

So You Want to Start a Celiac Support Group?

By Heather M. Cline

Former President of the Oklahoma Celiac Support Group

I was diagnosed in 1996 when “celiac” and “gluten free” were still foreign words. I remember the first conversation I had with a fellow Celiac. I sat on the floor in my bedroom, confused and overwhelmed, listening to the kind voice on the other end of the telephone talking me through gluten free condiment options. She introduced me to our local support group and within a few years, I was standing as the president.

Support groups serve a great purpose of providing grass root support from others in a similar situation. This is priceless for newly diagnosed Celiacs and those who love them. There can be an initial overwhelming sense of confusion and helplessness. The good news is that even though there is a learning curve, it gets much easier! And local support groups can be a huge help in the process.

Whether you want to start a support group or improve an existing one, these tips can help get you motivated and succeed.

1. **Is there a need for a support group in your area?** Evaluate the local community’s needs and see if there are any support groups already in place that would suit your needs. If there are, you should consider joining forces; all support groups need new, energized members willing to make a difference. If not, proceed full speed ahead.
2. **Are you up for the job?** Starting and running a support group is big responsibility. Some things to consider before you decide to take on the responsibility of being a support group leader are:
 - A. Time Commitment - Do you have the necessary time to plan and publicize the meetings, coordinate special events, and talk with individual members who call with problems or questions?
 - B. Personal Commitment - Are you committed to attending the meetings, even if you are busy or having a bad day?
 - C. Leadership Qualities - Are you comfortable in front of a group? Are you assertive enough keep the meeting on track, while being kind enough to create a supportive environment?
 - D. Positive Attitude - Do you maintain a positive, encouraging and hopeful attitude?

- E. Flexibility - Are you a good listener and flexible enough to heed criticism, warranted or not.
- 3. Build an Army.** Leading a support group is a lot of work. No matter how dedicated you are, there will be times when you cannot attend the meeting. You need to have other dependable people who will substitute for you when you are unavailable. Building an army of volunteers who share the same passion for helping other Celiacs as you do, allows you to divide responsibilities, both behind the scenes and at the meetings. Surround yourself with solid individuals who share the same qualities of a good leader and the same philosophies and goals for your group.
- 4. Game Plan. Covering the basics: Who, What, When, Where and Why.**
- A. Who? This is easy - a support Group for Celiacs and those who love us.
- B. What? You need a name that identifies your group and what you are.
- C. When? Meetings can be quarterly, bi-monthly, or monthly. Remember it is better to start slow and gain speed than the reverse. You will need to determine the day of the week and time of day you want to meet.
- D. Where? You need to find a good, reliable meeting place. Churches, hospitals, gyms and local libraries are all good options. You will want to find a space without charge, if you can.
- E. Why? Why you are forming a support group is a very important consideration and may be the most important question of all. Most groups want to educate and encourage members. Beyond that, do you want to spread awareness in your community or work to change policies relating to Celiac Disease, or raise funds for research. This is the time to set your beginning goals for the group. It is best to start small and expand your goals as your members express an interest and show a willingness to participate.
- 5. Meeting Format.** You need a simple meeting plan. Providing a written agenda at the beginning of each meeting keeps everyone on topic and time. A sample meeting plan follows:
- Meet and Greet - 30 minutes (time to chat and get to know each other)
Meeting Begins (promptly)
Welcome, Introductions, Announcements - 15 minutes
Program - 20 minutes
Questions and Answers - 10 minutes
Adjourn to gluten free refreshments provided by members

It is important that meetings always start and end on time. People will quit coming if meetings drag on or are boring. You have to be in charge and keep the meeting moving along and on time. In the beginning members may come and go but if you keep at it, you will eventually have a small core group that is always there.

6. **Provide written information to your members.** Prepare a hand out that includes contact names, phone numbers and e-mail addresses and a REMINDER of when the next meeting will be held. Encourage your members to talk with each other between meetings.
7. **Be Consistent.** Keep your meetings at the same place, same time and day. Have your meeting, whether or not any outside guests show up. Sometimes it takes time to start getting people to come on a regular basis. Be patient and stay encouraged! Bring new and fresh ideas, new guest speakers and have a written plan for each meeting to keep everyone on track. Keep it lively and interesting so the members look forward to together.
8. **Partner with a national Celiac group.** There are several national chapters that instantly legitimize your support group and can provide a lot of information and resources. These include: The Gluten Intolerance Group (GIG), Celiac Disease Foundation (CDF), American Celiac Society (ACS), and Celiac Sprue Association/United States of America (CSA/USA).
9. **Publicize your Support Group.**
 - A. Local newspapers may have a section for meeting and event announcements. Talk to a reporter or editor from the health, food or nutrition department to see if he/she would be interested in doing a feature story about how your illness has changed your life and why you are starting a support group.
 - B. Some radio stations, particularly in smaller towns, will announce meetings and events for local support groups.
 - C. Flyers. Create a simple flyer announcing your Support Group Meeting and distribute it to local churches, hospitals, pharmacies, doctors' offices, health food stores and public bulletin boards.
 - D. Online. A web site is a terrific resource for your Support Group. If you cannot create your own web page, find someone who can (a son/daughter, niece/nephew, neighbor, fellow Celiac).
 - E. Blogs. Blog about it. It's quick, easy and free. Check out blogger.com. or wordpress.com.

- F. Social Networking Sites: Sites such as Facebook are a great way to relay information about your Support Group. Interested persons can “like” or choose to join your Facebook group and actively participate by posting on the site.
 - G. Word of mouth. This may be the best publicity of all. Encourage all of your friends, family and fellow Celiacs to spread the word by telling everyone about your support group.
- 10. Programs.** Good, educational programs are the lifeblood of a support group. Contact local professionals about being a guest speaker. You can start with your own doctors and health care professionals. As the support group leader, it is your responsibility to serve as the gate keeper for your support group. Be sure that every speaker understands Celiac Disease and that Celiacs have to be on a strict gluten free diet for life. (You might be surprised at some professionals misconceptions about Celiac Disease.) It is a good idea to provide your speakers with a copy of basic information concerning Celiac Disease at least one week before your meeting. This will alleviate any concerns your speaker may have and ensure that your members are receiving accurate information about Celiac Disease.

It takes a very special person to reach out to others to make their gluten free journey a little easier. Support groups fill important voids in people’s lives and serve a very important role in a Celiac’s life. Thank you for making a difference!

Source: http://glutenfreeworks.com/So_You_Want_to_Start_a_Celiac_Support_Group.pdf

Author Information: Heather Cline

Heather Cline is the Former President of the Oklahoma Celiac Support Group. She is a dynamic leader in the celiac disease community and a practicing attorney in Oklahoma where she lives with her family.

www.OKceliac.com

Copyright © 2010 Heather M. Cline. All Rights Reserved.