period of remission and subsequent flaring after menopause.

It was during my years of remission, while working in a rehabilitation hospital, that I met "Ruth", an SLE patient who had been totally bedridden, but who had made an amazing recovery and subsequent return to employment. She needed an advocate as well as information about her disease. I found that a local society had been formed and accompanied her to several support meetings.

I was involved in advocacy work on behalf of the disabled, through my work in pediatrics and rehab, but in recent years had put my personal need for lupus education on the back burner. My thirst for information returned and it was not long before I became involved with the lupus group at the local level, and later as telephone contact person for new referrals. From there I moved to the provincial level and subsequently to the national organization.

Lupus Canada was in its infancy stage when, as a delegate from LESS, I attended my first national meeting in Vancouver; I was captivated by the goals and pulse of this young organization and enjoyed five years of involvement, two of which were spent serving as Education and Literature Committee Chair, and one as national secretary. It was exciting to be part of a national group focusing on education and awareness, and to serve as liaison with my peers provincially. Ill health forced me to leave in 1995 and to focus on a change in therapies. However, volunteerism is still important to me, particularly with respect to lupus education, and in recent years I have assisted with the organization of a mini-symposium and educational meetings for Saskatoon and area patients, utilizing the expertise of our own outstanding health professionals.

Over the years I have been called a "survivor" and medical professionals as well as spiritual leaders have encouraged me to tell my story. Until now I was not ready to do so. I did not wish to be branded only as a lupus patient for I have had a very full life, admittedly learning, often reluctantly, to walk hand in hand with this constant companion.

Coping mechanisms evolve slowly; for many years mine were misdirected as I struggled to prove my worth in the face of numerous seemingly unrelated symptoms. Now in my sixties, having seen many of the different faces of lupus, I am no longer reluctant, but hopeful that others may learn from my experiences.

So back to my personal story and that pregnant young woman searching for a diagnosis. I had been admitted to hospital early in the first trimester of this pregnancy, exhibiting an unusual facial rash, almost like a third-degree burn. Later it became known to me as a butterfly rash. Two weeks of in-hospital tests revealed nothing conclusive; my doctors knew what they were looking for, but I did not. As an aside, my natural reluctance towards medications caused me to refuse a new drug, thalidomide, which was offered for nausea at this time. The nausea to me seemed natural

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and temporary; I was happy to be pregnant and prepared to enjoy whatever pregnancy had to offer. However therein followed months of unusual inflammatory activity and opportunistic infections. With weekly obstetric appointments, but still no diagnosis, I was cautiously guided to a full-term pregnancy, managing to work until my sixth month. Once admitted on Boxing Day, I exhibited severe anemia, a condition which necessitated iron injections for many months to follow.

Informed of my diagnosis on New Year's Eve, I remained in hospital until Valentine's Day, two weeks after the birth of Doug, a healthy eight-pound three-ounce boy. Delivery was difficult with many specialists in attendance; sixty-five hours in labor, complicated by blood incompatibility, blood loss and overwhelming fatigue, but Doug, though slightly jaundiced at birth, was fine. Twenty-four hours later he was allowed to room-in with me for the duration of our remaining two weeks in hospital, not a regular occurrence in those days.

For me, my son's birth was an important milestone in life's cycle, but not only because of this new diagnosis. At the age of two, I had lost my father in a drowning accident and at the age of six had to face the loss of my mother as well. I was an only child, raised by a loving but stern maternal grandmother, always encouraged and supported by aunts and uncles, and as I grew, close to my cousins, but life was far from easy.

Growing up, my health was generally good, with the exception of a severe bout of whooping cough at the age of seven, and the diagnosis of an underactive thyroid at the age of twenty, as well as a recognized heart murmur. I enjoyed school, was a hard worker and with the help of several scholarships was able to attend university. During my final year at university, I experienced a severe unexplained anemia following participation in a student blood drive, but continued to work part-time as a lab assistant and to complete my degree in four years, graduating with a B.Sc. in H.Ec. at the age of twenty-one.

I was married six months later to Bob, the love of my life, whom I had met three years earlier, and to whom I am still married. We had nothing in the way of material goods, but we shared common goals and we laughed and loved a lot. Life was good!

Bob and I had been married for a number of years and hoping for a family. I was working in human services when I developed severe almost disabling arthritic symptoms. Rheumatoid arthritis was suspect; tests revealed nothing, nor did fertility tests. To alleviate the arthritis, I was finally placed on prednisone for a six-month course of therapy, warned about this new drug and its potential side effects, as well as the importance of gradual withdrawal, but the positive results were dramatic. Shortly thereafter I was able to conceive, and it was during that pregnancy that I was diagnosed.

