

JANUARY 2021

# The Saskatchewan Lupine

LUPUS SK SOCIETY INC. (LUPUS SK)

Registered Charity #11902 5880 RR00001  
Box 88, Royal University Hospital  
103 Hospital Drive, Saskatoon, SK S7N 0W8

1-877-566-6123 www.lupus.sk.com  
EMAIL: lupus@lupus.sk.com

## LUPUS SK MAKES IT EASIER FOR YOU!

You can now: **Make Donations**  
**Become a Member**  
**Re-new Memberships**  
**Send Memorials**

Please make your E-Transfer payments to:

**[lupus@lupus.sk.com](mailto:lupus@lupus.sk.com)**

Please fill out your security question & answer as follows:

Security Question: What city is Lupus SK located  
Security Answer: Saskatoon



## TABLE OF CONTENTS

Lupus SK Directors	Page 2
Upcoming Meetings	Page 2
President's Message	Page 3
Precious Memories	Page 3
Benefits of Change	Page 4
Save the Dates!	Page 5
Benlysta Approved	Page 5
2020 Regina WFL	Page 6
Sarcan Drop & Go Fundraiser	Page 6
2020 Lupus SK Raffle Winners	Page 7
Childhood Onset Lupus Study	Page 8
Childhood Onset Lupus - Cont.	Page 9
Welcome New Area Contacts	Page 9
Vaccines for Covid 19 & Lupus	Page 10
Welcome to the Lupus SK Board	Page 10
Lupus Canda & LFA Partnership	Page 11
<b>WORLD LUPUS DAY</b>	<b>Page 12</b>
No-Show Golf Tournamnent	Page 12



OUR MISSION: To provide support for those affected by LUPUS through understanding, education, public awareness and research.

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## **LUPUS SK SOCIETY INC. BOARD OF DIRECTORS 2020/2021**

### **EXECUTIVE**

President	Ann van der Wal	306-343-0232	Saskatoon
First Vice-President	Karen Gaudry	306-301-0857	Saskatoon
Second Vice-President	**Vacant**		
Secretary	Michelle Heichert	306-251-0821	Copper Sands
Treasurer	Irene Driedger	1-877-566-6123	Saskatoon

### **DIRECTORS**

Merle Klein	306-291-4640	Saskatoon
Linda Ulsifer	306-291-3203	Saskatoon
Danielle Rudulier	306-230-7509	Saskatoon

### **SOCIAL MEDIA CO-ORDINATOR**

Tammi Driedger	306-290-8513	Clavet
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### **NEWSLETTER CREATOR**

Tammy Schmidt	306-227-1156	Saskatoon
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### **MEDICAL ADVISORS**

Dr. A. Rosenberg

### **AREA CONTACTS**

PROVINCIAL	Irene Driedger	1-877-566-6123 (Toll free)
ESTON	Lori Reis	306-962-7660
HUMBOLDT	Susan Hall	306-682-3848
LEASK	Derril Rogerson	306-446-6950
MOOSE JAW	Chantelle Cushway	306-631-4698
PRINCE ALBERT	Karen Harder	306-764-4280
RABBIT LAKE/SPIRITWOOD	Merle Klein	306-291-4640
REGINA	Switzuena Whittaker-Gayle	306-502-1090
SASKATOON	Betty Cole	306-382-7136
TISDALE	Kerri Will	306-873-5524
WAKAW	Darleen Lange	306-233-4298
EMAIL	Lupus SK	<a href="mailto:lupus@lupus.sk.ca">lupus@lupus.sk.ca</a>

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## **UPCOMING 2021 MEETINGS**

**Board Meetings:** March 27th, 2021 - August 28th, 2021 - November 27th, 2021

**Annual General Meeting:** November 27th, 2021

**MEETINGS HELD AT:** Smiley's Buffet & Event Center - 702 Circle Drive E. Saskatoon, SK



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## **PRESIDENT'S MESSAGE**



Welcome to 2021!

Although COVID-19 continues to impact our daily lives, there is the promise of vaccinations, and the hope that we will gradually come out of these uncertain times.

