

## **PUBLIC RELATIONS GUIDELINES AND OVERVIEW**

If you are interested in contacting your local newspaper or another press venue and need help in your approach, please contact Jaye Isham, Vice President, Communications Strategy, at (800) 225-6872 for more information.

### **IS SOLICITING PUBLICITY OR MEDIA COVERAGE BEST LEFT TO PROFESSIONALS?**

Professionals definitely have a role in helping us with publicity through press releases, strategy and organized pitches. However, you have a compelling story that they cannot match if you are willing to share it.

### **WHY WOULD THE MEDIA LISTEN TO ME?**

Journalists report news and matters of public interest; they do not create it. They depend on the public to inform them of newsworthy stories.

### **BUT THE MEDIA IS SO BIG!**

Approaching the media can be intimidating. However, remember that they are people, too, and they are always looking for good human-interest stories. If you get brushed off, don't take it personally and try again. Realize that editors receive an overwhelming amount of phone calls and emails.

### **WHICH MEDIA ORGANIZATIONS SHOULD I APPROACH?**

There is no hard and fast rule. However, local and community newspapers as well as television and radio stations are good places to begin for local human-interest stories. If you think you have a broader human-interest story, fashion, lifestyle and health magazines are also good publications. Before you make your pitch, it's a good idea to find out who is the editor, health reporter or assignment editor so you can contact them directly.

### **WHY NOW? WHY NOT WAIT?**

Every day another child is born with TSC. Every day another family begins the lifelong journey of understanding and fighting TSC. Promoting awareness today will connect families and individuals with the TS Alliance, where they can get access to information, education and support. Awareness also can help raise funds that will bring us one step closer to fulfilling our mission of finding a cure for TSC while improving the lives of those affected.

### **HOW DO I GET STARTED?**

Contact the TS Alliance today. The Communications Department staff will gladly answer any questions you have and work with you to write, review and/or edit your press release.

### **GIVE THE TS ALLIANCE AS A REFERENCE**

The TS Alliance is the only national organization of its kind helping people with TSC, and it is a good reference for press wanting additional quotes or information. All staff members at the TS Alliance are professionals and can answer more difficult questions. In addition, the TS Alliance would love to receive the coverage, as it is another step in educating people about the help that they can receive.

# KEY MESSAGES TO SHARE WITH THE MEDIA

## Tuberous sclerosis complex (TSC) is ...

Tell the media what tuberous sclerosis complex is. Many people do not know what tuberous sclerosis complex is or understand the varying degrees of severity. You might want to use the following TS Alliance definition: Tuberous sclerosis complex is a genetic condition commonly characterized by seizures and tumor growth in vital organs such as the brain, kidneys, lungs and skin.

## One out of 6,000 newborns in the United States has TSC!

Dazzle the media with the facts. Share the statistics that we have for TSC.

## Are the tumors cancerous?

No, the tumors that form in these organs are benign (i.e., non-cancerous) but may cause problems. Tumors that grow in the brain can block the flow of cerebral spinal fluid in the spaces (ventricles) in the brain. This can lead to behavior changes, nausea, headaches or a number of other symptoms. In the heart, the tumors are usually at their largest at birth, and then decrease in size as the individual gets older. These heart tumors, called cardiac rhabdomyomas, can cause problems at birth if they are blocking the flow of blood or causing severe arrhythmia problems. The tumors in the kidney (renal angiomyolipoma) can become so large as to eventually take over all of the normal kidney function. In the past, the patient was left until they developed kidney failure. Today, doctors are more aggressive and remove individual tumors before they get too large and compromise healthy kidney tissue. The tumors in the eyes are not as common but can present problems if they grow and block too much of the retina.

## How does a person develop TSC?

Tuberous sclerosis complex is transmitted either through genetic inheritance or as a spontaneous genetic mutation. Children have a 50 percent chance of inheriting it if one of their parents has the condition. At this point, only one-third of TSC cases are known to be inherited. The other two-thirds are believed to be a result of spontaneous mutation. The cause of these mutations is still a mystery.

