

Lupus Ontario's ONLINE Newsletter "Lupus Link" February 2020

Lupus Ontario, 21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099

President's Message

By Cathy Ferren



Winter is definitely in full swing. Please dress for the weather and include sunscreen and eye protection in your preparations. Ice pick soles for your shoes or boots can help in preventing falls. Be safe out there.

Thank you to everyone who has renewed or started their annual membership. Your dues help us fund research, education, support and awareness. We can only do these with your help.

The Italian Dinner is a key fundraising event to enable us to fund research. If you will be in the Toronto area the end of February, get your ticket now so you won't be disappointed.

It is an exciting time to be part of the lupus community. Join us if you can. Attend an event, hold an event, volunteer or donate. Consider serving on the board of directors.

Together we can make a difference for people living with lupus.

Event: Italian Dinner Dance and Silent Auction ONLY ONE MONTH AWAY!

The Annual Italian Dinner Dance and Silent Auction. You sure don't want to miss an evening of great food, soothing music, dance until your shoes fall off. Grab your friends, family and co-workers tickets! If you're not sure what to expect. Click <u>here</u> to see!





You're invited to our annual Dinner, Dance and Silent Auction.

Saturday, February 29th, 2020 Riviera Event Centre, 2800 HWY 7, Vaughan

Doors open at 5:30pm | Antipasto Bar 6-7pm | Sit Down Multicourse Dinner | Dance Open Bar | Silent Auction | Raffle | 50/50 Draw | Door Prizes Adult \$100 | Child \$50 | Table of Ten \$950

For more information or to purchase tickets call toll free 1.877.240.1099 email us at info@lupusontario.org or visit lupusitaliandinner.com

All proceeds go to Lupus Ontario. Charitable #883331472RR0001

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Lupus Ontario, 21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099 Toronto Youth Support Group Monday Feb 3rd in person, and also an online youth support group coming soon.

There will be a new support group for youth starting in 2020. It will be held downtown at the Toronto Public Library, College Branch, 766 College Street, Shaw Meeting Room.

All youth under 18 must be accompanied by a parent or legal guardian. We welcome our new facilitator Joy Phillips. If you are interested in joining this group email us at info@lupusontario.org

The meetings will be posted on the support page at http://www.lupusontario.org/?page_id=210

Dates for the **in person** support group are Mondays: **February 3**, March 2, April 6 and May 4, 2020. Time 6:30 to 8 pm.

There will also be an online, monthly youth support group. Check the support page for detail. Dates TBA and will be at 3 pm on Sundays. Download and install zoom software prior to your first online meeting. First **online youth** support group meeting is **Sunday April 19** from 3 to 4 pm.

Contact Joy if you are interested in either group.

AGM 2020 & Lupus Education Day Medical Symposium on Saturday May 9 from 9 am to 4:30 pm

Keynote speaker: Dr. Murray Urowitz Dr. Easterbook on Lupus and the Eye, Dr. Landolt on Medical Marijuana Detailed agenda TBA. There will be a special speaker for the youth in the late afternoon.

Courtyard by Marriott Toronto Northeast Markham

Early bird price: \$25 until March 31st

Register online at https://app.etapestry.com/onlineforms/LupusOntario/AGM.html

Dental Hygiene In Lupus

Written by Gloria Checkley

There are some drugs that the lupus patient takes that cause the loss of saliva. Some of the common changes with the loss of saliva:

- Yeast infection
- Viral infection
- Ulcers oral lesions
- Decay
- Periodontal disease

In order to manage oral disease, we should make frequent (3) visits to the dentist; pay prompt attention to cavities; use fluoride treatments; practice daily flossing; periodontal disease management; and anti-fungal treatment, as needed.

Suggestions for Healing Dry Mouth

Take frequent sips of water, chew on sugarless gum, suck on lemon rind or cherry pit; drink frequently while eating; avoid caffeine; tobacco and mouthwashes with alcohol; use saliva replacement products and use oral care products.

Before and After Dental Work

You may need to stop medications that thin blood. You may also need to increase Prednisone for a short period before and after a procedure. Some antibiotics are suspect to causing flares. Consult with your family doctor or neurologist.

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Increased Risk of Infection

If you suffer from lupus and are on immunosuppressive drugs, you may be at an increased risk for a variety of infections. Infection prevention is of critical importance.

Identification

Dentists and hygienists play a significant role in identification of problems by being attentive to the signs and symptoms of dry mouth in patients.

Detecting early signs of dry mouth is critical to preventing other medical problems.

Resources

www.lupusontario.org www.lupuscanada.org The Lupus Fact Booklet WebMD Healthy Teeth for Life: 10 Tips For Families https://www.webmd.com/oral-health/features/healthy-teeth-tips#1

Volunteers

As a charitable organization, Lupus Ontario relies on the time and talents of dedicated volunteers in so many ways. Volunteers play a vital role in our organization, especially to those affected by lupus. Our Board Of Directors, Local Walk Coordinators, and Support Group Facilitators are volunteers, too!