Following Doug's birth, severe arthritic symptoms returned, this time in the arms and hands, to the point that lifting and handling my husky young son was difficult. I was subsequently treated with chloroquine, the forerunner of current Plaquenil, and within a few months the arthritic symptoms subsided. Eighteen months later, pregnant again, contrary to medical advice, I was confident since this pregnancy was so calm compared to the first. However, I miscarried during the second trimester; we know now that the presence of antiphospholipid antibodies in my system, a condition sometimes associated with lupus, was the probable explanation for this miscarriage. I was taken off chloroquine, but a twenty-five-year period of remission ensued, drug free!

We adopted our effervescent infant daughter Patti and our family was complete. I was able to enjoy our young family, to work part-time to assist Bob in his return to university for four years, and as our children grew, to return to full-time employment. Again, life was good!

I considered myself well, except for several recurring pneumonias, which seemed unusual to me, but at this point we had moved and my new doctors reassured me that these were not lupus related. This is what I wanted to hear.

Our children were now in their teens and I had returned to full-time employment, first in pediatrics and later in rehab. I was able to do some travelling with Bob and was enjoying advocacy work on behalf of the disabled, serving on Boards where I felt my understanding of a chronic illness allowed me to contribute towards the well being of others. Our life was hectic, 1987 an unusually busy year, for me punctuated with a sequence of seemingly minor gastrointestinal upsets and a nasty respiratory infection. In retrospect, I was burning the candle at both ends. My most difficult days lay ahead!

Early in 1988, I was admitted to hospital with what appeared to be an intestinal blockage. Allowed nothing by mouth but ice chips for fourteen days, I underwent numerous tests along with accompanying emotional highs and lows. A rapidly growing intestinal cancer was suspect; I was advised to get my life in order, for I had only two to three months to live. This was ruled out, as was Chron's Disease. Finally, a colonoscopy showed healing and the cause of all the

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inflammatory activity diagnosed as a bacterial infection.

I returned to work, to an active waiting caseload, one month later to be readmitted with exactly the same symptoms, this time with platelet levels falling to a dangerous low. Same routine, nasogastric tube, intravenous line, nothing by mouth but ice chips for another two weeks, more x-rays and tests. During this period, I was the only one who felt that this had to be the reappearance of SLE in my life and therefore requested an additional hemolytic consult. My suspicions were right, the severe thrombocytopenia was the clue; the intestinal pseudo blockage was due to vascular inflammation of the small intestine. Therein followed aggressive intravenous drug therapy, first as an in-patient, then as an outpatient, for many months.

Now I had many more questions and sought a consult with the hematologist, now practising in Ontario, who had first diagnosed me during that pregnancy twenty-seven years earlier. Clinically thorough and perfectly frank, he recommended a reduction in the aggressive intravenous regime which had been initiated in hospital and which was scheduled to continue for many more months. This could not be done abruptly; he therefore referred me to a colleague in Saskatchewan, who would guide the gradual withdrawal. This experience taught me a valuable lesson regarding the importance of a "second opinion", and particularly about listening to one's own instincts.

Several years later, I was to experience a reoccurrence of a "GI shut-down" while out of the country, and another in our own province. Each required hospitalization, but each treatment was markedly different, as was each recovery. Obviously, again there was much to be learned; I felt as if I was "training-on-the-job"!

My life was changing, and I knew it was time for reassessment. SLE, which if one can generalize, ordinarily goes into remission at menopause, in my case seemed to be doing just the opposite. On the basis of much respected medical advice, I made the most difficult decision of my life - to leave the work I loved. My involvement with lupus organizations as well as other community groups, certainly helped with this transition.

By this time, both of our children had graduated from university and settled outside of our province. Bob and I decided to sell our family home of twenty-two years in Regina and to return to our home town of Saskatoon, but to keep the summer cottage we had built as a family in the eighties, and to which the children continue to return each summer to reconnect.

Now in my sixties, as acute GI flares became chronic GI problems, and thrombocytopenia ever present, another course of aggressive oral therapy was initiated. The challenges were becoming greater as it was necessary to address yet different faces of lupus. Bone loss, due to SLE as well as steroid therapy, required treatment, as did shortness of breath and hypertension. Dental problems, accentuated by loss of supporting bone tissue, necessitated prophylactic antibiotics due to the presence of antiphospholipid antibodies. Seemingly insignificant insect bites would result in infections requiring antibiotics and drug sensitivities seemed to complicate most treatment plans. Moreover, I was entering an area yet uncharted, living with the effects of long term disease.

Education and knowledge is power, and once again I needed to feel some control, so I researched all aspects of "living well with lupus", searching for the balance necessary to achieve an increased measure of stability, always working with my family doctor, as well as the specialists on whom I rely. I can not emphasize strongly enough, how empowering a supportive medical team can be for a lupus patient!