## Many individuals with TSC lead full and productive lives.

Most people with TSC will live a normal life span. There can be complications in some organs, such as the kidneys and brain that can lead to severe difficulties and even death if left untreated. To reduce these dangers, people with tuberous sclerosis complex should be monitored throughout their life by their physician to eliminate potential complications. Thanks to research findings and improved medical therapies, people with tuberous sclerosis can expect improved health care.

## Is there a genetic test (prenatal test) for TSC?

A commercially available genetic test for TSC is now available.

# MEDIA INTERVIEW TIPS

## Keys to a Good Interview

- Talk in lay terms, using as little professional or technical jargon as possible. Tell stories and anecdotes that illustrate your point and give examples.
- Keep the answers short.
- Think about what you want to say before you speak.
- Define two to three main points you would like to make about your subject. Gather facts, figures, and anecdotes to support your points.
- Anticipate questions the reporter might ask and have responses ready.
- Speak in complete thoughts. The reporter's question may be edited out and your response should stand on its own. This is especially important for television interviews.
- Never say anything you do not want to read in print, hear on the radio, or see on television or the internet.
- Be confident. You are the expert.

## Preparing Before the Interview

- Prepare a single communication objective and two or three secondary points you want to make.
- Anticipate the reporter's questions, especially the hard ones. What are your key messages? Answer difficult questions as briefly as possible, then bridge to your message.
- If you can provide the reporter with a written summary of information, main points or statistics, do so. Reporters always need perspective (i.e., How many people are affected? When did the issue arise? Is this part of a national trend?). Don't hesitate to put the issue into perspective, even if the reporter doesn't ask.

## During the Interview

- State the most important information first – then provide the background.
- Keep responses brief, but long enough to help the reporter get quotes.
- Stick to your main points and do not allow yourself to get drawn too far off on tangents. Many people make the mistake of talking too much. Repeat your points if necessary to get back on track.
- Mention your subject by name several times during the interview, rather than saying "it" or "they."
- Make eye contact with the reporter.
- Don't overestimate a reporter's knowledge of your subject. If a reporter bases questions on information you believe is incorrect, do not hesitate to set the record straight. Offer background information where necessary.
- Identify anything you say as either fact or opinion. Your opinions are your own, but fact is fact.
- If you do not understand a question, ask for clarification rather than talking around it. If you do not have the answer, say so. Tell the reporter where to find the information, if possible.

## More Media Interview Tips

- If you feel unprepared to answer a certain question, tell the reporter you will get back to him/her with an answer. Avoid discussing hypothetical situations.
- Never say, “No comment.” Instead, if you cannot or do not choose to answer, explain briefly. *For example, “I can’t answer that because I haven’t seen the research paper you are referring to.”*
- Avoid saying things “off the record.” Reporters may or may not honor this, and it annoys them.
- Be honest. Don’t try to conceal negative information; rather, let your interviewer know what you are doing to solve a problem.
- Don’t joke. Be friendly, but not complacent. Assume everything you say, even in a social situation, may appear in print or on the air.
- Reporters can use silence to make you feel uncomfortable and talk or say things you may not want to say. It is best to stay quiet between questions. Don’t fill in with chatter or become hyperbolic (sometimes called “nervous talk”).
- Make your final comment clear and concise, reemphasizing your main point. If you feel that you failed to get the message out, force it in at the end. (“I think we’ve missed the real, critical issue here, which is....”)

# HOW TO BUILD A MEDIA LIST

Where do you send a press release and whom do you send it to? An up-to-date, complete list of media contacts that cover issues of importance to the tuberous sclerosis complex community is important to have in place before you begin any outreach to the media.

Here are some strategies for building a media list:

## Follow the media.

Read your local newspaper and watch news broadcasts that cover health-related issues. Take note of who wrote the article or reported on the news broadcast and add these reporters to your list.