Lupus SK has planned a full slate of events for fundraising this year, however, only time will tell if they can take place. Our newest fundraiser that we have started, is the the new Sarcan Drop & Go initiative, it is successfully underway.

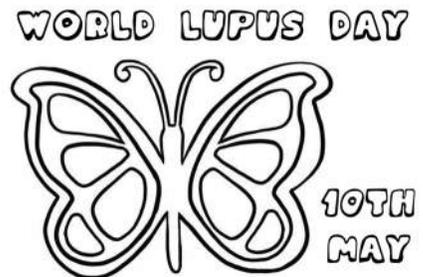
Thank you to all who have volunteered, donated, and supported Lupus SK through out the last year. Lupus SK wouldn't be able to succeed without you!

A special thank you and best wishes to Donna Driedger who has served as our amazing Lupus SK newsletter editor for the last eight years, we will miss you and your expertise! Assuming the role is Tammy Schmidt who has been doing the research and layout of the newsletter for the last seven years.

May the New Year bring good health outcomes for all! In the meantime, let us remain positive, patient, and persevering.

Be kind and continue to uplift others. Best wishes for 2021!

With warm regards,  
Ann van der Wal  
President, Lupus SK Society Inc.



## **Precious Memories**



Lupus Memorial Cards are available to give a lasting tribute to friends and family who are no longer with us, by making a commemorative donation to Lupus SK. The name of your friend or loved one who has passed away, and for whom the commemorative donation has been made, will be printed in the next published issue of The Saskatchewan Lupine following receipt of the donation.

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# What are some benefits of change?

## 1. Personal growth

You grow and learn new things every time something changes. You discover new insights about different aspects of your life. You learn lessons even from changes that did not lead you to where you wanted to be.

## 2. Flexibility

Frequent changes make you easily adapt to new situations, new environments, and new people. As a result you do not freak out when something unexpectedly shifts.

## 3. Improvements

We all have things in our lives we'd like to improve—finances, job, partner, house, etc. All of us know that nothing will improve by itself. We need to do things differently to make that happen. Without change, there'd be no improvements.

## 4. Life values

From time to time changes make you re-evaluate your life and look at certain things from a different perspective. Depending on what the change is, it may also reinforce your life values.

## 5. The Snowball effect

Often we give up because we cannot accomplish the difficult task of making a huge and immediate change. That is when small changes become extremely valuable. One shift at a time, small changes will eventually lead you to the desired big one.

## 6. Strength

Not all changes lead you to pleasant periods of life. Unfortunately we do not live in fairy tale and sad things happen, too. Overcoming the tough period will make you stronger.

## 7. Progress

Changes trigger progress. Things move forward and develop because of the them.

## 8. Opportunities

One never knows what each change may bring. When you turn from your usual path there will be plenty of different opportunities waiting for you. Changes will bring new choices for happiness and fulfillment.

## 9. New beginnings

Each change is a turning page. It is about closing one chapter and opening another one. Changes bring new beginnings and excitement to life.

## 10. Routine

Remember the movie *Stranger than Fiction*? The main character Harold Crick does the same things in exactly same time for years. He leads a completely dull, extremely predictable, and uninteresting life. That is how your life would be without changes.

So next time you get the temptation to avoid or resist the change, aim instead to initiate the ones that will lead you to where you want be.

***And remember—if there were no change, there would be no butterflies!***



The U.S. Food and Drug Administration (FDA) today approved Benlysta® to treat lupus nephritis (lupus-related kidney disease) in adults. The decision makes Benlysta the first lupus therapy authorized to treat this potentially life-threatening complication of the disease.



The FDA first approved Benlysta as a treatment for adults with active systemic lupus in 2011. Today's FDA decision extends that authorization for use specifically to treat lupus nephritis in adults.

"The FDA's approval of Benlysta for lupus nephritis represents an important milestone in treating one of the most serious consequences of lupus," said Stevan W. Gibson, president and CEO, Lupus Foundation of America. "Between 10 and 30 percent percent of people with lupus nephritis will develop end-stage renal disease or kidney failure. Effective treatment can greatly improve health outcomes and reduce the long-term costs associated with managing lupus-related kidney disease."

