



Simplifying it

Guide to Creating Local Fibromyalgia Awareness Events



National Fibromyalgia & Chronic Pain Association™

In This Issue

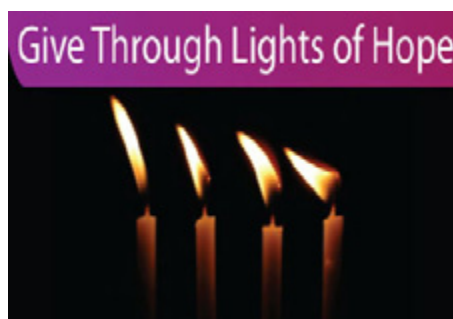


May 12

National Fibromyalgia Awareness Day Events How-to-Guide

Supplement to Fibromyalgia & Chronic Pain LIFE

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On our cover: (l-r) Joseph M.Pizzi, Ashley Rae Pizzi, and Dianne M. Pizzi at the Philadelphia Walk to CURE FM 2011 that Ashley organized last year to raise FM awareness in her community and as a fundraiser for the NFMCPA. [Read more...](#)

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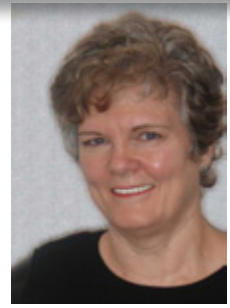
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Taking the Stress out of Creating a May 12 National Fibromyalgia Awareness Day Walk to CURE FM or Event

Create a great event from the start with good ideas and a solid plan. This event guide helps the beginner and the experienced planner with remembering walk/event details in the planning stages. We hope you see yourself hosting a local event!

Going to Willow Park with family and friends from our local support and education group is my favorite way to spend the second Saturday in May. The willow trees are still leafing out and the children run through our event to get from the playground to the small zoo. Our local walk has grown from four years ago when we started with a few families and a picnic lunch after a mile long walk by the river. Our detailed planning notes, check-off sheet and summary critique shortly after each year's walk became invaluable as stress busters when preparing the next Walk to CURE FM.

We think you'll like this May 12 National Fibromyalgia Awareness Day event guide. Comprehensive, time-tested, and full of ideas for a few or many people to gather and raise awareness of fibromyalgia. And to just have fun! This solid planning guide represents a significant amount of time, intellectual property contribution, and effort from many people far and near over the years. If you would like to use our copyrighted material in another publication or in reproduction, please contact us. We want to help you build successful fibromyalgia awareness events.

Please let us know about your May 12 National Fibromyalgia Awareness Day events. We like to share great ideas with others!

Best wishes for a more comfortable tomorrow!

Jan Favero Chambers



May 12, 2012

The NFMCPA Guide to Creating Local Fibromyalgia Awareness Events

**YOUR
EVENT CAN BE ANY
SIZE
OR
SHAPE.
MAKE THIS THE YEAR THAT YOU
DECIDE TO MAKE FIBROMYALGIA VISIBLE
IN YOUR COMMUNITY!**

FIBROMYALGIA AWARENESS DAY



National Fibromyalgia & Chronic Pain Association

Our Fibromyalgia Awareness Day theme is “Make Fibromyalgia Visible.” This program is designed to reach isolated people affected by FM and improve public understanding of fibromyalgia. By incorporating this theme into your awareness day activities, you are helping to rally the fibromyalgia community around this common message.

To access download versions of the “Make Fibromyalgia Visible” logo for use in your event materials, [click here](#).

IF NOT YOU, THEN WHO?



STEPS TO GET YOU READY

GETTING ORGANIZED

No matter what the size is of your event, it is always easier to work with a team who can share in the responsibility, creativity and satisfaction that comes from a job well done. Consider forming an Organizing Committee to share in the fun and responsibility of creating your event. Remember, committee members may or may not be members of your support group--or even have FM! Enlist the assistance of friends, families, and healthcare providers. It may be especially helpful to include someone who has participated in charity walks or runs before.

Q Event Chairman -- helps to keep the committee on task and sets forth the vision and objectives for the overall event.

Q Fundraising Chair -- designs a plan to request financial support from local businesses and individuals to support the cost of the event, and to raise donations to support the NFMCPA. The plan should include steps for others to make requests of support too.

