

## Issue 2 **SCLERODATA** 2021

### ***In This Issue:***

- **Highlights:** June Awareness, AGM & Conference, Meet & Greet, Virtual Seminar
- **Good to Know:** St. Paul's Foundation, SPIN, CHUM, Manitoba's Video
- **Interesting Reading:** Raynaud's and Niagara
- **Members Corner:** Disability Tax Credit, Macronutrients, Nicole Edwards



## ***Highlights***

### ***June's 2021 Scleroderma Awareness Month***

As we all know every June 1st, across Canada, starts the annual month of Scleroderma Awareness to raise not just awareness but also the much needed funds for research. Our community again did their part and raised over \$65,000. **A special shout-out and our heartfelt thanks goes out to this year's *Moving to Cure Scleroderma* Team Captains and their Participants** who not just raised their hands to fund-raise for research but also raised our spirits and immense gratitude.

***Scleroderma Research Continues Because of You!***

Again we thank the 8 teams and participants across our province who supported this successful virtual event:



Rosanne Queen, Peggy Riley, Suzanne Robert,  
David Queen, Lihong Yang, The Senges Family -  
Scleroderma Ride for Research



Beth Miller - Sea to Sky



Donna Gervais, Michelle Kennedy, June Richardson,  
Angie Reglin - Anywhere in BC



Teresa Colosimo - Valemount



Jen Beckett - Kamloops



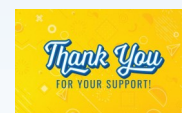
Jackie Alexander - Campbell River



Joshua Morven, Joycelynn Mitchell, Randy Fiddler -  
Team Prince Rupert



Linda Barnes, Sue Goss - Victoria



All monies raised this year directly supports the SABC Research Program.

Click here to check out the video showing everyone ***Moving to Cure Scleroderma*** on SABC's website, [sclerodermabc.ca](http://sclerodermabc.ca).



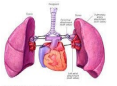
# Highlights cont'd

## October's 2021 AGM & Conference

Fifty-five (55) patients and their supporters registered for this year's 37th Annual General Meeting & Conference (2nd virtual) on Saturday October 2nd, 2021.

The AGM highlights included Rosanne Queen's recap of this fiscal year's support for research, education and awareness initiatives and the election of the 2021/2022 Board of Directors, returning and new.

The Conference portion of the morning included two presentations. This year we learned about the steps involved in receiving a lung transplant with **LUNG TRANSPLANT 101 – THE PROCESS WITH PERSONAL EXPERIENCE** with respirologist Dr. Jennifer Wilson, lung transplant nurse Mandeep Dhindsa and lung transplant recipients, SABC members and patient panelists Beth Miller, Cecille Soriano and Kathryn O'Neil.



We were also updated on all that SPIN has to offer by Dr. Brett Thombs with **SPIN UPDATE – PROGRAMS FOR PATIENTS, CARE GIVERS AND MEMBER ORGANIZATIONS.**

Click here to check out the two video recordings of the conference presentations on SABC's website, [sclerodermabc.ca](https://sclerodermabc.ca)

And similarly to previous years, the morning concluded with an opportunity for scleroderma patients, their families and supporters to stay online and virtually meet using Zoom's break-out rooms, saying hello to one another and chatting about various topics of interest.

---

## November's 2021 Virtual Meet & Greet



On Tuesday November 23rd at 7:00 pm, the SABC organized, for scleroderma patients across the province, an opportunity to chat, catch up and virtually meet new scleroderma patients.

The topics of conversation were Raynaud's Phenomenon and Difficulty Swallowing - How do these affect you and what helpful tips do you have to share.

This Meet & Greet was the second in a series of future group conversations, in a support group setting, facilitated by SABC members who have completed the SPIN Scleroderma Support group Leader Education (SPIN-SSLED) Program. Keep a look out for invites for 2022 in your email inbox!