Additional information related to today's FDA decision is available on [lupus.org/news](http://lupus.org/news).

*Sourced from: Lupus Foundation of America December 2020*

### **A VERY SPECIAL THANK YOU TO:**

## **HVB Chartered Accountants Prof. Corp.**

Thanks to Craig Hinz and the team at HVB Chartered Accountants for completing another year of financials and tax returns for Lupus SK, and their generous voluntary discount.

HVB Chartered Accountants Prof. Corp.  
102-333 25th St. E  
Saskatoon, SK S7K 0L4

### **SAVE THE DATES FOR 2021**

Saturday March 27	Lupus SK Board Meeting
Saturday April 24	Spring Symposium - <u>TENTATIVE</u>
Friday May 7	Spring Fling Fundraiser - <u>TENTATIVE</u>
Monday, May 10	World Lupus Day
Sunday, May 30	Saskatoon WFL - <u>TENTATIVE VIRTUAL WALK</u>
TBA	Regina WFL- <u>TENTATIVE VIRTUAL WALK</u>
Thursday June 24	BBQ-Stonebridge Co-Op Saskatoon - <u>TENTATIVE</u>
Friday June 25	Lupus No-Show Golf Tournament
Saturday July 3	Hafford Show & Shine Fundraiser- <u>TENTATIVE</u>
Wednesday August 18	Crossmount Cider Co. - Yoga on the Lawn - <u>TENTATIVE</u>
Friday August 20	BBQ-Attridge Co-Op Saskatoon- <u>TENTATIVE</u>
Friday August 27	BBQ-Stonebridge Co-Op Saskatoon- <u>TENTATIVE</u>
Saturday August 28	Lupus SK Board Meeting
Saturday Oct 23	Fall Symposium- <u>TENTATIVE</u>
Saturday, Nov. 27	Lupus SK Board Meeting & AGM

**\*We will continue to cancel/reschedule our events as needed due to Covid 19 restrictions and your safety\***



## SARCAN DROP & GO FUNDRAISER

Do you want to clear out your recycle, but DO NOT want to wait in the long line ups at Sarcan?

We have a solution for you, use the quick Sarcan Drop & Go program! You would be helping out LUPUS SK with your donation, PLUS you will not have to wait in the long line ups.

This fundraiser will work throughout SK at each Sarcan Drop & Go location using the

ID phrase/code: **lupussask**



Thank you for your support!

If you have any questions please contact Irene Driedger at: 306-227-9562 or [idriedger@sasktel.net](mailto:idriedger@sasktel.net)

## REGINA 2020 WALK FOR LUPUS

The Regina Walk for Lupus had two separate walks to keep within the covid safety. They were September 26th, and October 2nd. They both took place at the White Butte trails 10 minutes east of Regina.



On September 26th, they had a small gathering of 5 people on a very rainy day, however that didn't stop them from walking just over 5k.



On October 2nd, they had a beautiful sunny day, which brought out 9 people to make another 5k walk! It was an enjoyable day on the trails.

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## 2020 LUPUS SK RAFFLE TICKET WINNERS

Congratulations to all of the winners!

Delia Matsala (Regina) won 1st Prize: The One-Night Stay at Alive Sky Lodge & BINcredible, donated by owners, April & Darryl Anderson near Rosetown, plus a Handmade Afghan.

Chuck Bain (Saskatoon) won 2nd Prize: Autographed Sask. Roughriders Football Jersey, donated by Sask Power.

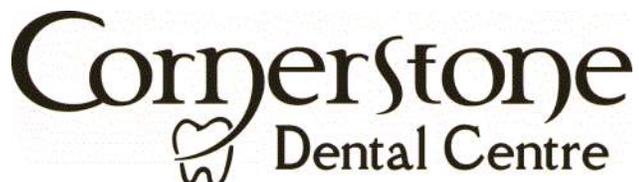
Gregg McFaydn (Saskatoon) won 3rd Prize: Phillips Sonicare Professional Rechargeable Electric Toothbrush, donated by Cornerstone Dental Centre.