Volunteers needed! Are you looking to create an impact and helping the lives of those you love? Do you have a passion for planning? Lupus Ontario is seeking volunteers to coordinate a walk in their local city for Walk for Lupus 2020!

Volunteers needed! Our Lupus Education Day and Annual General meeting is happening on May 9, 2020.

Are you a volleyball fan? Or you know anyone who is? SAVE THE DATE!

Saturday June 20, 2020

32nd Annual HOPE Charity Volleyball Tournament

Contact Kadian Clarke if you're interested in volunteering at any of the events listed.

Research News: Inflammation and Mental Sluggishness

Lupus is a disease with a lot of inflammation. This study makes a connection between inflammation and mental sluggishness. Finally a possible scientific explanation for brain fog.

Scientists at the University of Birmingham in collaboration with the University of Amsterdam have uncovered a possible explanation for the mental sluggishness that often accompanies illness.

An estimated 12M UK citizens have a chronic medical condition, and many of them report severe mental fatigue that they characterize as 'sluggishness' or 'brain fog'. This condition is often as debilitating as the disease itself.

A team in the University's Centre for Human Brain Health investigated the link between this mental fog and inflammation -- the body's response to illness. In a study published in *Neuroimage*, they show that inflammation appears to have a particular negative impact on the brain's readiness to reach and maintain an alert state.

Dr Ali Mazaheri and Professor Jane Raymond of the University's Centre for Human Brain Health, are the senior authors of the study. Dr Mazaheri says: "Scientists have long suspected a link between inflammation and cognition, but it is very difficult to be clear about the cause and effect. For example, people living with a medical condition or being very overweight might complain of cognitive impairment, but it's hard to tell if that's due to the inflammation associated with these conditions or if there are other reasons."

"Our research has identified a specific critical process within the brain that is clearly affected when inflammation is present."

The study focussed specifically on an area of the brain which is responsible for visual attention. A group of 20 young male volunteers took part and received a salmonella typhoid vaccine that causes temporary inflammation but has few other side effects. They were tested for cognitive responses to simple images on a computer screen a few hours after the injection so that their ability to control attention could be measured. Brain activity was measured while they performed the attention tests.

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The tests used in the study assessed three separate attention processes, each involving distinct parts of the brain. These processes are: "alerting" which involves reaching and maintaining an alert state; "orienting" which involves selecting and prioritising useful sensory information; and "executive control" used to resolving what to pay attention to when available information is conflicting.

The results showed that inflammation specifically affected brain activity related to staying alert, while the other attention processes appeared unaffected by inflammation.

"These results show quite clearly that there's a very specific part of the brain network that's affected by inflammation," says Dr Mazaheri. "This could explain 'brain fog'."

Professor Raymond says, "This research finding is major step forward in understanding the links between physical, cognitive, and mental health and tells us that even the mildest of illnesses may reduce alertness."

Dr. Leonie Balter the first author of the study which was completed as part of her PhD, concluded : "Getting a better understanding of the relationships between inflammation and brain function will help us investigate other ways to treat some of these conditions. For example, further research might show that patients with conditions associated with chronic inflammation, such as obesity, kidney disease or Alzheimer's, could benefit from taking anti-inflammatory drugs to help preserve or improve cognitive function."

"Furthermore, subtle changes in brain function may be used as an early marker cognitive deterioration in patients with inflammatory diseases."

The next step for the team will be to test the effects of inflammation on other areas of brain function such as memory.

University of Birmingham. "Link between inflammation and mental sluggishness shown in new study." ScienceDaily. ScienceDaily, 15 November 2019. <www.scienceDaily.

Are you a Canadian with disabilities? A RDSP may be for you.

Consider opening an RDSP - Registered Disability Savings Plan if you:

- have a long term disability
- are under the age of 60
- are eligible for the Disability Tax Credit
- have a social insurance number (SIN)
- are looking for a long term savings plan

You may contribute any amount, up to the lifetime contribution limit of \$200,000. The Grant and Bond are intended to encourage saving and should remain in a RDSP for at least 10 years. With written permission, anyone may contribute to the RDSP.

For more information

https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html

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. 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.



NEW WINDSOR support group stay tuned for dates and time.

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 <u>https://www.lupusontario.org/support/</u>

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

Lupus Education Days or **LED**s 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 <u>www.lupusontaio.org/education/</u> 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.

Upcoming webinars:

 Tuesday February 21 at 7 pm on Intermittent Fasting

 registration URL
 https://zoom.us/meeting/register/tZAvcuCgqj0p2K0UaL9BDwUcUSBCLNiAlw

Tuesday March 24 at 7 pm Relaxation Part 1 registration URL https://zoom.us/meeting/register/u50rfuyoqzwqXuofdg0EVcM484mrUXnsSQ

Webinar Summary: Jan 21st Fermentation on The Kitchen Counter

The webinar started with the role of beneficial bacteria in our microbiome and how fermented foods help maintain the proper balance of good and harmful organisms. We learned about lacto-fermentation using your own starter or using sea salt and spring water in 500 ml and 1 litre canning jars on our kitchen counters (no fancy equipment required). The foods we learned to make provide both prebiotics and probiotics. Recipes were included and we learned how to make different concentrations of brine for different foods.