---

## February's 2022 Educational Virtual Seminar

Next year the SABC is pleased to offer another educational virtual seminar this one specific to our mental wellbeing, entitled **Mental Health and Scleroderma: An Emotional Journey.**

Join us for a conversation about the emotional challenges of living with Scleroderma. Dr. Elaine Roth of Elaine Roth Counselling will lead the discussion of what is emotionally challenging for scleroderma patients, their family and supporters and what works for us to maintain a healthy mind set.



The *Time to Register* email will be sent out to members in January. Put your thinking caps on because as part of your registration, Elaine will be requesting your answers/comments (privacy assured) to her questions on this important topic!

## Good to Know



If the saying is “a picture says a thousand words”, then a recorded video must really speak volumes.

But who needs a thousand when just two will do?

Click here to check out **St. Paul's Thank-You video** to all of us who support the good work the group does there for scleroderma patients: the scleroderma clinic and the SABC research program, at

[sclerodermabc.ca](https://sclerodermabc.ca)

---

### SPIN's COVID-19 Study

The Scleroderma Patient-centered Intervention Network (SPIN) wants to **thank you** for your participation in the SPIN-COVID-19 Cohort, and for your contributions over the past year and a half. With your help, SPIN has learned how the COVID-19 pandemic has disproportionately affected those with a pre-existing illness, and is continuing to study the impacts of the pandemic on mental health and interference in daily life for people living with scleroderma.

As the COVID-19 situation is still evolving, SPIN will continue to send out questionnaires, and is extremely appreciative of your continued involvement in the study. And also thanks to those of you who reached out to SPIN with suggestions and feedback on the questionnaires!



### SPIN's Self Feasibility Study

If still recruiting, you may be able to sign up for the SPIN-SELF Feasibility Study to test SPIN's scleroderma self-management (SPIN-SELF) program! The SPIN-SELF program combines access to online modules, a toolkit that focus on topics important to people with scleroderma and 8 group videoconference sessions.

Interested in learning practical skills to help manage your symptoms?

[Check here](#) to see if you can join and access the participant information and consent form.



---

### Link to Scleroderma Manitoba's Video

You, or someone you love may be experiencing changes in the mouth, throat and esophagus as the result of scleroderma. This educational webinar: **Scleroderma Can Be Hard to Swallow** features Dr. Ada Man, Rheumatologist at the Manitoba Clinic and Assistant Professor, University of Manitoba, and Dr. Matthew Woo, Consultant Gastroenterologist at the South Health Campus, Calgary, Alberta and Clinical Lecturer in the Division of Gastroenterology at the Faculty of Medicine, University of Calgary, Alberta discussing the effects of scleroderma on the mouth, throat and esophagus, what to watch for, and potential treatment. [Click here](#) to watch the video and Thanks Manitoba for providing!

## Good to Know cont'd

### CHUM's Rhapsody Analytical Instrument

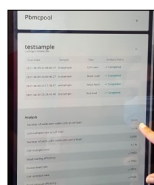
A **thank-you** email to the SABC from Dr. Jean-Luc Senécal, Scleroderma Research Chair, Professor of Medicine University of Montreal, Rheumatologist Autoimmunity Research Laboratory, Centre Hospitalier de l'Université de Montréal (CHUM) for our 2021 donation of \$10,000 to support CHUM research with the acquisition of the Rhapsody analytical system.

On behalf of the CHUM Scleroderma Research Group, I wish to express our deepest gratitude for your generous donations in support of the purchase of a Rhapsody apparatus from Becton Dickinson.

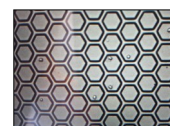
I am most pleased to inform you that the Rhapsody has been acquired according to plan and is now operative in the Immunoregulation Laboratory (headed by Marika Sarfati, MD, PhD) on the 12th floor of the CHUM Research Center in Montreal. Drs Sarfati and Heena Mehta, PhD, have already run preliminary experiments. Here is a picture of the Rhapsody and its accompanying module (the Rhapsody Express), taken on July 28th as myself and the team members spent several hours with Drs Sarfati and Mehta to get acquainted with this cutting-edge technology.



