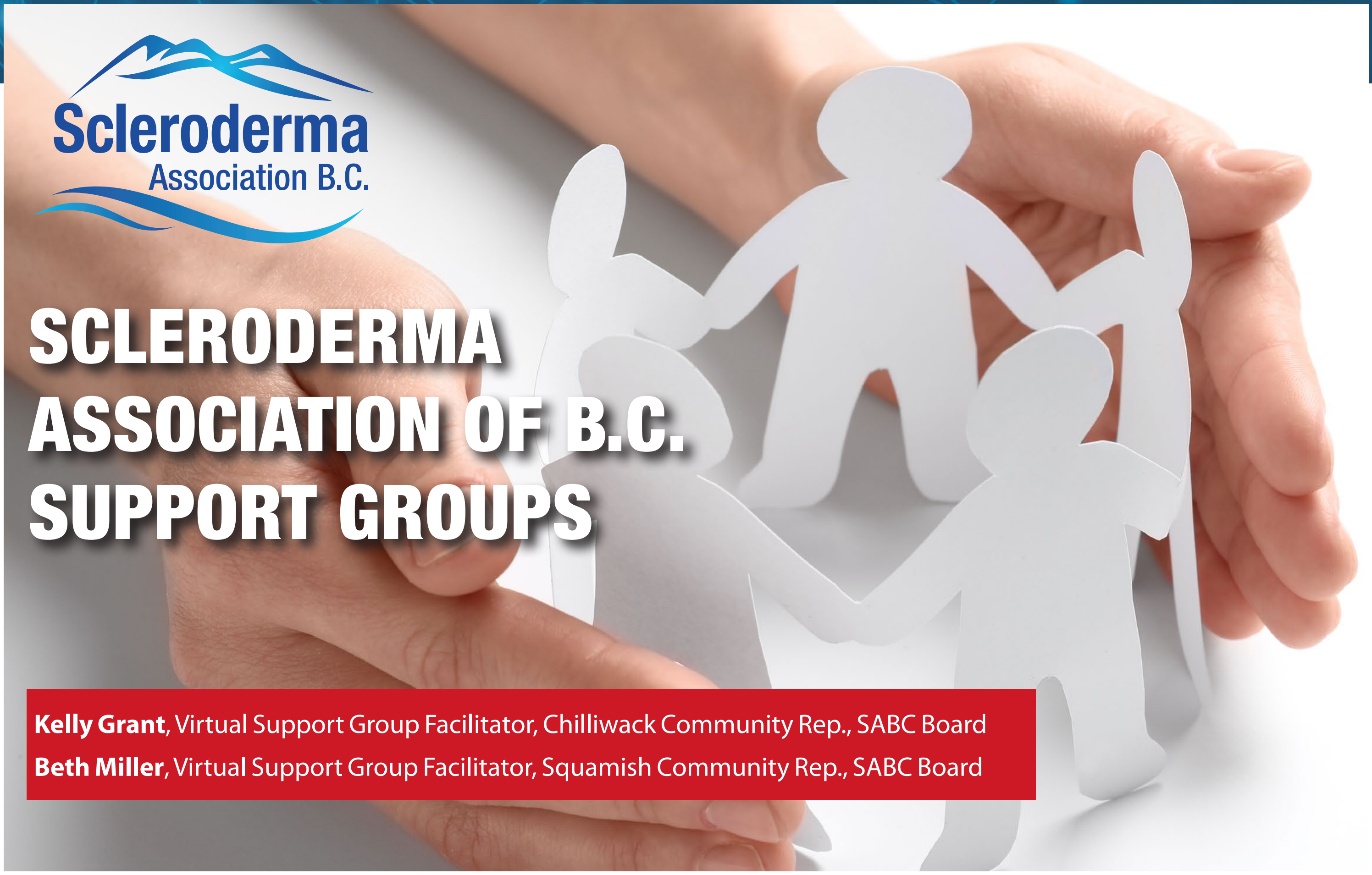
Scleroderma Association B.C.