Q Logistics Chair -- designs a plan and oversees the physical structure of the event.

Q Registration -- managing the registration process leading up to the event, and on event day.

Q Publicity -- everything from flyers, emails and press releases to help get the word out.

Q Site Coordinator -- works with the venue and volunteers to design what the event will look like (maps, routes, water, signage, etc.).

Q Volunteer Coordinator -- secures needed volunteers for the event from set-up to clean-up.

Q Traffic Management -- works with the local government to make sure participants are safe at all times, coordinating possible street closures, security, etc.

Q Exhibitor Coordinator -- works with vendors to coordinate their participation in your event (sampling booths, etc.).

Q First aid and other services -- coordinates staffing of first aid station and emergency protocols.

Q Entertainment Coordinator -- works to make the event memorable (local celebrities, cheer squads, face painting, etc.).

MAY 12TH NATIONAL FIBROMYALGIA AWARENESS DAY

DESIGNING YOUR EVENT

Following are some questions to help begin your conversation about a May 12 National Fibromyalgia Day event or Walk to CURE FM:

What is the purpose of your event? Do you want to simply raise awareness about FM, or do you want to raise money for the cause?

How many people will the event attract? Based on your anticipated attendance, you will need to search out a venue that can handle your crowd. Consider the comfort of your participants with FM when selecting a location.

When and where will the event be held? You are welcome to plan your event for a date and time that makes the most sense for your community -- however, National Fibromyalgia Day is May 12th, which is when national media will be talking most about fibromyalgia. Your event will enjoy the most “buzz” when being reinforced by these larger media outlets.

Q DIVIDE AND CONQUER! Depending on the size and scope of your event, you may want to put individuals in charge of different aspects of the event. The following brief job descriptions may get you started thinking about how to organize. Maybe one person can take on two or more tasks. Still others may need more than one person, or even a sub-committee to take it on.

If your event will be outdoors, avoid holding your event during the hottest time of day, which may be unwelcoming to FM patients. Outdoor events typically are the most vis-

SELECTING A VENUE

Does your community have an active management center, or is your support group bigger than 50 people? If so, your event has a potential to attract hundreds of participants and spectators; be sure that you choose a venue that can handle such a crowd!

5-50 Attendees: Gathering at a community center, support group meeting space, park or public area is suitable. Permits may not be necessary. A high-traffic indoor or outdoor shopping area might also be a good consideration.

5-250 Attendees: Park, schools, churches and public areas are suitable. Parking needs and restroom facilities should be considered.

250-500 Attendees: Regional shopping centers, regional parks and colleges are suitable. In addition to the considerations above, you should include security, first-aid and traffic control.

500 or more Attendees: At this size, you should consider contracting with an event company to provide staging, signage and audio needs.

Will your event include a wellness fair? Be sure your venue has an appropriate location for exhibitors to set up booths. Don't forget to consider how many hours your

event is likely to last, and what time of day is likely to attract the most participation.

Determine the type of Walk to CURE FM you are holding. How many miles, laps, or hours? Will we need to work with local law enforcement to close off streets temporarily, or will our walking course be self-contained? Will we have enough volunteers and/or signage to direct our participants?



Things to consider when choosing a location:

Be creative! Think about high school tracks, elementary school play fields, sports arenas, even malls or shopping centers. Does anyone on the organizational team know a member of management at one of these venues? If not, look up the venue phone number and put in a call to discuss holding your walk there.

Consider these factors as you narrow down your location choices:

- Is the location conveniently located so participants and sponsors can easily access it?
- Is it available for use on the date of your Walk to CURE FM?
- Are there electrical, water, and restroom facilities?

- Is there sufficient parking, and is it easy for cars and people to flow to and from the location?
- Does the location fit with your type of walk and is the path easy to navigate?
- Are there accommodations for the elderly and disabled?
- Are there accommodations for the elderly and disabled?
- Is the cost of reserving the location within your budget, or can you negotiate a lower price or free use of the location?
- Do regulations of the location prohibit any of your plans, for instance, will exhibitors be allowed to sell products?
- Are there adjacent property owners whose permission you will need if you if the Walk impacts their businesses due to foot or vehicle traffic?
- Is there a newly completed housing or commercial development who may want to show off their project to the public?

