

STRIDES



February

Scleroderma Society of Canada

2006

What happens to the money?

You may not know what the government does with your tax dollars, but we can tell you what happens to your money in the Scleroderma Society of Canada.

First, we remind you that the Society is based on volunteer service. We have no paid staff members nor do we rent office space. Expenses, such as postage and telephone (yes, we have all the receipts!) are paid through the membership fee. Individuals become members by joining one of our provincial Member organizations. Four dollars of that membership fee is forwarded to the Scleroderma Society of Canada. There are nearly 1,400 such members across Canada, thus we operate on a basic budget of approximately \$5,000 per year. (We seek supplementary funding for our Annual General Meeting.)

Donations are a major source of revenue for the Society. Some of these are memorial donations while others are simply contributions from individuals and some from corporations. In response to inquiries from people wanting to make a donation, we provide information about the scleroderma organization in their province, as well as information about the national organization, indicating that the choice is theirs to make.

All donations are dedicated to supporting research and to promoting greater awareness of scleroderma. We promote awareness through activities such as the printing and distributing of pamphlets and through the annual June 'Awareness' campaign. By far the largest proportion of funds received through donations goes to support research.

The Scleroderma Society of Canada is committed to supporting research through the Canadian Scleroderma Research Group. In the brief six-year history of our Society, we have contributed \$100,000 to their work. Our Board of Directors recently declared an objective of contributing at least that amount over the next six years as well.

We appreciate your support and encourage you to continue working with us in the fight against this dreadful disease.

(Inquiries about the above information or about making a donation may be directed to our Secretary-Treasurer, Grant Dustin at 95 Woodfield Road SW, Calgary, AB T2W 5K5, phone 403-281-7616, email dustin@spots.ca.)

Inside this issue:

Money	1
Predictions	2
New Book	2
Proclamations	3
At Long Last, Some Relief	4
Potassium	6
Medications	8



2006 AGM
to be held in
New Brunswick.
Look for details
in further
STRIDES.

NEW YEAR PREDICTIONS

Submitted by Bob Buzza, President

- 1) As a direct result of the major conference on systemic autoimmune rheumatic diseases that was held in December 2005, a plan will be approved and implemented that will move the research agenda forward, with significant funding from one or more of the national health institutes, for diseases such as scleroderma, lupus, sjogren's syndrome, myositis and vasculitis.
- 2) The Canadian Scleroderma Research Group (CSRG) registry will expand to include at least 450 scleroderma patients.
- 3) As a result of an application from the CSRG, in collaboration with our Society, the Canadian Institutes of Health Research (CIHR) will commit to providing \$300,000 to the CSRG for each of six years to undertake research utilizing the CSRG patient registry and data base.
- 4) The CSRG will publish at least 15 articles or abstracts in Canada and the US during the year. Several will be featured as 'posters' at rheumatology meetings involving as many as 10,000 in Mexico and the Netherlands.
- 5) As a result of an application from the CSRG, in collaboration with our Society, the CIHC will provide funds for at least one person who has completed training as a rheumatologist to become part of the CSRG and, over time, "... acquire the expertise to run independent research programs on multiple aspects of scleroderma, both clinically and in the laboratory".
- 6) As a result of the widespread distribution of note cards, pins, posters and pamphlets, combined with at least 50 proclamations from local, provincial and national bodies, attempts to feature June as *Scleroderma Awareness Month* will increase public and medical awareness about scleroderma, and its challenges, significantly.
- 7) Professor Dame Carol Black, President of the Royal College of Physicians and Surgeons and a world-renowned authority on scleroderma (systemic sclerosis) will be a smash hit when she highlights the good news about scleroderma developments, and responds to our questions during our annual meeting in Fredericton on September 23.

The foregoing predictions are **not** 'pie in the sky'. By working together and with our research colleagues, **all** are achievable. .

New Book

"The Scleroderma Book, a Guide for Patients and Families", by Dr. Maureen D. Mayes is widely recognized and well established as a resource on scleroderma. Dr. Mayes, who is internationally recognized in this field of study, has recently completed the **second edition** of her book. Among other revisions, the new edition has updated chapters on the genetics of scleroderma and on new treatments for complications of the disease.

Writing specifically for patients and their families, Dr. Mayes draws on her extensive experience treating scleroderma to provide up-to-date, practical information that will help patients manage their symptoms and improve their quality of life.

This new edition is available through the Scleroderma Society of Canada at a very special reduced price for a limited time.

For more information please contact Grant Dustin, Secretary-Treasurer of the Society, or your local contact person. Grant may be reached at 95 Woodfield Road SW, Calgary, AB, T2W 5K5, or telephone 403-281-7616, or fax 403-238-2773, or email dustin@spots.ca.

Proclamations

We need your help in obtaining proclamations, which are an inexpensive way of raising awareness about our disease –which most know nothing about.