## Contact your local media.

Call your newspapers, radio and television stations and ask for the appropriate contact person, address, phone, fax, and email information. You will want to know who covers health, medicine, children's issues, or other pertinent "beats." Your list should include reporters, health editors, assignment editors, news editors, editorial writers and producers.

## Share a list.

Ask another group in your community to share their media list with you. You may be able to combine your efforts for a joint media effort.

## Research media directories.

Local libraries will often have a copy of resources such as Burrelle's Media Directories, Bacon's Media Directories, News Media Yellow Book, and Gale Directory of Publications and Broadcast Media.

## Remember:

Developing a media list takes time and it should be updated periodically. You will have better results in your outreach to media if you have a good up-to-date list to start.

# HOW TO PITCH A STORY TO THE MEDIA

The news media constantly search for story ideas. Each media outlet must fill their print space or air-time every day and operate under tight deadlines. You are a resource on tuberous sclerosis complex and your story may be just what they need.

Media coverage is one of the best ways to gain the attention of decision-makers, like your local elected officials or members of Congress. All monitor the media. You can also use the media to publicize the TS Alliance and your activities. Getting media coverage of issues of importance to individuals with tuberous sclerosis and their families can take time. Investing this time can lead to significant payoffs when you do get coverage, thereby reaching thousands of people with your message.

## Establish a relationship with journalists.

Find out who the media are in your area and which ones report on medical/health or lifestyle issues. Follow their column or show. Offer yourself as a resource for the media. Don't be afraid or timid. Remember, journalists need your ideas. To get your foot in the door, you may want to call a local journalist to simply ask if you could drop off some materials on tuberous sclerosis complex. This will only take a few minutes of the journalist's time and most will gladly accept materials that they may be able to turn into a story. When you drop off the materials, go in wearing business attire, greet the journalist with a handshake, drop off your business card with a brochure, and leave. This whole process should take five minutes and now you have connected your tuberous sclerosis issue with a name and a face. You are now a resource for the journalist.

## Present your issue in a newsworthy way.

Try to match up your activities with the most appropriate media. If you have a good visual story, you may want to contact your local TV station. You can enhance your chances of being picked up by the local TV station by how you present your event. "More than 500 children take part in tuberous sclerosis bowl-a-thon," gives more of a visual image than "Local tuberous sclerosis group hosts fundraiser."

## Be persistent.

Contact journalists throughout the year with information on newsworthy items. This can be in the form of a press release or a follow-up phone call. Just remember that if the journalist does not run your story now, it does not mean they never will.

## Keep your pitches short.

Be concise and get to the point with any contact you have with the media. Know your key messages to share with the media before you contact them.

# HOW TO WRITE A PRESS RELEASE

Press releases are a powerful tool to get your message out to the media, whether it is general tuberous sclerosis complex awareness efforts or to promote a specific event. But there is a certain way to draft a press release and certain items the media expect to see in a press release. Overall, the release is like a pyramid with the quick summary points first and more information following in the order of importance.

Here are some general tips when writing a press release:

## Formatting

- Keep the release to one page. Use 8.5" x 11" white paper.
- Leave margins of at least 1" on each side of the page and double-space the document.
- Address the release envelope to a specific person by name.
- Give contact name, company or organization name, and telephone number so you can be easily reached for further information. Make sure you list a contact person who is easily accessible. Please also include contact information for the director of communications at the national office.
- Keep release to about 5 short paragraphs – the media will call you if they need more information.

## Headline

Give a descriptive phrase that gives the reader a quick summary of the release.

## Body

### First paragraph

- Give the key facts about your news. This is where you have to grab the reporter's attention!
- Give the "who, what, why, when, where, and how."

### Second and third paragraphs

- Include important information that expands on your news. Include more background facts and figures.
- Include a quote from an officer from your organization.

