



Chapter President, Mary Blades	Rhonda Costa
Vice President, Rhonda Costa	Rhonda Douglas-Larkin
Secretary, Rhonda Douglas	Rod Douglas
Treasurer, Bev Pogue	Julie Puckett-Gordon
Assist Treasurer, Debbie Morris	Debbie Morris
<b>Board of Directors</b>	Bev Pogue
Mary & Ben Blades	Anna Speaker
	Diane Weber
	Denise Williams

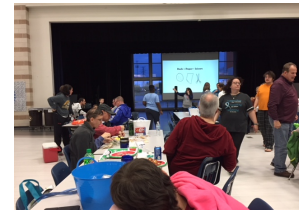
## Letter from the President.

I've always known one day I would have to write this article but I really thought it was going to come a lot sooner than now but one year led to another then another and before I knew it, it was 14 years later. How time flies when you're having fun is not really all the time but I certainly have gotten a great deal of satisfaction when I get a phone call from a newly diagnosed patient and am able to tell them I have and do suffer from their diagnosis and have lived with it for now over 20 years. They express surprise, relief and wow. I am always thrilled to go to the 5K in KC and the walk in St. Louis and see how many people turn out to support patients, families and all loved ones. The trips to DC to try to convince our legislators how important it is to us, their constituents, the many scleroderma bills that we have had and are still trying to get passed over the years, taught me first-hand how our government works. To see patients leave a Patient Education Seminar or the National Conference with a renewed sense of ability and energy to keep up the good fight. I have had the opportunity of doing a lot over the years and am so very grateful to have had the health that has allowed me to do it.

The one thing that has meant so much to me is the friends I have made over the years with the different Missouri Chapter board members that have come and gone but remain friends. I am not leaving the board so will continue to make more friends but I am leaving the Presidency, Rhonda Costa, Vice President will take over in January of 2019. You will love Rhonda, as we all do, she too gives from her heart as all the Chapter Board Members do. A big thank you to each and everyone of them in their support of me as president. They have through the years been there for me and the work we all believe in.

**It has been a privilege and an honor to have led with the help of many throughout the years. Thank you to all!!!**

The **Trivia Night Event** - was such a fun night, everyone learned how much they did or did not know. And they all knew a lot. I had never been to one and thought it was about all you know individually on varied subjects both old and new. Well this was a tablefull of people that were able to share their knowledge, so if you know about songs or stuff of today and grandma and grandpa know about songs and stuff of yesterday your table will be a winner. And while you're trying to figure out the answer to a query your laughing and eating with friends or family, what is better than that!



**Advocacy** - We have a Senate Bill, the "National Commission on Scleroderma and Fibrotic Diseases" (S. 3267) introduced and referred to the Committee on Health, Education, Labor and Pensions by Senators Kirsten Gillibrand and Charles Schumer. This is the same bill that we are working on to get through the House of Representatives the H.R. 4638. The difference is only the numbers as we have two Houses of Congress. Please, as with the representatives reach out to your senators to help us get each to sign on as a cosponsor. Please ask them to contact Jasmin Pallomares in Senator Gillibrand's office for the S. 3267. To cosponsor the H.R. 4638 Bill ask your Representative to contact Ryan Woodward with Congressman Peter King's office at: [Ryan.Woodward@mail.house.gov](mailto:Ryan.Woodward@mail.house.gov) or Catherine Rowland with Congressman Eliot Engel's office at: [Catherine.Rowland@mail.house.gov](mailto:Catherine.Rowland@mail.house.gov).

Please Senators Claire McCaskill and Roy Blunt, we the Missouri Scleroderma Community and all the Fibrotic Community do so need your help. Please sign onto the Scleroderma "H.R.4638" And please Representatives Billy Long, Blaine Luetkemeyer, Vickie Hartzler, Emanuel Cleaver II, Sam Graves, and Jason Smith, we so need your support. A heartfelt Thank You to Ann Wagner and William "Lacy" Clay, Jr. for already giving us your support by signing onto our Scleroderma and Fibrotic Bill.

**Stepping Out St. Louis** - was rained on, but it did not stop a lot of our supporters. Yes, we did lose some but those that braved the day were there for the fun, the support and the camaraderie. It really was a very good day even without the food, open spaces and not being able to walk or run but lots of time to interact with everyone and a really good raffle. If you missed it, I'm sorry you missed an excellent day even with the rain.



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See the Save-the-date box on page 3 for next year's St. Louis' "Stepping Out" information.

