



## **FSR Sarcoidosis Awareness Month Tool Kit April 2013**

The Foundation for Sarcoidosis Research (FSR), and the FSR Support Group Advisory Council invite you to partner with us to declare April 2013 Sarcoidosis Awareness Month to focus attention on Sarcoidosis and the need for research and to raise the visibility of your work to support individuals diagnosed with the disease.

### **PLAN EVENTS**

Join Sarcoidosis Support Groups around the world by sponsoring special events in your community and publicizing them to patients, media and the public. To see a calendar of events planned for April 2013, visit <http://www.stopsarcoidosis.org/news/events/>.

### ***Wear Purple & White on April 27, 2013***

Join with Sarcoidosis patients and their family and friends around the world and wear purple and white on Friday, April 27, 2013.

### ***IDEAS TO GET YOU STARTED***

Sarcoidosis Awareness Month is an ideal time to promote your support group and raise awareness about sarcoidosis among the public at large. For help in planning an event, contact the Foundation for Sarcoidosis Research and ask for the Event Starter Kit.

- Join us in working toward the goal of having all 50 states and as many towns and cities as possible proclaim April 2013 Sarcoidosis Awareness Month.
- Arrange for interviews on radio and/or TV talk shows or local news shows to publicize Sarcoidosis Awareness Month. Use the interviews as an opportunity to promote your activities and provide specific information on sarcoidosis and sarcoidosis research.
- Offer to provide speakers on sarcoidosis to local service organizations and clubs.
- Create a table or window display at your local public library, senior center, hospital, doctor's office or shopping mall to provide information and raise awareness.
- Encourage your group members to approach their churches, businesses they frequent, and their employers to ask if they can put up an informational table.
- Sponsor an educational program or seminar for health professionals.

- Join us in our purple ribbon campaign. Purple awareness ribbons will be attached to cards that will explain what sarcoidosis is. The back of the cards will be left blank so that groups if they wish may put their contact information on them.
  - Host a candlelight vigil. A candlelight vigil will be a great way for people to gather and show their support for greater Sarcoidosis awareness, hope for a cure of Sarcoidosis and remembrance of those who have lost their battle against Sarcoidosis.
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### **Tips on Organizing a Candlelight Vigil:**

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As far as event planning goes, a candlelight vigil is quite simple to set up. One thing to consider right away is that you'll need help. Ask for the support of family, friends, support group members and co-workers if they would like to volunteer for your candlelight vigil.

The main goal is to aggressively publicize that the vigil will be taking place so you will enjoy a large turnout. These are the things to consider when doing a candlelight vigil.

#### **Location and Time**

The first thing that needs to be decided is the location for the event. Most are held outdoors on public property, like a neighborhood park, or even right in front of city hall. Consider the following things when choosing your location:

- The place should be easy to find for participants from all over town.
- Ideally, you should have an indoor option available in case of bad weather. Indoor vigils can be held in community centers, auditoriums, or legion halls, for example.

Once you've selected a location, choose a date and time that will work for the occasion. Make sure it will be dark enough for all of the candles to have an impact, but not too late at night that participants of all ages would have trouble attending.

#### **Speakers**

To keep things running smoothly, someone should be designated the main speaker or master of ceremonies. This person will address the crowd, and introduce any other speakers who will be on hand. Guest speakers could share:

- Speeches to inform and motivate
- Memories
- Sharing of experiences
- Poetry, prayer, or prose

In addition to speeches and readings, music can be used during the vigil, either recorded or performed live. For speeches and music, you'll need to find audio equipment like microphones, amplifiers, and speakers that are suitable for outdoor use.

#### **Candles**

You'll have to have a supply of candles on hand for participant to light. Order these in advance so that, if it looks you'll end up with a very large turnout, you'll have to get more.

Plain white candles are generally used, but you could consider purple colored candles, or even feature several personalized memory candles. Another suggestion is to utilize flameless candles as they are safe for indoor candlelight vigils. Two companies that sell

flameless candles are Safe Flame Candles ([www.safeflamecandles.com](http://www.safeflamecandles.com) & Battery Operated Candles [www.batteryoperatedcandles.com](http://www.batteryoperatedcandles.com)).

### **Getting the Word Out**

Once you've got everything in place for your event, you'll need to spread the word so that people will be able to attend. There are several ways to advertise your event, including:

- Posting printed fliers in neighborhoods, stores, church bulletins and public bulletin boards
- Utilizing social media such as Facebook, and Twitter
- Utilizing public cable television
- Taking out a small ad in the local newspaper
- Contact local television, radio and newspaper media with details of the event.
- Word of mouth is also an important and valuable source of contact. Tell as many people you can about upcoming vigil, and ask them to tell anyone they know who might be interested in attending.