The Rhapsody is an advanced analytical system that identifies the expression of genes in thousands of individual cells that are studied in parallel. The Rhapsody allows analysis of the full transcriptomic signature (i.e. all the genes) of each cell. It works in tandem with the Symphony, another apparatus previously acquired thanks to a generous donation from Sclérodémie Québec, that identifies each cell according to certain phenotypic criteria. The cells studied include, for example, blood cells as well as cells from skin biopsies obtained from scleroderma patients. In lay language, using a biological sample that contains thousand of cells, we can now separate and study each cell based on its external features (proteins at the cell surface) and internal characteristics (gene expression). Individualized cellular analysis was not possible previously on such a large scale. As can be seen in this screenshot (under the heading Analysis) of our sample of human blood cells, 22,431 cells were counted and determined as viable by the Rhapsody.



The Rhapsody couples each cell to a bead bearing a unique bar code and then distributes each cell coupled to its bar-coded bead to a single microwell in a cartridge containing 250,000 microwells. This is shown in the picture below where the wells are recognized by their hexagonal shape: it can be seen that several wells contain a single bead (to which is attached a single cell, that is little or not visible). Several wells are unoccupied as we had 22,431 cells for 250,000 microwells. It is this unique separation process that allows subsequent transcriptomic (gene expression) analysis at the single cell level.



As one can imagine, the results generated by this technology are extremely complex and require bioinformatics and sophisticated software for analysis and interpretation, as well as time! As you know, our objective with this state-of-the-art technology is to establish the immune identity card of individual scleroderma patients. In time, this will allow us to move toward more personalized therapy of scleroderma.

Again, we express our sincere gratitude to you all for your invaluable assistance in acquiring this cutting-edge technology.

# Interesting Reading

## Raynaud's patient curious if Viagra can save cold fingers

This article appeared in the Kelowna Courier newspaper and was kindly submitted by Angie Reglin, our Kelowna Community Contact Representative. I found the below original article by staff writer Dr. Keith Roach, The Daytona Beach News-Journal, August 21, 2019



**DEAR DR. ROACH:** I have scleroderma with Raynaud's phenomenon, and friends and family members have told me that I might get help from Viagra.

Frankly, I hadn't read or heard that from either of my rheumatologist or dermatologist. I already tried a short course of nifedipine over a decade ago (it just gave me a headache), so I just stick with mechanical means to keep my hands warm in winter and, maybe surprisingly to some, in summer.

Believe me, air-conditioned grocery stores are torture from April to October. — M.A.P.

**ANSWER:** Raynaud's phenomenon is an excessive response of the blood vessels in the skin to changes in temperature, and sometimes to emotional stress. While most people will get cold hands and feet when it is cold, a person with Raynaud's can get a drastic response, even to air conditioning or freezer sections of grocery stores. The skin will turn white and then blue, then quite red on being rewarmed. Not everybody goes through all three colors, however.

Raynaud's can exist by itself, but is often seen in the presence of autoimmune conditions, such as the systemic sclerosis (scleroderma) you have. Treatment for Raynaud's is generally the same with or without other conditions. Everybody with Raynaud's should quit smoking and avoid medications that can trigger an attack (over-the-counter cold and flu remedies are the most common).

The mainstay of treatment is avoiding the temperature changes wherever possible, but as you point out clearly, it's almost impossible to do so completely. Putting your hand in a refrigerator or holding a cold drink can trigger an attack. Many people with Raynaud's learn to keep gloves with them all the time and dress their entire body warmly. An attack can sometimes be aborted by rubbing hands in warm water or getting them into a warm place.