**Patient Education Seminar** – Dr. Richard Brasington, who is one of our biggest supporters, explained the SCOT Trials (Scleroderma Cyclophosphamide or Transplantation). He was an investigator on the trials. The trial compared stem cell transplantation to immune-suppressing drug cyclophosphamide. The trial found that trans-plantation offered significant long-term benefits, but also carried short term risks, such as infections and low blood cell counts. The option but only for those with a poor presentation of "Pulmonary Hypertension to expect from this disease and how-to better cope with its devastations. Maureen Hughes and Nadine Rivera who brought us techniques on message therapy and relaxation for scleroderma were so very helpful and exhilarating. One showed us how a good message can relieve stress while the other literally relaxed us. Such a wonderful day!



**Newsletter**-Due to the cost of mailing this is the last hard copy Newsletter, we will do an **email** Newsletter **only**. If you do not have an email or just prefer a hard copy please contact me or leave a message on your support group lines. My email is: [meblades1141@yahoo.com](mailto:meblades1141@yahoo.com) or [mblades@scleroderma.org](mailto:mblades@scleroderma.org) and you can call me call me at 417-887-3269, the KC support group line is: 816-561-7633, St. Louis is: 314-567-1260 and Springfield's is: 417-890-1502. Oh, be sure to get me your email address.



Before I sign off, I want to recognize these people in this picture as just a few of the Missouri volunteers that help at each event and beyond, they give of their time, efforts and talents. The Missouri Chapter would not be able to raise research dollars, help patients and their families or even exist without the help of these devoted people who are so very dedicated to the day there will be a cure for this unforgiving disease. From the bottom of my heart a big thank you to each and every one of them and those not pictured. From left to right is: Anna Speaker, Denise Williams, yours

truly, Julie Puckett-Gordon, Rod Douglas, Rhonda Costa, Debbie, Morris and Ben Blades. Not Pictured are: Diane Weber, Rhonda Douglas-Larkin, and Bev Pogue.

Stay Warm, stay safe and be well,  
Mary Blades, Missouri Chapter President

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## Should You Take Dietary Supplements?

### A Look at Vitamins, Minerals, Botanicals and More

When you reach for that bottle of vitamin C or fish oil pills, you might wonder how well they'll work and if they're safe. The first thing to ask yourself is whether you need them in the first place.

More than half of all Americans take one or more dietary supplements daily or on occasion. Supplements are available without a prescription and usually come in pill, powder or liquid form. Common supplements include vitamins, minerals and herbal products, also known as botanicals.

People take these supplements to make sure they get enough essential nutrients and to maintain or improve their health. But not everyone needs to take supplements.

"It's possible to get all of the nutrients you need by eating a variety of healthy foods, so you don't have to take one," says Carol Haggans, a registered dietitian and consultant to NIH. "But supplements can be useful for filling in gaps in your diet."

Some supplements may have side effects, especially if taken before surgery or with other medicines. Supplements can also cause problems if you have certain health conditions. And the effects of many supplements haven't been tested in children, pregnant women and other groups. So talk with your health care provider if you're thinking about taking dietary supplements.

"You should discuss with your doctor what supplements you're taking so your care can be integrated and managed," advises Dr. Craig Hopp, an expert in botanicals research at NIH.

Dietary supplements are regulated by the U.S. Food and Drug Administration (FDA) as foods, not as drugs. The label may claim certain health benefits. But unlike medicines, supplements can't claim to cure, treat or prevent a disease.

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### **2019 Support Groups Meetings, Times, Dates and Where:**

**Kansas City Area Support Group:** Bev Pogue facilitator, email at [bebs1316@hotmail.com](mailto:bebs1316@hotmail.com) or call 816-561-7633 and leave a message, your call will be returned.

**Northeast Area Support Group:** We are looking for a volunteer to lead this group.

**St. Louis Area Support Group:** Debbie Morris, facilitator, e-mail at: [debbiefeb19@yahoo.com](mailto:debbiefeb19@yahoo.com) or call 314-567-1260 and leave a message, your call will be returned. Meetings are at Barnes Jewish West Hospital, Olive Blvd & Mason, 1pm. March 16, May 19, July 20, September 21, November 16.

**Springfield Area Support Group:** Gerry Robertson, facilitator, email at: [robertson1942@sbcglobal.net](mailto:robertson1942@sbcglobal.net) or call 417-890-1502. All meetings are Mondays 6:30pm at Mercy Hospital, one of the Rooms through the main entrance, to the right and down the hall. March 4, June 3, Sept. 9, Dec. 2.

