A Guide for Developing Cancer Support Groups in Rural Counties

A Case Study from the Polk County Cancer Support Group Mena, Arkansas

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Acknowledgements

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Purpose of This Guide

The guide will serve as a useful tool to help guide a person or an organization in developing a cancer support group in a rural community. One word of advice is never give up! There is always a way to make things happen. Remember, community support and partnerships are the keys to a successful group. A rural community is a little different; you have to grow your group by supporting it and putting in time to make it strong. Start with a good foundation. For example, draft bylaws, create an organizational chart and put policies in place. Remember that cancer is a touchy subject. Some people do not want to open up about their cancer, some want to cry with you, and others just want an ear to listen. You have to be a good listener and know that on some days, it is okay to cry as a group. Another important thing to remember is that Rome was not built in a day. Making change in a rural community takes time.

How We Got Started

The PCCSG got started because my mother had kidney cancer, and my mother-in-law had breast cancer. I had been a member of the ACC since 2008 and attended meetings. I heard people talk about the support systems that were in place across the state and thought to myself:

“Why not start a cancer support group in Polk County? For a rural community we have some of the highest cancer rates in the state.”

Next, I wrote a mini-grant to the ACC to host a breast cancer awareness event called “Puttin’ on the Pink.” I wanted to test the waters to see how many cancer survivors would attend the event. It was a good way to see if the community was ready for a cancer support group, and what kind of support the group would receive, if any.

There were four community-based organizations that supported the event: Healthy Connections, Inc., Union Bank, Rich Mountain Community College and Mena Regional Hospital. The bank and community college were very unlikely partners. However, the key was to understand our community’s demographics and knowing these organizations had customers and employees fighting cancer, some who were survivors, and others who had passed away from cancer.

Knowing that the group had strong community support was an indicator that we were ready for a group.

The first meeting of the PCCSG was held in January 2012, just two months after the Puttin’ on Pink event. We have met every month since.
Cancer in Polk County

Polk County has some of the highest cancer mortality rates in the state. According to the Arkansas Department of Health’s 2011 Arkansas Cancer Facts and Figures, female breast cancer and lung cancer rates were 10 and 3 percent higher than the statewide prevalence respectively.

*Polk County also ranks high in its rates of tobacco use which is a part of the culture.*

We have the seventh highest number of adult smokers in the state according to the 2013 Arkansas Epidemiological Report, while the average age of a first time tobacco user, according to 2011 APNA data, is age 12.

Managing a Cancer Support Group

Organizing the Group

The PCCSG has registered to be a 501c3 nonprofit organization. The group decided this would help get larger donations that could serve as tax deductions for companies. It is important to have officers and committees help in governing the support group as it needs to be run like a business.
Having an open mind is the key to keeping a good group.

We also vote on issues and have to have a majority to do so. Bylaws have been very useful in keeping the group in order.

Having rules and regulations to fall back on is critical.

When we drafted the bylaws it was on the understanding that they could be changed. We have a board that has term limits as well. Different members serve different term limits so that we never have to start with a brand new board. Bylaws help with the overall structure of the group and serve as our foundation.

**Attendance at Group Meetings**

The PCCSG is only open to cancer survivors, people going through treatment, and cancer caregivers. It is a tough rule, but no one else is allowed to come to the meetings unless they are a guest speaker. This keeps meetings and personal health discussions private. We have a rule among all members that what is said in a group meeting stays confidential among members.

We have our meetings every third Thursday of the month. The board meeting starts at 4:30 p.m. to 5:30 p.m. and then the support meeting follows.

The meetings are posted in the two local papers and on the radio. We also let people know about the meeting through Facebook, and there is an email reminder sent out the Monday before the meeting. If someone does not have email, then a friendly phone call reminder is made.

The meetings are also held on a neutral ground at the local bank’s community room. There are agendas for both meetings.

We average 15 people in attendance at each meeting and have 29 members.
**Raising Funds**

Finding funding sources for the group is not easy.

*Thinking outside of the box and having partners help us fundraise has been a huge success for the group's efforts.*

Having one large fundraiser a year works for this group. We also do small fundraisers throughout the year. We let people know that their money stays in the community and helps local community members. This helps with funding because people like to see the money that they have worked hard for go to local community members.

Living in a rural community like Polk County, everyone knows or has heard of everyone who lives here. Everyone in Polk County has been touched by cancer in one way or another. This also makes it easier to raise money or ask for community support.

**Civic Membership**

*Becoming a part of the local Chamber of Commerce is important in a rural community.*

It keeps you connected to what is going on and helps get the name of the group out to the public. It costs us $50 a year. The chamber sends out emails through its listserve which helps let their members know what events are going on and where they are; it has been a big help in growing our group. The chamber also lets local businesses know that the PCCSG is vested in the community, which makes businesses more likely to help out.