When medication treatment is necessary, a calcium channel blocker like nifedipine is often the first choice. Headache and dizziness can limit effectiveness of this treatment. Studies have shown these medications can cut the attacks by about 50%.

Sildenafil (Viagra) has been used in people with Raynaud's, and is about as effective as calcium channel blockers. However, for people with scleroderma, ulcers and Raynaud's, sildenafil has been shown in small trials to be very effective.





# Members Corner

## Steps to Applying for the CRA's Disability Tax Credit

By Michele Gervais, SABC Board Member



If you are anything like my Mom, you save every single paper receipt, no matter what the amount, in a large file folder labeled *Health Expenses*, hoping that come tax time, some of them, or better yet all of them, can be used as deductions on your annual tax return. We are talking big and small receipts for the whole gamut of scleroderma symptom expenses: skin—bandages and creams; joints—rubs and heat packs; gastro—antacids and boost drinks; lungs—air purifiers and mentholated oils; etc., etc., etc.

If you are anything like me, you look at this bursting folder and say, with your inside voice, 'good grief...what do I do with these?'

If you are anything like a Caregiver, you've learned to consult the experts. And that is what I did. Here are the steps to get the ball rolling in dealing with that file folder before tax time.

**Step 1:** Talk to your tax accountant/consultant. I learned that some of these receipts could be claimable but there is a process to go through first with the Canadian Revenue Agency (CRA) to apply for a disability tax credit that helps persons with disabilities reduce the amount of income tax they may have to pay. And of course it starts with a form.

**Step 2:** Search, download and print out all 16 pages of the CRA form T2201 Disability Tax Credit Certificate. Complete Part A and sign it.

The image shows the first page (Part A) of the CRA form T2201 Disability Tax Credit Certificate. It includes sections for the taxpayer's name, address, and date of birth, as well as a section for the taxpayer's signature and date. There are also checkboxes for 'I am the taxpayer' and 'I am the caregiver'.

**Step 3:** Call ahead to your Dr.'s office, warning them you'd like this giant form completed by the patient's Dr. To my surprise, my Mom's office was very familiar with this form, promptly made a telephone appointment for the Dr. to complete the form with us over the phone and casually mentioned the \$80 fee to do so.

**Step 4:** Drop off the 16 page, signed in Part A, paper copy of the form to the Dr.'s receptionist before the telephone appointment day. (I put it in a large neon pink folder so it could not possibly be lost!).

**Step 5:** After the telephone appointment, give the office at least a week before calling back to ask, ever so nicely, if the entire 16 page form, now complete and signed by the Dr. on page 16 of 16, is ready for pick-up.

**Step 6:** Once you've checked all the pages are there, have the form in hand and are \$80 less wealthy, swing by the tax accountant's office. They will scan the form so you can keep the paper copy, as instructed on the form, for your files. They will submit the form for you electronically to the CRA.

**Step 7:** Wait anywhere from 2 to 4 months to get your *Notice of Determination* mailed directly to you from the CRA. This notice informs you of the CRA's decision whether or not to grant you the disability tax credit. (Mom and I are stuck at this step so unfortunately I don't have a nice visual to show).

**Step 8:** If granted the credit then I'm hoping to tally up all those receipts and have the amount entered on Mom's tax return?

**Step 9:** And whoa—maybe not so fast in shredding that fat file folder! I'll have to store it for the required 7 years in case Mom is audited?

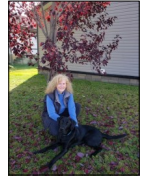
(Like a good Caregiver, I'll be consulting the experts re next steps...), *Michèle*

# Members Corner cont'd

## PROTEIN FAT MACRONUTRIENTS CARBOHYDRATES

### What are Macronutrients??

By Teresa Colosimo, our Valemount, Prince George and Northern Rural Communities Contact Representative



Macronutrients are Proteins, Carbohydrates and Fats. They are called 'Macro' because we need them in fairly large quantities. They are also essential nutrients as we need them to maintain healthy functioning.