### **Balloon Releases:**

Balloon releases are another way to generate Sarcoidosis awareness in communities across the country during 2013 Sarcoidosis awareness month.

***\*\*Please Note that you will need to contact your local police department to find out if there are any ordinances that prohibit balloon releases in your area.***

It's important to note that *balloon releases are considered by many to be harmful to the environment*. However, here are some ways you can make balloon lifts more environmentally-friendly:

A good place to begin is by visiting [BalloonRelease.com](http://BalloonRelease.com). This site provides an excellent overview of balloon releases and tips for making them "green," including an important tip for making sure that your balloons are *biodegradable*  
<http://www.balloonrelease.com/faqs.htm>

One source for biodegradable balloons at a reasonable cost is Greenopolis  
<http://greenopolis.com/marketplace/products/100-biodegradable-helium-quality-latex-balloon>

If you plan on attaching ribbons to balloons, make sure that they, too, are fully biodegradable, such as those offered by Sweet Organics and Naturals. They have inexpensive cotton ribbons (such as "Organic Twist: Nature's Gift Accessory" that is beautiful hand-twisted and naturally-dyed paper ribbon, available in multiple colors)  
<http://sweetorganicsandnaturals.com/natural-ribbon.html.com>

If you are looking for *high-impact alternatives* to outdoor balloon releases, please consider the following:

- Plant a tree or a garden to honor victims and survivors.
- Blow bubbles; you can purchase individual bubbles at any Dollar Tree store [www.dollartree.com](http://www.dollartree.com) or at Oriental Trading [www.orientaltrading.com](http://www.orientaltrading.com)
- Drop non-helium-filled balloons from a tall building (this is a great activity to engage children!).
- Release balloons *inside* a building, such as a gymnasium, courthouse or faith institution.
- Release butterflies in lieu of balloons. A wonderful alternative to a balloon release event is a butterfly release. Amazing Butterflies <http://www.amazingbutterflies.com> (800-808-6276) offers release butterflies that are shipped overnight in cardstock boxes (if you visit the website, click on the link for "Live Butterfly Release Brochure" for more information). However, butterflies are *not* inexpensive; ordered in bulk, they are \$65.00 a dozen. Yet they can contribute to a truly eco-friendly event.

#### **FUNDRAISER SUGGESTIONS:**

- Sponsor a fund-raising activity to raise money for research: a yard sale, raffles, silent auctions, pet walks, black tie events, Zumbathons, a walk, a concert, etc. The main thing to remember is that these are only suggestions. We invite you to be creative and do fundraisers that are fun and you feel most comfortable doing.
- As a special service to the community Applebee's, Chick-fil-A and Fazolis will do fundraisers. For more in depth information about these fundraisers please contact your local Applebee's restaurant or go to [www.applecreekusa.com/appfundraising.html](http://www.applecreekusa.com/appfundraising.html). For information about Fazolis restaurant fundraisers please go to [www.fazolis.com](http://www.fazolis.com) click on contact and scroll down to fundraising/sponsorship opportunities. For information about Chick-fil-A fundraisers please go to [www.chick-fil-a.com](http://www.chick-fil-a.com) click on Kids and Family and click on the In Your Community tab.

#### **Distinctive Automobile License Plates:**

Distinctive Automobile License Plates combine fundraising with Sarcoidosis awareness. The application process varies by state. Contact your county department of revenue where automobile license plates are purchased or your state Department of Motor Vehicles to obtain the application process for your state.

A 501(c)(3) nonprofit status with the United States Internal Revenue Service will be needed for the application process.

There will be a minimum number of licensed plates pre-purchased in order to justify the state creating the plates. For instance, the state of Alabama requires that 250

Commitment to Purchase at \$50 each be purchased within a year before the plates will be manufactured.

A percentage of the revenue from license plates sold will go to the specified non-profit organization.

***Please note that there will be specific forms and processes that vary per state.***

### ***How To Get The Word Out:***

Create a press release about Sarcoidosis Awareness Month and the events you have planned to commemorate it. For tips on writing a press release, visit:

[http://www.ehow.com/how\\_8793\\_write-proper-press-release.html](http://www.ehow.com/how_8793_write-proper-press-release.html)

<http://www.prlog.org/tips/1016-how-to-write-a-press-release.html>

See a Sample Sarcoidosis Awareness Month Press Release created by the Houston support group on page 8 of this document. Please feel free to tailor it to fit your activities and needs.