Please, contact the office of at least one mayor or councilor or premier or MLA to find out how to have June proclaimed as “Scleroderma Awareness Month”. It’s likely simple.

Last year, Katherine Dewar, the coordinator of the scleroderma support group in PEI, contacted the premier’s office, and received red-carpet treatment.

She and three others met Premier Pat Dinns, and talked to him about the disease. A proclamation was signed, pictures were taken, and newspapers noted the event. One published an in-depth article about the disease.

Barbara Stanyer, the President of the Scleroderma Association of BC, contacted the Vancouver mayor’s office. She also received an immediate, positive response. Avuncular Larry Campbell, who is now a Senator, asked questions from an ex-coroner’s perspective, and posed for pictures with Barb’. Press coverage and calls to the association office and Barb’ followed.

The script for a proclamation can vary greatly. Here’s an abbreviated example.

Office of the Mayor

CITY OF VANCOUVER

PROCLAMATION

“SCLERODERMA AWARENESS MONTH”

WHEREAS

Scleroderma is a disease in which connective tissues of the body become hardened and rigid, impeding normal function of limbs and organs;

AND WHEREAS

Scleroderma is a chronic and often progressive disease That may result in death;

THEREFORE

I, Larry Campbell, Mayor of the City of Vancouver, DO HEREBY PROCLAIM the month of June 2006 as

“SCLERODERMA AWARENESS MONTH”

You can likely get agreement in January to have the proclamation issued in May, which will help set the stage for our other awareness-raising efforts in June. Our Secretary-Treasurer, Grant Dustin, will be keeping tabs on proclamation results, so please let him know how you make out. Our target is 50! And don’t worry about the House of Commons. Once we know who’s in and who’s out, your Directors will seek all-party support for a proclamation from the House.

At Long Last, Some Relief

By Lori Jacobs (Mohawk Nation at Kahnawake)



I've always had a health problem. It started with my digestive tract when I was a little girl. I was so severely constipated that I had to be hospitalized. I didn't know I was constipated because I never felt the urge to go, sometimes for a week or more. The doctor told my mother that there was nothing physically wrong with me, that I was "just stubborn." So that was the beginning of my physical ailments that I manifested in my mind because I was "*just stubborn.*"

Then there were dozens of bouts with bronchitis, and the appearance of small patches of skin discolorations on my arms and legs, like a concoction of milk and Pepsi. It seems my joints were always sore, sometimes even infected, although I didn't do anything to get an infection. In my teens, I would venture out into the cold with no hat and an open coat to be cool like my friends. But boy, *the cold literally hurt me.* My friends would say "Hey, what's wrong? You got no blood?" Being a North American Indian, that was a strike against my pride and "Indian ness" so I would suffer the consequences in silence. After all, it was all in my head! Or was it?

I never knew I had Scleroderma until I was having my second child when I was 26 years old. I was working as a data entry operator in Montreal, back in the days when the main computer of a company took up a whole room, and the temperature of that room had to be kept very cold so the computers wouldn't overheat. My fingers were blue, but I kept on punching those keys, until a co-worker put a scare into me, saying I must have a heart problem because her brother had the "same thing" and died of heart failure. So I went through emergency, was diagnosed with scleroderma *and pregnancy*, and was sent home with a photocopied page of a medical book that predicted I'd be dead in five years. That was 24 years ago. *Boy, talk about stubborn!*

I have the **CREST** syndrome of Limited Scleroderma. Over the years, I've taken calcium channel blockers to help with the **C**alcinosis, and heart and blood pressure medication to help with the **R**aynaud's. I've had a severe swallowing problem (**E**sophageal dysfunction), so I just didn't eat until I was so ravenous that I didn't care if the food got stuck in my throat, and then I'd suffer. I've had tons of creams and potions to alleviate the tightening skin on my hands and arms (**S**clerodactyly), and by rights, I should own stock in all the cosmetic companies whose face make-up I've used to camouflage the tiny red veins on my face (**T**elangiectasia). I even had to take medication for thyroid because I was tired all the time, and antibiotics when my joints flared up. By when all the medications failed to do what the doctors said they would, they'd just put me on another type of medicine, or add another medication to combat side effects. I was getting fed up being used as a guinea pig, for I knew that the doctors really didn't know what scleroderma was all about or how to treat it. I've read countless books on nutrition, vitamin and mineral supplements, and even tried traditional alternative medications of my people, the Mohawks, with limited success.

But with all the advances in modern medicine to alleviate the symptoms of scleroderma, I never really experienced any long lasting relief. So I kept on searching, telling myself that maybe that next fad would work for me. But alas, that miracle never materialized.

I'm no doctor or health professional but I know that I needed to take responsibility for my own health care. What I did learn was that, despite our ethnic backgrounds and cultural differences and similarities, we as North Americans are eating ourselves sick.