**Promoting the Group**

The support group’s events and meetings are marketed in multiple ways: through local newspapers, social media, radio, community events, cancer awareness events, the local oncologist at Healthy Connections, Inc., the chamber, the local faith-based community and through word of mouth.

*Having a good working relationship with the local media helps to get media coverage.*
Services Offered

The PCCSG works with local organizations and state support groups to help fill the needs of cancer patients going through treatment.

A lot of the time only a small number of people can receive treatment in Mena because the oncologist only comes to HCI once a week. Additionally, HCI can only provide chemotherapy treatment. If radiation is needed, patients have to go to Fort Smith, Hot Springs or Little Rock. This makes having cancer in a rural community even more difficult. Not only are families dealing with a cancer patient, they are also struggling with out-of-town travel, food costs and overnight stays, if their patient needs treatment more than once a week or takes radiation treatment.

This is why being a part of the ACC really helps. Our group can find the services that others provide and connect the dots.

There are also local groups that step in and help provide services such as meals, transportation, wigs, and funding for other needs such as electricity bills. The PCCSG itself also tries to fill these needs from its own resources, including paying for truck payments, water bills and meals for families with children. We try to help take these burdens off the family and person with cancer so that their main worry is winning the fight against the disease.
Hosting a Cancer Awareness Event

Hosting our first cancer event, Circle of Hope, was not an easy task. There are many months, weeks, days and hours that go into planning the event. Below is a checklist that can be used to organize your event.

- Develop a work group to help plan the event and know that hosting an event takes lots of time and effort.
- Make sure you have an educational section as part of your agenda.
- Get a speaker who can appeal to your members and audience.
- Open the event to the whole community.
- Send special invitations to survivors and those you know going through treatment. It gives a personal touch.
- Have good strong partners to help with food and media costs, and to help set up and clean up. That way, everyone can get some good free public relations in the community. Every CEO loves to receive free public relations, especially if they donate space or services.
- Make sure you get pre- and post-media coverage. You need media coverage to get people there, to thank everyone for coming, and to thank your sponsors.
- Make sure you send out a sample agenda so those helping to work the event can keep things running smoothly. Don’t worry if the agenda changes.
- It is okay if the event does not go as planned. Sometimes this is a hard lesson to learn.
- Make sure you pick a location that has space for both the event and parking.
- If the event is outdoors always have a backup plan in case it rains.
- One of the lessons learned is that you should have fun. Do not show worry at an event, because your guests will see that you are worried and feel uncomfortable. Something unplanned for is often bound to happen.
- Always have a follow-up meeting to see what can be done better next time. That is the key to having a great event next time.
Challenges Faced by the Group

The PCCSG faces many challenges:

1) Some members feel that there is a stronger focus on breast cancer than any of the other cancers. So the PCCSG works hard to engage members with all types of cancer. This seems to be our biggest challenge.

2) It is hard to get men to attend support groups in a rural community.

3) It is difficult to get people to understand that after you register as a 501c3 nonprofit organization, you have to run the support group as a business.

4) Having people in the group know that their ideas and thoughts are heard is difficult.

5) Letting the group make a mistake that you already know will not turn out well is challenging.

6) Knowing that you are not always going to make everyone happy in a group and knowing that some people will always be negative is a challenge.

7) Keeping everyone engaged in a meeting is difficult.

8) Losing members to cancer is one of the hardest things the group faces.
Successes

The group’s successes are that it has been in existence for almost two years and continues to grow. We share in each others’ victories, and like a family, want the best for each other. The group has also built a strong system of community support.

We plan on making the Circle of Hope - our first public event- a biannual event, changing the meeting time from early in the morning to late in the afternoon or evening. We will also host it on a different day and have it in a different location like at Healthy Connections, Inc., or the local community college. For our first meeting, we sent out over 500 invitations, and used all three papers and radio to promote it. Unfortunately, only 50 attended the event. So, the group is willing to make modifications to make the event even bigger and better. The group is even talking about changing the name of the event to make it more descriptive. The good thing that came out of the event for the group is that two women who were in attendance subsequently attended a PCCSG meeting and then joined the group. They learned about PCCSG during the Circle of Hope event.
Future Plans

Our future plans are to grow the group, and keep raising funds to help more people in Polk County with cancer. We know that some of our members are living on borrowed time, and it makes us happy to see each other once a month.

Group members teach each other to enjoy life and to be thankful for what they have.

We hug a lot, laugh often and shed tears. Group members worry about each other like they belong to one family. We celebrate in the joys and successes that we, our children and grandchildren have. We smile and have a good time. As many of the members say, “Life is too short to waste time doing things that you do not love.”

The PCCSG has lost members, some members have had their cancer return, and some have beaten cancer. The group offers support, love and celebrates life and living. Our members could not ask for more!