Smiley's Buffet & Event Center in Saskatoon donated the location, and Army, Navy & Airforce Veterans donated the use of the Draw barrel for the Draw on October 24th, 2020.

Lupus SK appreciates all the donations that were given to make this raffle happen!

THANK YOU to all members, family, friends and supporters of Lupus SK for selling and buying tickets. Special mention to Kristin Sinclair and Danielle Rudulier for selling the most tickets.

The provincial Lupus SK Raffle Ticket was one of the few fundraisers which Lupus SK could successfully hold during this time of COVID-19. Super job done!



## **STUDY CONFIRMS URGENT, UNMET NEEDS in CHILDHOOD-ONSET LUPUS**

Experts identify lupus nephritis and neuropsychiatric disease among highest research priority areas.

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) and Lupus Foundation of America (LFA) conducted a first-of-its-kind, multidisciplinary research effort on childhood-onset lupus to assess research priorities for addressing this life-threatening disease.



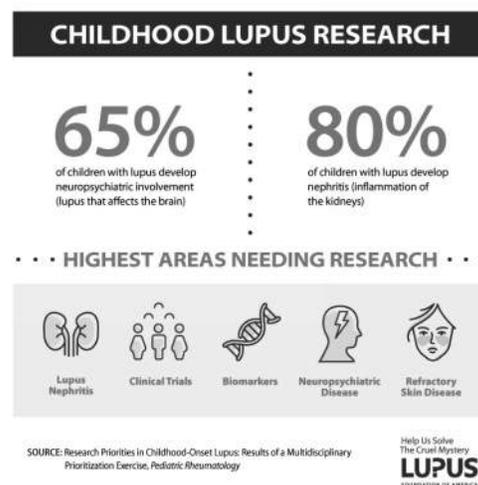
Results from the study, “Research Priorities in Childhood-Onset Lupus: Results of a Multidisciplinary Prioritization Exercise” published in *Pediatric Rheumatology*, conclude that the highest areas needing research in childhood lupus are nephritis, clinical trials, biomarkers, neuropsychiatric disease, and refractory skin disease.

The study also revealed a strong need for multidisciplinary collaboration moving forward. When asked which sub-specialties in addition to rheumatology should collaborate in childhood lupus research, 92% suggested collaborating with nephrologists, 73% with dermatologists, and 68% with mental health specialists.

Children with lupus have more pervasive and life-threatening organ involvement compared to adults with lupus, and an estimated 6,000 US children and adolescents are currently living with the disease which has few treatment options and no cure. Over 250 members of CARRA, Midwestern Pediatric Nephrology Consortium (MWPNC) and Pediatric Dermatology Research Alliance (PeDRA) Connective Tissue Disease Group participated in the study.

### **Inflammation of the Kidneys:**

Nephritis (inflammation of the kidneys) was identified as the number one research priority. Up to 80% of children with lupus develop nephritis, which increases risk of kidney failure, cardiovascular disease and death. Lupus nephritis (LN) requires prolonged therapy, often with toxic medications, and complex treatment plans. Although there have been many advances over the last several decades and many people with lupus can enjoy good health and normal activities, LN is still a driving factor in increased complications, hospitalizations and mortality rates, especially in children versus adults with lupus.



### **Cognitive Impairment:**

Lupus commonly affects the brain in children and can cause strokes as well as severely impair the ability to think through tasks. Neuropsychiatric disease (involvement of the nervous system) was also identified as a top challenge for clinicians and researchers treating children with lupus. Neuropsychiatric complications can have substantial negative impact on cognitive development, educational and vocational outcomes in children and adolescents with lupus.

Cont.

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Up to 65% of children with lupus develop neuropsychiatric involvement over the course of their disease, with up to 85% developing neuropsychiatric involvement in the first two years from diagnosis. The burden, ranging from missed school or even school failure to major challenges with treatment adherence, can have an enormous impact on a child's psychological development and quality of life. Today, the treatment of childhood lupus is generally extrapolated from adult clinical trials data and optimal drug dosing, duration of therapy and outcomes measurement may differ for pediatric patients.