We had always been an active family, with what seemed to be a healthy lifestyle, but there was much room for improvement. Chronic GI symptoms necessitated immediate dietary changes. This was the easy part: elimination of coffee, red meats, reduction of saturated fats and reduced salt and sugar intake, with an even greater focus on fresh fruits and vegetables, some home-grown in Bob's "salad bowl" garden at the cottage, and others from local markets.

The immune system, not so easy to address, overactive on many levels, failing on others, and often further compromised by therapies necessary to address disease activity, still mystifies me, but is bolstered according to medical advice, with Vitamin B Complex, Vitamin E for heart benefits, and calcium and Vitamin D to address bone loss. On the recommendation of a nephrologist, milled flax seed, to address the inflammatory processes, has been added to our daily diet.

"The sun is our enemy" is an expression well known to lupus patients, but sun exposure can be limited, and on the advice of my dermatologist, sunscreen SPF 60 is a fact of daily life, year-round.

The need for exercise is ever present but increasing mobility problems have restricted my love of walking for "wellness". I have been referred to a cardiac exercise group and do upper body exercises three times weekly for cardiovascular and respiratory benefits, Bob accompanying me as a support person. The benefits of this regular

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program are evident, markedly reducing angina episodes.

Recreational activities are dependant on one's mobility levels as well, and goals must be realigned constantly. Bob and I had taken up square dancing in our 40's, moving through the various dance levels, "hooked" on the physical and mental exercise and the fellowship that went with it, not only at home but wherever we traveled. However, as we entered retirement, even this favorite past-time required reappraisal.

Travel presents many new challenges and requires constant reassessment. With an eye on pain management and fatigue levels, living one day at a time is not as easy as it sounds. "Flexibility" takes on a whole new meaning when adequate rest periods must be factored into the day, limiting one's ability to plan ahead.

Stress, ever present in our lives, must be taken into consideration. Overachievers function better under stress; SLE seems to thrive on it!

One's coping skills are tested constantly, but I believe I have learned to grieve my losses and to move on, albeit reluctantly at times. Most importantly, I am no longer driven to overachieve in order to compensate for my own feelings of inadequacy related to this chronic illness. The faces of SLE may be ever-changing but even in the darkest hours, to quote an expression you have heard before: "there always is a brighter tomorrow".

As I tell this story, I can not minimize the place of spiritual support and the love of family and friends. Laughter, love and prayer are immune boosters too! The birth of our three grandchildren has been one of life's greatest blessings and the completion of the "normal" life cycle.

Maintaining the necessary balance is a daily challenge but taking charge of what you can is empowering to the human spirit. Life is still full of hope and promise!

Peer Support Groups

Lupus Ontario offers in person and online peer support groups.

Check the support page on the web site for schedules and locations. Peer support groups are a safe place to share your lupus journey and learn from others in the group what has worked for them. They are not therapy sessions. Check the Support page on the web site for locations and schedules. During COVID 19 we have online meetings only using Zoom. Imagine never having to leave the comfort of your safe place, no need to travel and not having to worry about the ever changing weather; join us for our live online audio/visual lupus peer support group.



You need to **REGISTER IN ADVANCE**. After registering, you will receive a confirmation email containing the link and information about joining the meeting. Provincial Meetings are 7 to 8 pm EST. The time varies for other online support meetings see <https://www.lupusontario.org/support/>

June 9 click <https://us02web.zoom.us/join/register/uZUqcu2urj8vkEGZnlondVXoWBVuajutNA>

July 14 click <https://us02web.zoom.us/join/register/u5EkcOGtrT0owX6DYbkyIUVZ-PRIMU33xw>

August 11 click https://us02web.zoom.us/join/register/uJlrcO6qqjvGxoKNen69XfC_cJLs-3kGA

Lupus Education Days and Online Workshops

The Lupus Ontario Support and Education Committee organizes information and education events about lupus, treatment, coping and support.

Lupus Education Days or **LEDs** include a variety of speakers and presentations on lupus related topics. Whenever possible, an education day includes a rheumatologist, pharmacist, and other treatment professionals.

Online workshops are generally one (1) hour long online meetings with Q&A time at the end. Watch for a special workshop emails and social media posts. Details at www.lupusontario.org/education/

Let us know if there is a particular topic you are interested in. We will do our best to find a suitable presenter on the topic.



Lupus Ontario's ONLINE Newsletter

"Lupus Link" June 2020

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Fibromyalgia Online Support Group

Offered by the Scarborough Fibro Support Group and Action CIND on Wednesdays from 4 to 6 pm. Contact onlinezoomers@actioncind.org for more information.

Mission Statement

Lupus Ontario is a team of caring and enthusiastic volunteers and staff who are passionately committed to helping those with lupus live longer and better by raising funds that deliver vital support, education, awareness and research.

Goal: Life Without Lupus!