POSSIBLE WALK TO CURE FM EVENT AGENDA:

8:00 to NOON: WELLNESS FAIR
6:00 VENDORS SET-UP
7:30 WALKERS REGISTRATION
8:30 OPENING CEREMONY
WELCOMING REMARKS
"PASSION" TESTIMONY
9:00 WALK BEGINS
10:00 AWARD PRESENTATIONS
11:00 FEATURED SPEAKER/PERFORMER
11:45 AWARDS & CLOSING CEREMONY

Q Establish a budget, if needed.
Don't forget to develop reimbursement policies. Be specific! Consider these expense as you expenses as you develop your budget.

- Location permits or usage charges (check with site management, health department and law enforcement)
- Insurance policy
- Equipment (tables, chairs, canopies, etc.)
- Flyers, T-shirts and other event-related materials

Q Develop a timeline.
What time of day will your walk or event take place?

How many hours will you need your walk venue? If you are also hosting a wellness fair, will it be open the same hours as the walk, or will the schedules differ?

Q Contact your local law enforcement agency or city to find out about local ordinances that may impact your event. Be sure to obtain any necessary permits.

Q Find out about insurance coverage. Ask the location property owner and the city what their insurance requirements are then contact your insurance agency to get the policy (the appropriate policy will differ, depending on whether it is a group, nonprofit or an individual purchasing it). In some cases, your facility may be able to add your event on a temporarily "additionally insured" activity.

REGISTER YOUR EVENT on *FMcpAware.org*

Once you have booked your venue, be sure to **register** your event or Walk to CURE FM on FMcpAware.org. Your event will be added to our list of events which is available online to all our constituents.

- **Click here** to access information about 2012 walks and events."
- If your Event *WILL NOT* include fundraising, complete and return the **External Events Agreement**.
- If your Event *WILL* include fundraising, complete and return **Fundraising Event Form**.




APPROACH POTENTIAL SPONSORS AND EXHIBITORS

Businesses, civic and community organizations, and foundations are a good source to help finance, publicize or even organize your Walk to CURE FM. You may want to create a list of benefits for the sponsorship (booth space at your event, logos on shirts and signage, opportunity to put items in participant goodie bags, etc.). Based on your facility permits, determine if vendors may sell food, provide samples, etc.

The management of your local sporting-goods or running store may be accustomed to helping local groups organize walks/runs (there may be a fee involved). You can approach businesses in your area for donations of water, energy bars, and other items to be given to walk participants. Athletic stores, fitness clubs, massage therapists, and doctors' offices, chiropractors, hospitals, pain clinics, libraries, and community centers are all great locations to pin up fliers and help publicize your event.

When working to secure sponsors it is customary to provide them with a written letter of request and a list of sponsor benefits. Be clear on what you are asking for:

a financial donation;
in-kind/donated product or service; or
or assisting with publicity (locations to hang poster, etc.).

 **Keep an organized list of sponsor solicitations**, who you spoke to, and be sure to follow up with phone calls and face-to-face requests. Your list of sponsorship prospects may include:

- Local hospitals - health promotions department may perform health screenings
- Food and nutrition departments may provide a dietitian to work at a booth
- Pain clinics
- American Heart Association, American Lung Association, American Diabetes Association and other groups may perform screenings or provide information
- Local fitness vendors, including sporting goods stores, running stores, fitness centers, massage therapists, chiropractors, etc.
- Local health food vendors. Think beyond health food stores--try your local grocery store, too
- Local occupational clinic or physical therapy office
- Local businesses may be willing to provide goodies to walk participants
- Local police and fire departments
- Local nonprofit or community organizations
- Bottled water may be donated by a local grocer or water distributor
- Waste management (to provide standing waste boxes and bags)
- Photographer (team photos, event photos, etc.)

Q After securing a sponsor, be sure to follow up with written confirmation, a thank-you, and the details of the event, including the date and location of your event, set-up and tear-down time, general guidelines, and reminders to bring any special equipment they may need such as extension cords, adapters, etc.

MAKE YOUR EVENT MEMORABLE

Q As you are planning your event, think of things that will be your “highlights,” those things that your participants will be talking about for days to come.