Use all the connections you have to get the word out about the ways you will celebrate Sarcoidosis Awareness Month. Members of your group may work for media outlets or know people who do. Ask them to help develop a public relations plan to publicize your events.

Don't limit yourself to the obvious choices of television, radio and newspapers. Other places to advertise include: community service calendars, church bulletins, sarcoidosis chat rooms, bill boards, Facebook, Twitter, the Foundation for Sarcoidosis Research web site, doctors offices, and hospital waiting rooms. Many communities have local cable access channels which are looking for events like yours to highlight. Someone in your group may have connections with a local radio or television station.

You may want to offer a feature article on one of your group members or any speakers you are inviting to your events to your local newspaper or television or radio stations. Often people who are computer savvy like to produce brochures and flyers. Make sure the members of your group have an ample supply of these to pass out and put on community bulletin boards wherever they go.

### ***Additional Resources:***

Camera-ready artwork with the logos for Sarcoidosis Awareness Month is also available for use on flyers, newsletters and invitations. Contact the Foundation for Sarcoidosis Research at [theresa@stopsarcoidosis.org](mailto:theresa@stopsarcoidosis.org) to obtain a copy of the logos.

Visit the Foundation for Sarcoidosis Research web site <http://www.stopsarcoidosis.org>

### ***After Your Event:***

Send a brief summary of your events along with news reports, photos, etc. to Yvonne James at [yvonnelj3110@aol.com](mailto:yvonnelj3110@aol.com) . All information may be posted on the Foundation for Sarcoidosis website.

### ***Request A Government Proclamation***

Our goal is to have Sarcoidosis Awareness month recognized in all 50 states in the United States and as many countries and communities as possible. The best way to do this is to request a proclamation from your elected officials. (See a Sample Proclamation on page 7 of this Tool Kit.)

### ***Where to Begin***

As soon as possible, contact the office of your elected officials and inquire about the process of obtaining a proclamation. (In the United States, you can find the phone numbers on-line, in the phone book on the government pages, or by calling information.) Be sure to ask about the time line for getting a proclamation issued. The application form may be available on-line or they may ask you to submit a request by mail.

### ***What should you include in your application?***

Be sure to answer fully all the questions on the application form. If there is no form, tailor the sample on page 7 of this Tool Kit to fit your situation.

***What*** - Sarcoidosis Awareness Month, April, 2013.

***Why*** - Brief synopsis of what Sarcoidosis is and why you want to raise awareness. Be as specific as possible about how sarcoidosis affects citizens of your community. Often what you write will be what is put on the proclamation. Include links to credible sources like your group's web site if you have one; the Foundation for Sarcoidosis Research: [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org) and the National Heart, Lung & Blood Institute:

[http://www.nhlbi.nih.gov/health/dci/Diseases/sarc/sar\\_what.html](http://www.nhlbi.nih.gov/health/dci/Diseases/sarc/sar_what.html)

***Who*** - A statement about your group including your mission statement.

Be sure to ask how far in advance the application should be submitted. Ask about the process for requesting someone from the office to present the proclamation to your group. Be sure to offer to provide any additional information needed and give them a contact person with phone number, address and email.

### ***What to do when you're notified that a proclamation will be issued***

Be sure to call the office to thank them and ask for the date when the proclamation will be signed. Find out who you may contact in the office to follow up on the process. Once you have a date for the proclamation signing, confirm the number of guests who can attend. The office may ask you to submit a list of guests in advance of the presentation. Prepare a press release about the signing and send to local media. (See a Sample Press Release on page 8 of this Tool Kit.) Make sure you have a photographer at the signing. Inform the Foundation for Sarcoidosis Research about the date of your signings so that they can be added to the calendar of events on the web page for Sarcoidosis Awareness Month.

### ***How to promote the signing of your proclamation***

Write a press release. See a sample press release developed by the Houston group on page 8 of this Tool Kit. Send your press release to local newspapers and radio and TV stations. Notify physicians and hospitals that treat sarcoidosis patients. Make sure you also notify the office issuing the proclamation about the publicity you are sending out. Send a copy of your press

release to Yvonne James at [yvonnej3110@aol.com](mailto:yvonnej3110@aol.com) and she will make sure information about your proclamation gets posted on the Sarcoidosis Awareness Month page on the FSR web site.