Specific to nephritis and neuropsychiatric disease, important focus areas across all lupus experts were determining best treatments, biomarkers/pathophysiology, drug discovery/novel treatments, understanding long term outcomes, and refining provider reported quality measures. Of note, understanding long term outcomes was ranked highly important across every research area.

**80%** of children with lupus develop nephritis

“This study underscores the urgency for childhood lupus research. We are committed to investing in this area, and our partnership with CARRA as leaders in this field will bolster our progress as we work together to elevate childhood lupus research,” said Stevan Gibson, President and CEO, Lupus Foundation of America. “The findings from the study offer a roadmap to guide future research endeavors, so that the scope and devastation of lupus in children aligns with received funding.”

“This is the first published research prioritization effort among experts in childhood lupus, which highlights the lack of evidence that exists specific to this disease. There are important differences between adults and children, and significant knowledge gaps limit our understanding of the best treatments and long term outcomes in children with lupus,” said Aimee Hersh, Chair of the CARRA Systemic Lupus Erythematosus Committee. “This multidisciplinary approach to identifying research priorities emphasizes the need for collaboration for childhood lupus care and research. The results from this exercise will help set a research agenda moving forward.”

*Sourced from: Lupus Foundation of America July 1, 2019*

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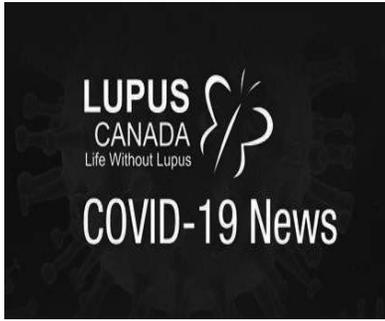
## **WELCOME TO OUR NEW AREA CONTACTS**

A warm welcome to two members, Lori Ries of Eston and Kerri Will of Tisdale who who have agreed to become Area Contacts for their respective areas.

Lupus SK aims to have Area Contacts throughout all parts of the province, both rural and urban. This network can disseminate information which helps the organization realize its goals in service to those with lupus, their families and others.

Some areas of the province are under represented. If you or someone you know may be in one such area, and may be interested in being an Area Contact, please contact the Lupus SK office:  
Phone: 1-877-566-6123 or email: [lupus@lupussk.com](mailto:lupus@lupussk.com)





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## **VACCINES FOR COVID-19 AND LUPUS**

Lupus, and some of the medications used to treat lupus, lowers the immune system's ability to fight infections, including COVID-19. This means people with lupus may be at higher risk of severe illness from COVID-19. For this reason, current recommendations are for adults with lupus to be immunized against COVID-19 when it becomes available. (The vaccines

have not yet been tested or approved in children or pregnant women).

The vaccines for COVID-19 help protect against COVID-19 by imitating an infection and allowing you to safely develop immunity to the virus. The vaccine causes the immune system to produce cells that will learn and remember how to fight that disease when you are exposed to it in the future.

Because the vaccine imitates a very mild version of an infection, but rarely causes illness, sometimes you might get minor symptoms such as a fever. This is a sign that the body is building up immunity to the disease. Like any medication, vaccines can cause side effects, but serious side effects are very rare. For most people, side effects are mild such as soreness at the spot where a shot was given.

"Live" vaccines are contraindicated in some lupus patients; none of the vaccines currently approved or in development for COVID-19 are live vaccines.

The two vaccines that have been approved for COVID-19 have been tested in thousands of people, and their safety and effectiveness has been carefully evaluated by Health Canada, the FDA, and other national oversight bodies. Long term monitoring will continue to detect any long-term safety concerns. So far, there are no serious safety concerns for these two recently approved vaccines for COVID-19. While we don't yet have a lot of information about the safety and effectiveness of these vaccines in lupus patients, so far there do not appear to be any specific concerns. This will be carefully watched and studied in the coming months and years.