In our everyday, fast-paced, convenience oriented, junk food society, 70% of us don't eat the minimum recommended daily nutrients that our bodies need to keep healthy. So when we deprive our bodies of these basic nutrients, we open ourselves up to a wide range of illness and disease.

Research shows supplementation can substantially improve health by bridging the nutritional gap, and that 50% of us already use some form of nutritional supplement.

80% of cancers are diet related.

We feel sick, so we go to our doctors, get a prescription, go to the pharmacy, and get a bunch of pills to make us feel better. But how long do the pills sit in our stomachs before they are actually absorbed into our bodies to do its work? Some estimate that less than 25% of the pills we ingest actually get into the system.

Everyone knows that our healthcare professionals are probably the most important people in our lives besides our families, because we entrust our health to them. What I now know is that every time a doctor writes out a prescription, and it's filled by a pharmacist, both get a cut from the company whose drug name brand appears on your prescription.

We, as patients, sometimes allow ourselves to become prisoners to our afflictions instead of building partnerships in our healthcare regimen with our doctors, nurses and pharmacists.

But the biggest revelation of all my research was that diseases and illnesses begin in our colon, a holding station for bodily waste products before they are excreted from the body. Our bodies store toxins / poisons in the colon.

In the summer of 2003, I came across a product that turned my life around. It was actually a Mother's Day gift from my son. It's called *Reliv*, a soy-based vitamin and nutritional supplement in powdered form. **Soy? Yuck! That's what I said too.** I am such a cynic and sometimes my own worst enemy, but I told myself that I can't stop searching for what might work for me. Besides, Hippocrates said it best, "Let food be thy medicine and medicine be thy food." After it sat on my kitchen shelf for a while, I took it out, dusted it off and finally gave it a try. My first shake was the test, and I was hooked, not from the taste, but from how it made me feel.

Check out their website: www.reliv.com. or more information, please contact.

Lori" (450) 638-1831, or email me for more information at ljacobs@paulcomm.ca.

Disclaimer

The Scleroderma Society of Canada does not endorse any drug or treatment. Information that is provided is intended merely to keep people informed. The manifestations and severity of scleroderma vary. Individualized medical management is therefore essential.

The Society of Canada strongly recommends that all drugs and treatments be discussed with one or more doctors or health care providers to assure proper evaluation and treatment.

Donations

Donations can now be made to Scleroderma Society of Canada online through Canada Helps.

(www.CanadaHelps.org).

If you check their website and click on 'I am a donor', you will see the categories of service. If you type in 'scleroderma' as a search word, you will see that all of our Canadian organizations that are registered charities are listed there. Same for 'sclerodermie', it brings up the name for Sclerodermie Quebec.

Donations can also be made by Mastercard or Visa.

1-866-279-0632

Checks made out to Scleroderma Society of Canada.

mailed to:

Grant Dustin

95 Woodfield Rd, SW

Calgary, Alberta

T2W 5K5

What foods are high in potassium?

According to guidelines issued in 2004 by the Institute of Medicine, adults should consume at least 4,700 milligrams (mg) of potassium a day. A potassium-rich diet can help reduce blood pressure and the risk of stroke. It may also lower the risk of some types of kidney stones and help prevent bone loss.

Need more potassium in your diet? Try these foods		
Food	Serving	Amount of
Sweet potato	1 cup, baked	950 milligrams
Acorn squash	1 cup, cubed	896 mg
Papaya	1 medium	781 mg
Dried apricots	1/3 cup	734 mg
Baked potato	1 medium	610 mg
Pinto beans	1 cup	583 mg
Spinach	1 cup, cooked	574 mg
Tomato juice	8 ounces (oz.)	556 mg
Blackstrap molasses	1 tablespoon	498 mg
Orange juice, fresh	8 oz.	496 mg
Cantaloupe	1 cup, balls	473 mg
Chocolate milk, low fat	1 cup	425 mg
Banana	1 medium	422 mg

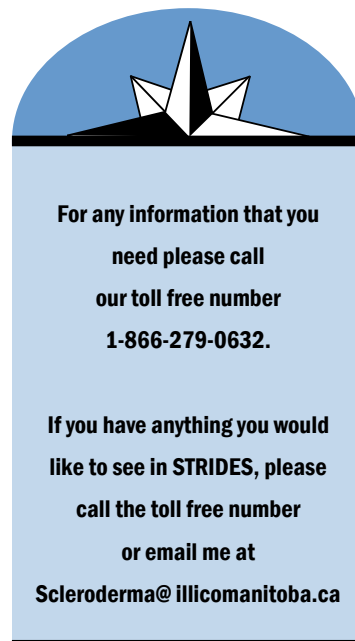
Source: USDA National Nutrient Database for Standard Reference, 2004

Too much potassium can be harmful for people with certain medical conditions. Consult with your doctor before increasing your potassium intake if you: Take certain medications, such as angiotensin-converting enzyme inhibitors

Little Johnny's kindergarten class was on a field trip to their local police station where they saw pictures of the ten most wanted criminals. One of the youngsters pointed to a picture and asked if it really was the photo of a wanted person.