**One or two weeks in advance of the signing**

Confirm the date and time of the signing. Let your contact know how many people will attend the event and, if you are planning to present the proclamation signer with a gift or thank you, please inform your contact. Unfortunately, in this day and age, surprises are not always welcome.

**SAMPLE SARCOIDOSIS AWARENESS MONTH PROCLAMATION**

WHEREAS, the Foundation for Sarcoidosis (insert your group's name here) is observing Sarcoidosis Awareness Month with the 2013 theme "...";

And WHEREAS, sarcoidosis is a disease that affects many of our fellow citizens in chronic and debilitating ways and is a potentially fatal inflammatory disease that can appear in almost any organ in the body and can strike people of all races and of all ages;

And, WHEREAS, while some progress has been made in understanding the symptoms and better diagnosing the disease, the cause remains undetermined and very little is known about the true burden of this illness;

And, WHEREAS, April 2013 would be appropriate to designate as Sarcoidosis Awareness Month with worldwide events to increase public awareness of the need to support individuals with sarcoidosis; to raise awareness of the need for more research funding; and to educate medical professionals who are for individuals with sarcoidosis;

And, WHEREAS, through increased research, quantifying prevalence, discovering the cause, improving treatment and finding a cure for sarcoidosis may be well within reach  
Now, therefore, in resolution, I (Governor of State), do hereby proclaim April, 2013 as Sarcoidosis Awareness Month in (state).

On this occasion, we recognize the efforts of (insert your group's name here) and the FSR International Coalition to Stop Sarcoidosis to raise awareness of the disease and to support research efforts of concerned physicians and scientists throughout the United States. We also salute the victims of sarcoidosis who demonstrate great courage and determination in their efforts to cope with the disease; and we pay tribute to their family members and to other concerned Americans who are engaged in grass-roots efforts to promote awareness of sarcoidosis, as well as improved treatment and support for its victims.

**SAMPLE PRESS RELEASE**

Janine's Sarcoidosis Outreach Foundation

**News Release**

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P.O. BOX 1008 Houston, TX 77411 832-248-6621

<http://www.jsf.org>

**FOR IMMEDIATE RELEASE**

**March 31, 2013**

**Governor Rick Perry Proclaims April Sarcoidosis Awareness Month  
In the State of Texas**

**Houston, Texas – March 31, 2013**-----The 20th day of April has been designated worldwide “Sarcoidosis Awareness Day” to call attention to sarcoidosis, which affects many Americans and countless others around the world, as an important global public health concern.

Governor Rick Perry of Texas has proclaimed April Sarcoidosis Awareness Month in the State of Texas. Governor Perry’s proclamation was issued in response to a request from Emma Carroll, Founder and Executive Director of Janine's Sarcoidosis Outreach Foundation and Support Group (JSOF) and a member of the Foundation for Sarcoidosis Research’s Sarcoidosis Advisory Council. JSOF joins millions around the world to observe Sarcoidosis Awareness Month.

Janine’s Sarcoidosis Outreach Foundation hosts sarcoidosis support groups in Texas and Florida, as well as an international on line Support Group for Sarcoidosis Awareness, Education and more Research into a cause and cure.

In his proclamation Governor Rick Perry said, “In official recognition whereof, I hereby affix my signature this the 15th day of February 2013, and encourage all Texans to learn more about Sarcoidosis, the risk factors, the symptoms, the treatments available and how we can help the people afflicted with this disease,”.

According to Ms. Carroll, “Our goal is to have all 50 states, other countries and communities recognize April as Sarcoidosis Awareness Month and celebrate with awareness raising events. We also call on everyone to wear purple and white, the nationally recognized colors for sarcoidosis awareness, on April 20, 2013. This day will bring together patients and families around the globe who are dealing with some very challenging issues with sarcoidosis.”

**Sarcoidosis** is a systemic disease that can affect multiple organs, create a variety of symptoms, occur chronically and cause blindness, debilitation or even death. The exact cause of this condition is unknown, but it is characterized by the formation of cells that can inflict serious damage on these organs, resulting in scarring, weakness, reduced function, and nerve damage. While some treatments exist, there is currently no cure.

For more information about sarcoidosis, contact Emma Carroll at [sarcoidosis@jsof.org](mailto:sarcoidosis@jsof.org) or 832-248-6621 or the Foundation for Sarcoidosis Research at [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org) or 866-358-5477.