For additional information on the COVID-19 vaccine please visit:

<https://www.canada.ca/en/health-canada/services/drugs-health-products/covid19-industry/drugs-vaccines-treatments/vaccines.html>

*Sourced from: Lupuscanada.org*

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## **WELCOME TO THE LUPUS SK BOARD**

*Welcome*

Congratulations to Danielle Rudulier who was nominated and elected to the Board as a Director-at-Large at the Lupus SK Annual General Meeting on November 28, 2020..

Danielle and her family have had a long-standing association with Lupus SK. Her parents, Linda and Gerry Clouthier, served on the Board and also volunteered at our Lupus SK golf tournaments.

More recently Danielle, her husband and family have been volunteering at the barbeque fundraisers.

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## **Lupus Foundation of America and Lupus Canada Partner to Advance Lupus Research**

Today, the Lupus Foundation of America (LFA) announced their partnership with Lupus Canada to fund innovative lupus research through the Lupus Canada Catalyst Award. The award supports research projects that have the potential to significantly advance the field or impact the lives of people with lupus.

“In order to accelerate lupus research to improve drug development, find better treatments and ultimately discover a cure, we must work together. Collaborating with Lupus Canada allows us to join forces to increase the impact of lupus research in North America and work towards our common goal of improving the lives of people with lupus and ending this disease,” said Stevan W. Gibson, president and CEO, Lupus Foundation of America.

The Lupus Foundation of America’s research program has contributed to every lupus research breakthrough of the past 40 years. The LFA is dedicated to uniting lupus experts and groups throughout the world to identify the cause, control the symptoms of and ultimately discover a cure for lupus.

“Lupus Canada is fiercely committed to improving the lives of Canadians living with lupus by funding the best and brightest lupus researchers in Canada. By partnering with the Lupus Foundation of America we will be able to further our mandate and bring greater attention on a global perspective to this debilitating disease,” said Tanya Carlton, volunteer President, Lupus Canada.

*Sourced from: <https://www.lupus.org/news/lupus-foundation-of-america-and-lupus-canada-partner-to-advance-lupus-research> February 2020*



The Disability Tax Credit (DTC) is a non-refundable tax credit used to reduce income tax payable on the income tax and benefit return. A person with a severe and prolonged impairment in physical or mental functions, may claim the disability amount once they are eligible for the DTC.

The purpose of the DTC is to provide greater tax equity by allowing some relief for disability costs, since these are unavoidable additional expenses that other tax payers don't have to face. Being eligible for the DTC can open doors to other federal, provincial, or territorial programs such as the registered disability savings plan, the working income tax benefit, and the child disability benefit.

For more information: [www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/dtc/menu-eng.html](http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/dtc/menu-eng.html)



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## **WORLD LUPUS DAY - MONDAY MAY 10, 2021**



This year, World Lupus Day will be observed on May 10th, 2021. More than five million people, mostly women, face an unpredictable future as they struggle daily with the often debilitating health consequences of lupus.

The World Lupus Day Proclamation was first developed in 2004, and is a call to action for governments around the world to increase their financial support for lupus research, awareness and patient services. The Proclamation serves to give a single voice to all individuals affected by this devastating and debilitating chronic disease.

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## **LUPUS SK "NO-SHOW" GOLF TOURNAMENT**



***Save the date! June 25, 2021 will be our 8th Annual Lupus SK "No-Show" Golf Tournament.***

***The Lupus SK Society Inc. greatly appreciates the support from many individuals and businesses over the years. As a result of this support, Lupus SK is able to provide many services, education, and awareness projects to people and families living with lupus.***

***We invite you to assist us in continuing to fulfill our mandate by joining our 8th Annual "No-Show" event. We are a registered charitable organization; therefore, official tax receipts will be issued for all monetary donations over \$20.00.***

***Instead of having to take the day off work, give your employees the day off, arrange for a sitter, etc. you can send a tax-deductable gift to support Lupus SK.***

***Thank you for all you have done for us in the past, and we hope you can continue on with us in the future!***

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The articles appearing in The Saskatchewan Lupine do not necessarily reflect the opinions of the Lupus SK Society Inc. or it's members. It is very important that persons diagnosed with, or suspected of having SLE consult their own physician to ensure proper evaluation and treatment.

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