Think about why people are coming to your event. They may suffer from FM, know someone who has FM, or want to learn more. Provide experiences that are directed to each of those populations. Experiences that evoke emotion such as laughter, joy, passion, pride and even tears can raise the spirit of your event in ways. Businesses, civic and community organizations, and foundations are a good source to help finance, publicize or even organize your Walk to CURE FM. You may want to create a list of benefits for the sponsorship (booth space at your event, logos on shirts and signage, opportunity to put items in participant goodie bags, etc.). Based on your facility permits, determine if vendors may sell food, provide samples, etc.

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Develop a list of local officials or celebrities to invite to your event. If you have requested a proclamation from the mayor, governor, senator, or other official, invite those individuals to present the proclamation at your event.

- Reach out to local TV and radio personalities, athletes, cheerleaders, costumed mascots, local pageant queen, etc. Your celebrities can be used as your event emcee, photo opportunities, autographs and help to create a general excitement about your event.

- Invite your local ROTC, police or fire academy or military branch. They make a very inspiring presence jogging in formation, and it's great PR for them.
- Create a "Butterfly Garden" -- using the butterfly theme of the NFMCPA, cut out paper butterflies, and ask people to write a personal message about FM on it. Display the butterflies for your participants to enjoy. Or consider selling paper butterflies to raise funds.
- Orchestrate a live butterfly release as a part of your opening ceremony.
- Plan a "Lights of Hope" ceremony using battery powered candles at your event closing. Each candle represents a person at your event with FM.
- Post signs about FM along your walk route or in your wellness fair.
- Plan an exhibit of arts and crafts created by FM patients and caregivers -- expressing what it means to them living with fibromyalgia.
- Use the Pledge to Care with participants--Pledge for Family and Friends, Pledge for HCP, Pledge for Individuals.

ENTERTAINMENT

Make your event more fun and memorable by providing entertainment. Consider providing entertainment in your event staging area/health fair and on the route.

- On your stage: a soloist to open with the "Star Spangled Banner," a walk warm-up session with local gym instructor, a live band.
- In your festival area: a marching band to kick off the start of the walk, jugglers, sidewalk chalk artists, clowns, drum troops, dance troops, show cars, face painting, removable tattoos, etc.
- On your walk route: cheer squads and inspirational signage.

PUBLICIZE YOUR WALK TO CURE FM OR EVENT

Q To spread the word about your event, you can design fliers and distribute them among your support group; ask each member to place fliers at the places they frequent--a bulletin board at their place of worship, in their doctor's office, at their favorite stores and restaurants. You may choose to pay for an ad in a local publication, but it's also a great idea to send out "public service announcements" that local radio and cable television stations run at no charge. Fax or email press releases to newspaper and magazine reporters who may choose to write a feature about the event or your support group. Don't forget to send calendar announcements to local publications, your local cable stations, and local radio stations. Be sure to include a phone number or web address to direct people who may have questions about your event. Use the increasing number of on-line resources available, also, such as community calendars, Facebook, e-newsletters, etc.

EVENT DAY SIGNAGE

Q When sponsors, exhibitors, volunteers and participants arrive at your event, **you will want to have signage that directs them efficiently to the correct location.** When placing signage, make sure it is highly visible. Signs in front of tables are great, until you have people standing at your table and blocking the sign. Consider posting signs high enough that they can be seen from a distance. Helium-filled balloons are also eye-catching. Consider the following list of signage needs:

- Directional signs leading to the venue (on the street leading up to the venue, and pointing out parking)
- Check-in area (for participants, volunteers and exhibitors)
- Festival area signage for restrooms, first aid, children's area, etc.
- Exhibitor booth signs
- Signs to recognize top sponsors or fundraisers in your festival area and on the route
- Start/finish line
- Walk route signs (both directional and inspirational). Place volunteers at key locations to keep walkers on the correct path
- Signs to point out important aspects of your event, i.e., "Take the Pledge to Care Here."