**Poplar Bluff Area Support Group:** Fran Atwell, facilitator, email at: [francesatwell68@live.com](mailto:francesatwell68@live.com). Fran will let you know meeting schedule, times and place.

**Renew your Scleroderma Foundation Membership!!!** Renew your Foundation membership and you will not miss out on the **Scleroderma Voice** featuring updates on the latest Scleroderma research & treatment, articles by leading doctors and other professionals. Stories of Hope and joy from some fellow patients, discounts for the National Conference and discounts on certain publications. Your \$25.00 membership fee also, helps fund around a million dollars in research, supports all the publications for Scleroderma education and helps to staff the Scleroderma information line.

# Save <sup>the</sup> Date(s)

Please Mark Your Calendar and plan for a fun filled day at the park, while raising money to find a cure.

## Scleroderma Stepping Out for a Cure St. Louis

**Saturday, September 7, 2019**

**2348 Creve Coeur Mill Rd**

**Creve Coeur Park, Tremayne Pavillion**

**St. Louis, MO 63146**



Stepping Out for a Cure Kansas City will be in June, we will have an exact date in February when the park takes reservations for the new year.

Statewide Patient Education Seminar will be in October, more details to come soon.

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“There’s little evidence that any supplement can reverse the course of any chronic disease,” says Hopp. “Don’t take supplements with that expectation.”

Evidence does suggest that some supplements can enhance health in different ways. The most popular nutrient supplements are multivitamins, calcium and vitamins B, C and D. Calcium supports bone health, and vitamin D helps the body absorb calcium. Vitamins C and E are antioxidants—molecules that prevent cell damage and help to maintain health.

Vitamin B12 keeps nerve and blood cells healthy. “Vitamin B12 mostly comes from meat, fish and dairy foods, so vegans may consider taking a supplement to be sure to get enough of it,” Haggans says.

Research suggests that fish oil can promote heart health. Of the supplements not derived from vitamins and minerals, Hopp says, “fish oil probably has the most scientific evidence to support its use.”

“It’s important to know the chemical makeup, how it’s prepared, and how it works in the body—especially for herbs, but also for nutrients,” says Haggans. “Talk to a health care provider for advice on whether you need a supplement in the first place, the dose and possible interactions with medicine you’re already taking.”

For vitamins and minerals, check the % Daily Value (DV) for each nutrient to make sure you’re not getting too much. “It’s important to consider the DV and upper limit,” says Haggans. Too much of certain supplements can be harmful.

Scientists still have much to learn even about common vitamins.

Because supplements are regulated as foods, not as drugs, the FDA doesn’t evaluate the quality of supplements or assess their effects on the body. If a product is found to be unsafe after it reaches the market, the FDA can restrict or ban its use.

Manufacturers are also responsible for the product’s purity, and they must accurately list ingredients and their amounts. But there’s no regulatory agency that makes sure that labels match what’s in the bottles. You risk getting less, or sometimes more, of the listed ingredients. All of the ingredients may not even be listed.

To make it easy to find reliable information, NIH has fact sheets on dietary supplements at: [ods.od.nih.gov/factsheets/list-all/](https://ods.od.nih.gov/factsheets/list-all/). NIH also recently launched an online Dietary Supplement Label Database at: [www.dsld.nlm.nih.gov](http://www.dsld.nlm.nih.gov). This free database lets you look up the ingredients of thousands of dietary supplements. It includes information from the label on dosage, health claims and cautions.

For more personalized, on-the-go information about dietary supplements, check out NIH’s free updated app for your smart phone or tablet: My Dietary Supplements (MyDS).

The MyDS app provides the latest supplement information and lets you keep track of the vitamins, minerals, herbs and other products you take. You can even keep track of supplements taken by your parents, spouse or children.

“Deciding whether to take dietary supplements and which ones to take is a serious matter,” says Coates. “Learn about their potential benefits and any risks they may pose first. Speak to your health care providers about products of interest and decide together what might be best for you to take, if anything, for your overall health.”

To read the complete article go to [newsinhealth@nih.gov](mailto:newsinhealth@nih.gov)



# Merry Christmas



Happy Hannakah



**Disclaimer:** The Scleroderma Foundation and the Missouri Chapter in no way endorse any drugs or treatments reported in this newsletter. Information is provided to keep readers informed. Because the manifestations and severity of Scleroderma vary among individuals, personalized medical managements are essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) to assure proper evaluation and treatment.