# SCLERODERMA ASSOCIATION OF B.C. SUPPORT GROUPS

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Scleroderma Association of B.C. Support Groups meet on Zoom for mutual support with the challenges of living with scleroderma. These groups are composed of people living with scleroderma and may also include spouses or caregivers. They are led by one or more trained facilitators who have taken a course through SPIN-SSLED (Scleroderma Patient-centred Intervention Network - Scleroderma Support group Leader EDucation) specifically designed to equip them to facilitate the groups. The facilitators are SABC volunteers, and most are themselves living with scleroderma. The meetings include pertinent information for coping with scleroderma and are facilitated by our well-prepared, warm, and welcoming hosts. Participants are encouraged to share their experience of living with scleroderma with others who understand. Participants feel that belonging to a support group has changed their lives for the better.

# WHY JOIN A SCLERODERMA SUPPORT GROUP?

## FOR COMMUNITY

Many people living with scleroderma feel alone because their condition is not well known or understood. Joining a group of people who have this disease and are willing to share the tricks of the trade for living better with symptoms can give a real sense of well-being and community. Madone Coulombe has been a part of a support group for close to ten years. She writes:

***"I believe that medical appointments are not sufficient for really understanding the complexity of this disease. Through sharing with people living with scleroderma I recognize myself, and it makes me realize that I am not alone in living with these sometimes-difficult symptoms that are so hard to explain to those who do not have this disease."***

Support group members are good listeners for each other. They have personal knowledge of the disease, and they are very supportive of one another.

## FOR INFORMATION

Although one of the important rules in support groups is to not give medical advice but rather to refer one another to medical professionals, members can and do share their experiences. Often another person's experience can be a valuable source of information, hope, and inspiration.

Various themes are discussed, and information is shared from reputable sources including among other topics:

*nutrition with scleroderma, bone health, mindfulness, pain management, dental health, digestive issues, skin health, managing anxiety, getting the most from your medical appointments, communicating about your disease with family members and others, becoming an expert on your own health and keeping a personal health record, coping with changes in appearance, accepting your limits and learning to live the best you can with them, living with Raynaud's syndrome, managing energy, how to promote better sleep habits, travelling with scleroderma, and many more subjects.*

Participants are welcome to suggest subjects that are important to them and to bring their questions and concerns to meetings.

## FOR CONFIDENTIALITY

Support groups are safe, caring, and confidential spaces to share about life with scleroderma. Confidentiality is an important value in these support groups. Anything said in a group remains in the group. Meetings are not recorded. Your in-person attendance is required to participate in these sessions and no AI generated Bots are allowed. Our commitment to confidentiality is explained and reviewed at each meeting and new members are introduced to all the guidelines that help our groups maintain a positive, caring, and confidential space.

## FOR FUN

Our hope is the meetings will bring a smile and a laugh to the participants. Meetings may include Christmas parties, games, humour, costumes, and silliness. As we know, "Laughter is the best medicine." In the groups, you may be asked to talk about and share your hobbies, travel experiences, pets, favourite memories, etc.

## WHAT SUPPORT GROUPS ARE NOT?

Support groups are not led by medical professionals. They do not diagnose or treat individuals. They do not provide therapy.

# WHO ARE SUPPORT GROUPS FOR?

### FOR THE RECENTLY DIAGNOSED

Support groups can be very valuable for people who are newly diagnosed. They will be reassured that people with scleroderma have full and active lives even after many years of living with the disease. They will find compassionate listeners who understand the distress of a scleroderma diagnosis, and they will gain more understanding of their disease and learn where to look for pertinent and accurate information.

### FOR ANYONE WITH SCLERODERMA

No matter how long a person has lived with scleroderma there may be new challenges or symptoms. Anyone living with scleroderma, no matter the length of time, will find a community to support them. Being able to give support and share experiences with the more recently diagnosed can be an incredibly positive experience. You may benefit from a support group, but the support group will also benefit from your presence and your experiences.