### Fourth and fifth paragraphs

- Expand on any other information relevant to your issue.
- Wrap up with information on your local group and give your contact information.

## Establish the end

Editors and reporters look for a "###" or a "-30-" at the end of a release signifying its end. There is also a shortened version of a press release called a *media advisory* that is helpful to use a few weeks in advance of your awareness activity. A media advisory is usually just bulleted information on the "who, what, why, when, where, and how," followed by your contact information and either a "###" or a "-30-".



**FOR IMMEDIATE RELEASE**

OCTOBER 11, 2008

(123) 456-789 [name@email.com](mailto:name@email.com)

**PRESS CONTACT:**

Jane Doe

**AN EVENING OF HOPE AND LAUGHTER WITH MARK GIANGRECO**

*Comedy for a Cure to raise awareness and much-needed funds to find a cure for devastating genetic disease.*

(Schaumburg, IL) On October 30, the TS Alliance of Greater Chicago will host its Second Annual Comedy for a Cure at the Schaumburg Improv Comedy Club. The event will raise funds to support research in finding a cure for tuberous sclerosis complex (TSC), a devastating multi-symptom genetic disorder that affects over 50,000 people in the United States and is the leading known genetic cause of epilepsy and autism.

This year's Honorary Chair is Mark Giangreco, Primary Sports Anchor for ABC 7. Honorary Hosts include U.S. Congresswoman Melissa Bean, Chicago Rush Head Coach Mike Hohensee and IHRA driver Terry McMillen.

"We all know laughter is the best medicine," says Event Chair Sandy Smiley. "We put together Comedy for a Cure so anyone can be a part of the laughter while helping in our quest for better treatments and a cure."

The evening begins at 6 p.m. with a VIP reception sponsored by Diageo, the world's largest spirits company, followed by silent and live auctions including a chance to bid for a walk-on role on the TV show *CSI:New York*, and finishes with a cabaret comedy show at 8 p.m. featuring a live performance by headliner Jim Short of *Late Night with Conan O'Brien*, *Comedy Central* and the *Late Show with David Letterman*. Tickets are \$50 each and sponsorships are still available.

"This unique and exciting event gives us a chance to raise awareness about a disease that robs far too many children of their chance for a normal and happy life, as well as raise much-needed funds for research and support programs" Giangreco asserts. "I am happy to help make a difference in the lives of those who need it most."

The Tuberous Sclerosis Alliance is the only national voluntary health organization dedicated to finding a cure for TSC and improving the lives of those affected. TSC is a multi-system disorder that causes tumors to form in various vital organs, primarily the brain, heart, eyes, kidneys, lungs and skin. People with TSC often develop epilepsy, autism and learning and behavioral problems. Currently there is no cure. To purchase tickets or for more information about the TS Alliance or TSC can go online at [www.tsalliance.org](http://www.tsalliance.org) or contact the organization toll-free at (800) 225-6872; or by e-mail at [info@tsalliance.org](mailto:info@tsalliance.org).

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**FOR IMMEDIATE RELEASE**

JANUARY 14, 2009

(414) 281-5599

[PAMCHEF@WI.RR.COM](mailto:PAMCHEF@WI.RR.COM)

**PRESS CONTACT:**

Pam Sztukowski

**Local Mom's "Cookin' for a Cure" to Benefit Devastating Genetic Disease**

(Cudahy, WI) – The Tuberous Sclerosis Alliance (TS Alliance) of Wisconsin will hold its *16<sup>th</sup> Annual Cookin' for a Cure* Pampered Chef Auction Sunday, January 25, from 1 to 3 p.m. at the Cudahy Family Library, located at 3500 Library Drive in Cudahy. The event is organized by local resident Pam Sztukowski, whose son Joey died in 1992 due to complications from tuberous sclerosis complex (TSC), a devastating genetic disease.