Below is a breakdown of each Macronutrient:

**Proteins:** Maintain and repair tissues. Essential for producing hormones and enzymes. They are used as a source of energy when carbohydrate energy is insufficient. All body and cells contain proteins that are used in the production of many molecules essential for life.

Recommended Daily Percentage is 10-35%

Proteins are classified nutritionally as being either *"Incomplete or Complete"*

**Complete proteins** contain all the essential amino acids we need in our bodies for tissue and growth.

**Examples:** eggs, dairy, seafood, tofu, and meats.

**Incomplete proteins** can maintain life but lack one or two essential amino acids to promote growth.

**Examples:** Nuts, seeds, whole grains, vegetables, and legumes.

The combination of two incomplete protein sources such as beans and brown rice forms a complete protein.

**Carbohydrates:** Are the body's main source of fuel. All cells and tissues in our bodies use glucose which is a simplified form of a carbohydrate. A lack of carbohydrates could result in energy loss, ketosis, depression, nutritional deficiencies, and loss of essential body protein.

Recommended Daily percentage is 45-65%

\*\*\* There are times with Scleroderma and GI issues when we are unable to eat properly. When there are not enough carbohydrates in our diet, unfortunately our bodies will take the energy from our muscles. This happened to me and I lost a lot of muscle mass\*\*\*

There are two categories of carbohydrates *"Simple and Complex"*

**Simple Carbohydrates** are naturally occurring single sugars and include glucose, fructose, galactose, sucrose, lactose, and maltose. Eating sugary treats and processed foods can lead to obesity, hyperglycemia, and diabetes.

**Examples:** Baked goods, white flour, white rice, boxed cereals, chips, and candy

**Complex Carbohydrates** are high in fiber and digest more slowly. This also makes them more filling, which means they're a good option for weight control.

**Examples:** Whole grains, legumes, vegetables, and fruit.

## ***Members Corner cont'd***

**Fats:** We need dietary fat for energy storage, insulation, healthy cell membranes, absorption of fat-soluble vitamins A, D, K and protection of the nervous system. Fat supports energy storage, as too much fat storage could result in health complications like heart disease, stroke, metabolic syndrome, gastrointestinal issues, high blood pressure, fatty liver, cancer, and weight gain.

Recommended Daily Percentage is 20-35%

There are good and bad fats.

### **Good Fats:**

**Monosaturated Fats:** Avocados, oils (canola, olive, sesame), olives, nuts (almonds, cashews, filberts, pecans, pistachios), peanut and almond butters (natural) and pumpkin, sesame, and sunflower seeds

**Polysaturated Fats, including omega 3's:** Fish (salmon, mackerel, sardines), flaxseeds, hempseeds, chia seeds, nuts.

### **Bad Fats:**

**Trans Fats:** Hydrogenated or partially hydrogenated fats, margarine, shortening, non-dairy creamers, many processed baked or fried foods.

**Saturated Fats:** Fatty cuts of beef, pork and lamb, lard, bacon.

Now that we know about Macronutrients, we can incorporate healthy food sources into our diets to help sustain good health and well being.

If you would like to discuss more about nutrition and/or how I might be able to help you achieve your health goals through nutrition, support, knowledge, and experience, please email me, Teresa, at [tacnc202@outlook.com](mailto:tacnc202@outlook.com). I am really interested in hearing from you regarding your GERD symptoms and how you are managing them.

I look forward to chatting with you, *Teresa*



### ***Music by Nicole Edwards***



We all were introduced to Nicole, a SABC member and scleroderma patient living in the Yukon, in 2014 when she graciously provided 'her story' for the SABC to post on our website. We learned Nicole released her first original album in 2001 and she delighted in blurring music genres, always staying true to her voice with song titles like 'Love, Serve and Uplift' and 'Apathy is Boring'.