### FOR ANYONE SUPPORTING SOMEONE WITH SCLERODERMA

Spouses and family members can also feel alone and overwhelmed by their role in caring for a person with scleroderma. Joining a support group can give them valuable information and resources.

### FOR MEN WITH SCLERODERMA

There are more women than men living with scleroderma. Groups are open to both men and women but tend to have many more women members. To offer men with scleroderma their own space, there is a men's group sponsored by the National Scleroderma Foundation. Please see the SABC Website under the heading, Find Support, for more information about "The 20%: A Virtual Support Group for Males Living with Scleroderma."

### FOR YOUNG PEOPLE WITH SCLERODERMA

Scleroderma affects people of all ages, from children to seniors. Young people with scleroderma often feel more alone. Not only do they have a rare disease, but they are also a minority of the people living with this disease. And it is important to recognize that fewer young people have chronic conditions. To give young people living with scleroderma a place to share their experiences and form a community with their peer group, there is a virtual support group available through the National Scleroderma Foundation. Young people are also welcome to participate in SABC Support Groups.

# WHAT ARE MEETINGS LIKE?

### VIRTUAL MEETINGS

Our Come Zoom With Us meetings can have special guests and free or structured discussions. Zoom meetings usually last an hour. Because they are online, there is no geographical restriction. Please see the list of meeting dates and times on the SABC website.

### IN-PERSON MEETINGS

Our goal at SABC is to broaden the impact and scope of our support groups by increasing the availability of in-person meetings. We encourage people living with scleroderma to reach out to their Community Reps or to the Support Group facilitators if they are interested in having in-person meetings. Please see the SABC website for the list of Community Reps and their contact information.

## WHAT DO I NEED TO JOIN A ZOOM MEETING?

To join a Zoom meeting, you will need a computer, tablet or cell phone. If you are on our membership list, you will receive an email invitation in advance of each meeting with a link to register. You can also register by visiting the SABC website under Events-Virtual Support Meetings and click on the registration link. If you are unfamiliar with this technology and would appreciate some help in becoming proficient, please email **info@sclerodermabc.ca**. They will connect you to one of our team members who would be more than happy to help you. For those who do not have Internet, it is still possible to join a Zoom meeting by telephone but please note that would incur long-distance charges if you do not have a long-distance phone plan.

## WHEN DO SUPPORT GROUPS MEET?

Our Come Zoom With Us meetings are usually once a month with a break in August. We usually meet midweek in the evening. For more details, check the SABC website.

## HOW CAN I BECOME A LEADER OF A SUPPORT GROUP?

SABC is always recruiting support group facilitators for both in-person and Zoom groups. Many facilitators find this volunteer commitment contributes to their own well-being. There is great value in using our talents such as organization, communication, and compassion to support others. SABC requires our facilitators to participate in and receive certification from the SPIN-SSLED (Scleroderma Support Group Leader Education) Program. It is especially important to our association that leaders feel affirmed and supported in their volunteer work and this program provides a solid foundation.

If becoming a facilitator interests you, we suggest you participate in a Come Zoom with Us session to learn how these groups function. Subsequently, please contact your support group facilitators or SABC to start the SPIN registration process. Most groups have co-facilitators to ensure ongoing collaboration and support.

## THANK YOU

Many thanks to all the volunteer facilitators who have pioneered the SABC support groups over the last forty years. Sincere thanks to SABC volunteers who make these groups possible by providing the structure within which the groups can thrive. Special thanks to SPIN and Brett Thomas for developing the SPIN-SSLED program that equips leaders to develop healthy support groups.

## IN CONCLUSION

Joining a support group can be a real help to many people living with scleroderma. Sharing with others who have the same condition reduces the feeling of isolation. Groups offer a safe, positive, and confidential space to share concerns and learn more about coping with the disease. Members experience increased hope and resilience. Facilitators are well-trained and supported under the supervision of SABC. There are well defined guidelines for group members which help maintain the quality of the interactions. If you are interested, please contact SABC by phone at 604-371-1005 or by email at info@sclerodermabc.ca for more information. We are looking forward to hearing from you.