TSC causes tumors to grow throughout major organs, primarily the brain, kidney, lungs and skin. It is the leading known genetic cause of autism and epilepsy, and many people with TSC also suffer from cognitive difficulties and daily seizures. TSC affects more than 50,000 people nationwide – more than Lou Gehrig's disease (30,000) and even cystic fibrosis (30,000). Having TSC has been described as similar to having heart disease, epilepsy, autism and cancer all rolled in to one.

"My son Joey had TSC," Pam says. "We had never heard of it back in 1990 when he was diagnosed. Joey had his first seizure at the dinner table during our Thanksgiving meal in 1990. We took him to the hospital, stayed through numerous tests and got the diagnosis of TSC."

As an infant, Joey suffered from more 100 infantile spasms a day. Infantile spasms are a type of seizure that is devastating to mental ability and a child's life. Pam was told he might not ever walk or talk. Pam did not accept that prediction.

"I searched locally, nationally and even internationally until I found a doctor that could help Joey," Pam explains. "A doctor in England finally prescribed a drug called vigabatrin to stop the infantile spasms, which is only available overseas."

After the first hour of his first small dose, Joey sort of "woke up," Pam recalls. "He had not previously smiled, crawled, talked, laughed, or had any type of interaction with his world. Then after that first dose at a dinner table again, Joey began to smile. Then he laughed. Then he just looked all around as if seeing his world for the first time."

Six months after starting vigabatrin, Joey started to crawl. He never had another seizure. Joey passed away in his sleep at 25 months old in June of 1992. His heart, filled with tumors caused by TSC, simply stopped. (Last week, a U.S. Food and Drug Administration professional advisory committee recommended that the FDA approve the drug vigabatrin for use in the United States.)

Despite Joey's death, Pam was inspired to continue to fight in his memory by raising money to help find a cure and better treatments for TSC. Her experiences, insistence and conviction truly create hope for many families facing the daily struggles of the disease.

"I've been 'cooking up a cure' with this event for 15 years," Pam says. "Every year, I solicit sponsors, donations, and people that want to help make a difference to join me in fighting a disease many have never heard of so it also increases awareness."

Of course, for a person as driven as Pam, this event is not enough. She has chaired the local ***Step Forward to Cure TSC*** walkathon for the past four years; this year's walk is scheduled for October 3 at Grant Park. Between both events, she has been the leader in the area, raising almost \$100,000 for TSC research and family support programs. All proceeds of both events go directly to the Tuberous Sclerosis Alliance. For more information on the TS Alliance or TSC, please visit [www.tsalliance.org](http://www.tsalliance.org).

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## PUBLIC SERVICE ANNOUNCEMENTS (PRINT & RADIO)

Many local media outlets (including radio stations, newspapers and other publications) will run public service announcements (PSAs) free of charge on a space available basis.

The TS Alliance has print PSAs available in PDF formats upon request. Contact Jaye Isham at [jisham@tsalliance.org](mailto:jisham@tsalliance.org) for the print PSAs. Radio PSAs are available as MP3 files to download from our website; simply go to [www.tsalliance.org](http://www.tsalliance.org) and click "For Volunteers" on the left navigation menu, then choose "Outreach & Awareness Tools."

To place a radio PSA, first determine which local stations you want to approach; requirements for submitting PSAs vary from station to station. Many stations have a programming director with whom you will work so find out who it is. You may be required to fill out forms that explain the purpose of your announcement and certify its production authenticity.

You should make contact early because some stations plan their programming schedules weeks or months in advance. Share your key messages to underscore the significance of the PSA for the local community (i.e. your upcoming walkathon). Encourage the station to air the PSA more than once, maybe multiple times a month.

After you event, follow up with your contact to share news/results as appropriate.

# CONDUCTING INTERVIEWS

The media tend to like story ideas that are local and relevant to your community. So it is important to present your story idea or press release with local resources should the media have any questions or wish to conduct an interview.