"Yes," said the policeman. "The detectives want very badly to capture him."

Little Johnny then asked, "Why didn't you keep him when you took his picture?"



Good Health To You!

Health problems are a major concern for many of us. We are often less concerned about good health but we likely all agree that sustaining and improving the health of Canadians is desirable. The governments in Canada agree as well and are in the process of developing public health goals for Canada.

The process started with a meeting of Canada's First Ministers in September, 2004. They recognized the need to better coordinate inter-governmental efforts to improve the health and safety of their citizens. They made a commitment to work together in setting goals and targets for improving the health status of all Canadians.

Federal Minister of State (Public Health), the Honourable Carolyn Bennett, and Manitoba Minister of Healthy Living, the Honourable Theresa Oswald, were appointed to co-lead the process of developing common public health goals and targets. They have divided the process into two phases. The first phase, now completed, was to focus on developing public health goals. The second phase will focus on each jurisdiction developing targets relative to those goals.

They have established a detailed website, www.healthycanadians.ca. You are encouraged to check the website to monitor their progress and to learn more about public health in Canada. There are links to various websites, including the Public Health Agency of Canada website and to those of each province and territory. There is also information on how to access government funding.

Establishing national public health goals is not just a matter of stating that we want Canadians to be healthy. It means consideration of many factors and it involves all of us, regardless of our own state of health.

At the Doctor's Office

- Before your appointment, make a complete list of all medications you take, including prescription and non-prescription medicines and nutritional supplements. Whenever your medications change, be sure to update your list.
- Take your medications list with you to every doctor's appointment.
- Ask your doctor to explain your prescription, including the drug name, how often you should take it and what the purpose of the medication is.
- At least once a year, bring all of your medicines with you to your doctor's appointment-this way you can talk about all aspects of your medications and your doctor can make certain your records are up to date.
- As you age, some drugs may affect your body differently, so ask your doctor periodically if it may be time to adjust dosages of medications you have been taking for a long time.

Three vampires walk into a bar and sit down at a table. The waitress comes over and asks the first vampire what he would like. The first vampire responds, "I would like some blood."

The waitress turns to the second vampire and asks what he would like. The vampire responds, "I would like some blood."

The waitress turns to the third vampire and asks what he would like. The vampire responds, "I would like some plasma."

The waitress looks up and says, "Let me see if I have this order correct. You want two bloods and a blood light?"

**SCLERODERMA
SOCIETY OF CANADA**

95 Woodfield Rd SW
Calgary, Alberta
T2W 5K5

Email: Dustin@spots.ca

Phone: 1-866-279-0632

Fax: 403-238-2773

Email: scleroderma@illicomanitoba.ca



Scleroderma Society of Canada

WWW.SCLERODERMA.CA

INFO@SCLERODERMA.CA

Board of Directors for Scleroderma Society of Canada

President– Bob Buzza

Vice President– Marion Pacy

Secretary/ Treasurer– Grant Dustin

Research Information Coordinator– Linda Shauf

Directors-at-Large

Mary Beth Clark

Gillian Little

Shirley Haslam

Normand Ricard

The mission of the Scleroderma Society of Canada is to promote awareness of scleroderma, to support those affected by this disease, and to support research dedicated toward a cure.

- Keep medications in their original, labeled containers. This can help you identify each pill and to follow the proper directions.
- After opening a container of medicine, take out the cotton plug, which may draw moisture into the container.
- Do not store medications in the bathroom medicine cabinet or in direct sunlight, because humidity, heat and light can affect a medication's potency and safety.
- Do not store medicines in the refrigerator unless instructed to do so, and keep liquid medicines from freezing.
- Store medications where children cannot see or reach

them-for example, in a locked box or cabinet. Teach children that medications can be dangerous if misused.

- Keep medications for people separate from pet medications or household chemicals.
- Do not keep tubes of ointments or creams next to a tube of toothpaste. They may feel similar when you grab quickly.
- Do not chew, crush or break capsules or tablets unless instructed to do so.
- With liquid medication, use only the measuring device that came with it. Many household teaspoons and tablespoons are not accurate.
- Keep phone numbers for your doctors and pharmacist in a convenient location, along with the

numbers of your local EMS and poison control centers. Know the locations of pharmacies that are open 24 hours a day in case of an emergency.

- Do not take medications in the dark - although you may think you know exactly what the bottle on your nightstand contains, turn on a light to be sure.

Never take another person's prescription medication or share yours with anyone, even if the other person appears to have the same medical condition as you.