EVENT DAY SUPPLIES

Q As your big day arrives, you will want to be sure to have the necessary supplies on hand for everything to run smoothly. Divide your supplies into "teams" so that they can be available where they are needed. Depending upon the size of your event, it might be helpful to divide your supplies up as follows:

- Signage Team (prepared signs and plans of where to post them), hammer, stakes, string, tape, extra poster board, heavy duty staple gun, broad tip marker)
- Registration Team (blank paper, pens, scissors, stapler, paper clips, paper weights, clip boards, highlighters, post-it notes, envelopes, cashier box, first aid kit, etc.)
- Expo Team (brooms, trash cans, extra trash bags, rubber gloves, tape, zip ties, duct tape, ladder)
- Photo Team (clipboard with list of photos to capture such as vendor booths, volunteers, walk teams, mascots, event start, awards, etc.)

PLANNING TIMELINE

2 - 4 MONTHS BEFORE

- Form a planning committee
- Establish a budget
- Develop an FM event day schedule
- Choose event site
- Secure required permits from site management, law enforcement and health department
- Determine insurance requirements
- Contact exhibitor and sponsor prospects
- Book entertainment and celebrities
- Secure vendor for event T-shirts (if applicable)

2 MONTHS BEFORE

- Register your event on the NFMCPA website
- Provide written confirmation to sponsors and exhibitors
- Send out press releases
- Distribute and post event posters in your community, Facebook, community event calendars, etc.
- Recruit event day volunteers

1 MONTH BEFORE

- Contact local media regarding event coverage (before, during or after the event)
- Connect with in-kind/product donors to finalize logistics
- Continue to post event fliers around town
- Make event map (festival area and walk route)
- Review responsibilities with key volunteers for event day
- Gather your event day supplies

- Create and distribute to key volunteers a list of all your important event contacts, including cell phone numbers of vendors, facilities, emergency services, rentals and key volunteers.
- Create a master binder with copies of all permits and event agreements

EVENT DAY

- Arrive in plenty of time to set up your space before participants arrive.
- Direct the activities of the day, and say "thank you" as much as possible (nothing can make your participants and volunteers feel more appreciated than your gratitude and a smile).
- Enjoy the day and know that you have helped to "Make Fibromyalgia Visible" in your community.
- Be sure that your event site is clear of trash and debris.

AFTER YOUR EVENT

- Send "thank you" letters to everyone who participated: committee members, exhibitors, sponsors, media, site management, walk team captains, etc.
- Consider including a photograph in your "thank you." If you are handy with digital photography you can overlay text on a photo to say "Thank you for Making Fibromyalgia Visible in Our Town," or order custom photo greeting cards from your local retailer.
- Consider hosting a "thank you event" to show your appreciation (or better yet, find a sponsor to underwrite it for you).
- Share your event highlights with the NFMCPA at www.fmcpaware.org!

NFMCPA's Pledge to Care

We pledge to:

BE THE VOICE for millions of people suffering with fibromyalgia and to actively advocate on their behalf for an improved quality of life.

IMPLEMENT INFORMATIONAL AND EDUCATIONAL PROGRAMS and provide personal support to offer hope and real solutions to the life-altering challenges faced by people with fibromyalgia, and their caregivers.

CREATE AN ONGOING MEDIA PRESENCE THAT RAISES AWARENESS, communicates facts and changes perceptions about fibromyalgia.

DEVELOP COLLABORATIVE PARTNERSHIPS that will result in continuing medical education programs to help healthcare providers diagnose and treat fibromyalgia patients.

ADVOCATE FOR AND FACILITATE NEW RESEARCH by encouraging government funding, holding scientific research symposia and supporting programs aimed at enticing innovative scientists to focus their expertise on fibromyalgia.

REPRESENT AND HELP EMPOWER INDIVIDUALS with fibromyalgia in order to improve the quality of health care and access to treatment options no matter the patient's circumstances.



"THANK YOU" FOR BEING A FIBROMYALGIA HERO!

Thank you for taking up the call to "Make Fibromyalgia Visible" in your community. We rely on champions like you to be our voice in the community. Through efforts such as yours, you are making an impact where it matters most -- where YOU live and work.

Fibromyalgia is a chronic pain condition that affects an estimated 10 million people -- many of them undiagnosed. On behalf of those who will gain hope and understanding through your event, we say "thank you."

National Fibromyalgia & Chronic Pain Association
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