Here are some general tips that are applicable to any media interview:

- Pick three or four points you want to get across and practice working in them in (See the “Key Messages to Share with the Media” section).
- Anticipate hostile or difficult questions and rehearse your answers. Take a cue from politicians - if you get a question that you feel is hostile or unrelated to your purpose, feel free to acknowledge the question but then immediately refer back to your key messages. An example is “*I understand what you’re asking, but the fact is that...<FILL IN KEY MESSAGE>.*”
- Always return reporters’ phone calls immediately.
- Do your homework. Know where your facts come from - TS Alliance, NIH, CDC, local data, etc.
- Don’t be put on the defensive; never speak “off the record.”
- Try to speak in layman’s terms or offer a brief explanation of terminology the reporter may not be familiar with.
- Respect deadlines. Ask what their deadline is. Reporters often need to arrange an interview within a few days, so try to be flexible and work with them as much as possible.

## For *print* interviews:

- Expect quotes to be edited. Even if the reporter writes out your whole quote, his or her editor may cut it down due to space limitations.
- Ask for clarification of a question if you need it.
- Always avoid the phrase “no comment.” If you are not aware of something or do not know the answer to a particular question, just be honest. Tell them where they can get the information, another person at your group, TS Alliance, your local clinic, etc.

## For *radio* interviews:

- Rehearse what you will speak about. During the interview take a few moments to think before you speak. Do not fill dead air with “ums” and “wells” and don’t be afraid of silence.
- Be aware of the microphone, but don’t speak directly into it. Microphones can easily pick up voices that are reasonably close. Be careful not to tap the microphone.
- Know when you are on and off the air. The microphone might still be on while the segment is ending!
- Avoid sounding monotone by using intonation and inflection in your voice.
- Check your voice by practicing speaking at a normal volume; there is no need to speak loudly.

## For *television* interviews:

- Dress appropriately and conservatively – business attire is best. Wear minimal and/or plain accessories.
- Speak naturally; gesture as you would in a normal conversation. If makeup is offered, don’t turn it down.
- Sit on the chair’s edge and lean forward slightly; keep your hands relaxed on your lap. Cross your ankles not your legs.
- Smile when you speak.

# MEDIA TIMEFRAMES AND FOLLOW-UP GUIDE

Timing is important in your fundraising and awareness efforts, especially when you are doing outreach to the media! Here are a few guidelines and timeframes for working with the media:

## ***A month (or more!) before your activities:***

Start building your media list. Begin talking with other community organizations that you think may be willing to share their list or that may want to do a joint activity.

If your activity will take place over the course of time, you may alert the media with a media advisory when you are starting your activities or when you get good results from your past activities. (See *How to Write a Press Release* section for media advisory information.)

If you are planning an event, try to choose a time of the day when reporters would most likely be available to come. The best times are between 9:30 and 11 a.m. or between 3 and 4 p.m. If you do an evening event, plan it for after 7 p.m. Be prompt. If you say your action will start at 7 p.m., start it at 7 p.m.

Draft your media materials. Decide if you will write a media advisory in addition to a press release. Talk with other local members of the tuberous sclerosis community about being available for follow up interviews with the media. You may want to draft biographies and quotes for local contacts who are available to speak with the media.

## ***Two weeks before your activities:***

Send a press release two weeks prior to your activity to your local media contacts. It is best to send a press release to a reporter by name, but if you do not have a name, you can email the release to the News Assignment Desk and follow up by calling the News Assignment Editor. If you do not have access to email, mail it 7 days in advance of the event.

## ***A few days before your activity:***

Follow up with a phone call the day before or the day of your activity to make sure the local press have received notification of the event or activity. Prepare responses to basic questions before you call. The best times to call are between 10 a.m. and 3 p.m. on weekdays.

If the reporters still have not received your information, offer to fax, drop off, or e-mail your press materials to your local news media.

## ***A few days after your activity:***

If you have an event, contact any reporters who came and ask them if they need any additional information. Ask them when they will be covering the event and use the techniques from the *How to Pitch a Story to the Media* section.