We have enjoyed Nicole's music so much so, the SABC reached out to her to set our last two June Awareness campaign videos to her inspiring lyrics and folky beat. Our favorites include 'Raynaud's Blues', 'I Still Have Something', 'Be the Change' and 'Miracle'. Click on these two links to view the videos and again enjoy Nicole's musical talent:

[2020 June Video](#) and [2021 June Video](#)

Sadly we lost Nicole on September 8th, but she continues to shine brightly in our lives with her everlasting gift of music. For those wishing to keep enjoying Nicole's music, please visit [nicoleedwardsmusic.com](http://nicoleedwardsmusic.com) and share her music with your friends and family as it was Nicole's wish her music remain accessible to all.



## **SABC Board of Directors 2019 / 2020**

President	Rosanne Queen	604-984-9425	rq.sabc@telus.net
Vice President	Michele Gervais	604-761-7782	gordmich17@gmail.com
Secretary	Jeff Gammon	604-809-6939	jeff.t.gammon@gmail.com
Treasurer	Patrick Livolsi	778-791-7834	treasurer@sclerodermabc.ca
Board member	David Queen	604-984-9425	dq.sabc@telus.net
Board member	Tiasha Burch	778-984-3745	burchtiasha@gmail.com
Board member	Beth Miller	604-815-8740	bethmiller@telus.net
Board member	Grace Kim	778-926-0118	ggkim@student.ubc.ca
Board member	Valerie Doyon	250-202-9449	valerie.doyon@alumni.ubc.ca
Board member	Jessica Jun	778-887-0523	jessjun@student.ubc.ca
Patient Liaison	Chelsea Fitzpatrick-Lindsay	778-288-2936	cjofitz@hotmail.com

## **Community Contact Representatives**

Campbell River	Jackie Alexander	250-830-7287	jackie.alex97@gmail.com
Chilliwack	Kelly Grant	604-378-1806	thekellygrant@gmail.com
Creston	Betty Kuny	250-428-8875	rkuny@telus.net
Kelowna	Angie Reglin	250-860-5700	angiereglin@gmail.com
Kamloops	Jen Beckett	250-574-3151	jenniferbecketts@hotmail.com
Maple Ridge	<i>Seeking Representative</i>		
Nanaimo	Linda Allen		llallen.52.14@gmail.com
Nelson	<i>Seeking Representative</i>		
New Westminster	<i>Seeking Representative</i>		
Penticton	Barb Creighton	250-770-7836	mischief2@shaw.ca
Quesnel	Leah McAnena	250-925-0281	almcanena@hotmail.com
Squamish	Beth Miller	604-815-8740	sabcbeth@gmail.com
Surrey	<i>Seeking Representative</i>		
Valemount, Prince George & Northern Rural Communities	Teressa Colosimo	250-566-3165	pattess72@hotmail.ca
Victoria	Susan Goss	250-479-8586	susangoss@shaw.ca
Vernon	Lisa VanDyk	250-542-5231	SanNicolaswest@shaw.ca
Williams Lake	Cecelia Jaeger	250-392-3656	cecejaeger@gmail.com
Yellowknife	Helen White	867-873-5785	hwhite@theedge.ca

SCLERODERMA ASSOCIATION of B.C.  
PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2  
604-371-1005  
Email: [info@sclerodermabc.ca](mailto:info@sclerodermabc.ca) • Website: [sclerodermabc.ca](http://sclerodermabc.ca)

### **Disclaimer**

The Scleroderma Association of B.C. does not endorse any drug, treatment, or dietary material presented in this newsletter. Always discuss alternative medical options with your doctor before including them in your treatment plan. Although we aim to keep you informed and engaged, the opinions shared through this newsletter are not those of the Scleroderma Association of B.C. and are intended to spark discussion.

*Sclerodata* may still be received in print form but may also be received as an email attachment (just send us your email address if we don't have it yet).