

Scleroderma Foundation Michigan Chapter

Parents of Children with Scleroderma Support Group

As a parent, you'd do anything for your child. When you found out your little one had scleroderma, you were likely filled with some shock, confusion and fear. Maybe you didn't know what scleroderma was. Or its effects. Or what it would mean for your child's future.

Luckily, the Scleroderma Foundation Michigan Chapter makes it our mission to increase awareness, raise funds for research and build support.

To help Parents of Children with Scleroderma, we're excited to announce our newest support group designed specifically for you. This group joins a collection of existing groups throughout the state. Each week, we'll focus on a different juvenile scleroderma topic – from social interactions to dietary tips.

It's our hope that you'll join us, ask questions, find comfort, and leave with a sense of hope and support for your child.



DATE

- 2/6/19** [My child's not different, scleroderma is](#)
- 4/3/19** [Helping your child navigate the educational system](#)
- 6/5/19** [Navigating the scleroderma medical community](#)
- 8/7/19** [Cooking with creativity for the scleroderma child, eating healthy and still fitting in with friends](#)
- 10/2/19** [Medications and the side effects: finding the best way to help your child cope](#)
- 12/4/19** [Anger, sadness and all those emotions you may be feeling: what to do with them?](#)



TIME

7:30 - 9:00 p.m.



LOCATION

Please visit the "Support Group" page on our website,

Scleroderma.org/Michigan to register



CONTACT

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2019 Parents of Children with Scleroderma Support Group Agenda

My child's not different, scleroderma is

- I. Welcome remarks (5 minutes)

 - II. Opening ice breaker (20 minutes)
 - Reflective question: "How do you help your child manage scleroderma related changes to his/her body and the emotions that come with the changes?"

 - III. Education (20 minutes) **Helping your child adjust to the changes that having a chronic illness can bring**

 - IV. Helpful tips (10 minutes)
 - What tips do you have for dealing with bullying and teasing that your child encounters?
 - Open discussion about helpful tips for buying the right clothing for a scleroderma patient

 - V. Mindful moment: A take away until we meet again (5 minutes)
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2019 Parents of Children with Scleroderma Support Group Agenda

Helping your child navigate the educational system

- I. Welcome remarks (5 minutes)

 - II. Opening ice breaker (20 minutes)
 - Reflective question: "What is the biggest obstacle you are facing with your child's school system?"

 - III. Education (20 minutes) **Working with your child's school**

 - IV. Helpful tips (10 minutes)
 - Open discussion about helpful tips for scheduling medical appointments around your child's academic and extra curriculum needs.

 - V. Mindful moment: A take away until we meet again (5 minutes)
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2019 Parents of Children with Scleroderma Support Group Agenda

Navigating the scleroderma medical community

- I. Welcome remarks (5 minutes)

 - II. Opening ice breaker (20 minutes)
 - Reflective question: "What have you found is the most challenging aspect about communicating with medical professionals about scleroderma and your child?"

 - III. Education (20 minutes) **Communicating your child's needs to medical professionals**

 - IV. Helpful tips (10 minutes)
 - Open discussion about helpful tips for preparing you and your child for a doctor's appointment.

 - V. Mindful moment: A take away until we meet again (5 minutes)
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2019 Parents of Children with Scleroderma Support Group Agenda

*Cooking with creativity for the scleroderma child, eating healthy
and still fitting in with friends*

- I. Welcome remarks (5 minutes)

 - II. Opening ice breaker (20 minutes)
 - Reflective question: "What recipe/food have you found to be your child's favorite since being diagnosed?"

 - III. Education (20 minutes) **Managing your child's dietary needs**

 - IV. Helpful tips (10 minutes)
 - Open discussion about helpful tips for preparing meals that your whole family will enjoy and will meet the dietary needs of your child with scleroderma

 - V. Mindful moment: A take away until we meet again (5 minutes)
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2019 Parents of Children with Scleroderma Support Group Agenda

*Medications and the side effects: finding the best way
to help your child cope*

- I. Welcome remarks (5 minutes)

 - II. Opening ice breaker (20 minutes)
 - Reflective question: "How do you as a parent handle the emotional effects of watching your child manage her/his medication regimen?"

 - III. Education (20 minutes) **Helping your child manage medication side effects**

 - IV. Helpful tips (10 minutes)
 - Open discussion about helpful tips for finding the most accurate information about your child's medication.

 - V. Mindful moment: A take away until we meet again (5 minutes)
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2019 Parents of Children with Scleroderma Support Group Agenda

*Anger, sadness and all the emotions you may be feeling:
what to do with them?*

- I. Welcome remarks (5 minutes)
 - II. Opening ice breaker (20 minutes)
 - Reflective question: "What is the hardest part of having a child with scleroderma?"
 - III. Education (20 minutes) **Working through your emotions**
 - IV. Helpful tips (10 minutes)
 - Open discussion about making time for yourself as a caregiver
 - V. Mindful moment: A take away until we meet again (5 minutes)
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