Fermentation makes the nutrients in the foods more bioavailable, meaning that the food is easier to digest and the nutrients are easier to absorb. This can be very helpful to our nutrition status with both lupus and medications taking a toll on our gut microbiome.

Interesting fact: milk kefir (fermented cow milk) contains 32 different species of probiotics and tastes great. For those who cannot tolerate dairy, coconut mik kefir and water kefir are good options.

Beet Kvass

1 500 ml canning jar 1 medium organic beet 3⁄4 tsp (3 ml) sea salt Spring water to fill the jar

Cube beets and place in jar. Add sea salt and fill jar with spring water leaving 1 inch (25 mm) space at the top of the jar. Place the lid on top and ferment for 7 days. You can speed up the process by adding 1-1/2 to 3 tsp (8-15 ml) whey or $\frac{1}{2}$ to 1 tsp (3-5 ml) vegetable starter and it will be ready in 3 days. To improve the flavour if you do not like beets, do a mixture of cabbage, beets, and onions or use celery instead of cabbage. Try yellow beets.

Nutrition: Have Your Tried Bone Broth?

Soup is part of my menu year round using seasonal vegetables. In fall and winter I use more root vegetables and legumes. In spring and summer I use less dense vegetables and lentils.

It's trendy and popular right now. But what is bone broth and how does it differ from regular both. All broths are made from boiling food in water. But unlike a typical chicken or vegetables broth, bone broth is made from boiling mainly bones with little meat.

The goal is to simmer the bone for a long time, anywhere from 14-48 hours to get as many amino acids, minerals and collagen out of the bones. Advocates will tout all kind of benefits it probably does not have. However, do not dismiss it either. The nutrients it does have are very nurturing for the gut and improving gut health can help all kinds of other conditions.

Sometimes carrot, onions and celery are added for flavour and more nutrients. It is believed that adding apple cider vinegar will help draw out the nutrients from the bones.

There are no current studies to support the benefits but do we need them? Soup does not have studies and we know that it's good for us. The problem with studying gut health foods is the complexity of the gut. There is no magic bullet

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It is also soothing and nourishing. It feels good when you drink it. More importantly, you can use bone broth to make amazing soups and stews. Too busy to make a recipe? Just drink it as a beverage. Heat the broth and add some sea salt or miso, pepper and your favourite herbs. Then sit down and relax. Sip the broth and savour the flavour, just as you might a tea or coffee.

And, as you enjoy the broth, you have the pleasure of knowing that you are getting all kinds of minerals and amino acids that your body will love, too.

My Best Broth Tip: Be sure to simmer the broth long enough that the water level drops by half. That is when you have finally cooked out the taste of water.

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from https://nebula.wsimg.com/231aef9a5a1e69a8919db377d4e3a06b?AccessKeyId=5360108EAF4C5ACAAD50&di sposition=0&alloworigin=1

Healthy Recipes: Bone Broth

Ingredients:

4 lbs or 1.8 kg bones (chicken, turkey, beef)
1 onion, cut into quarters (leave the skin on)
2 carrots, each cut in half (do not peel)
2 stalks of celery, each cut in half
4-6 tbsp apple cider vinegar 6 peppercorns
1/2 bunch parsley or lovage
2 bay leaves (optional)



Place all of the ingredients in a 16 or 20-quart pot. Fill the pot with water. Bring to a boil and lower to a simmer. Cover but leave it slightly ajar to let out the stream or it will take much longer. Let it simmer until the water level is reduced by half. As it simmers, use a sieve to remove any froth that surfaces. It can take 10-14 hours to do this depending on the temperature and how much the lid is left ajar exposing the broth to air and increased evaporation. Strain out the broth using a large sieve or a metal colander. Transfer the broth into containers with lids in 2 - 3 cup portions. Store in the freezer or put in the refrigerator if using immediately. Broth can be seasoned with sea salt and pepper if desired.

Tips:

- Bones can be purchased at large health food stores or local butchers. Try to get organic, if possible.
- Leftover cooked bones are fine to use. For example, if you roast a chicken, remove the meat and save the remainder.
- Freeze the bones to use when you are ready to make a big batch.
- If using chicken bones, chicken feet are great for extra gelatin.
- If using raw beef bones, roast them in the oven at 350°F for 30 minutes to brown the bones and give the broth more flavour.

The recipes used by Lupus Ontario have been reviewed and approved by Cathy Ferren RHN, Registered Holistic Nutritionist and CAHN-Pro member M000163.

Submit your healthy recipes for consideration for future newsletters to info@lupusontario.org

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!

We are social. Click to see updates on our social media platforms. Facebook Instagram

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