REACHING OUT TO THE MEDIA
A Guide for Increasing Public Awareness of Pediatric Cardiomyopathy
Dear CCF family, friend and supporter,

We extend our heartfelt thanks for your interest in raising awareness of pediatric cardiomyopathy. You play an important role in helping us educate the public about pediatric cardiomyopathy and inform them of the value of CCF’s services. Our goal in garnering media coverage is to make it clear that pediatric cardiomyopathy is a disease that is critically in need of more attention. Our aim is to reach key influencers and motivate them to lobby for increased research spending and more comprehensive care services for affected children and their families.

We have developed *Reaching Out to the Media* to outline the steps needed to get optimal coverage for your story and the disease. Families interested in fundraising for CCF can also use this handbook to increase awareness of their event and focused cause.

By participating in this media initiative, you are taking the first step towards making a positive change for those living with this chronic heart disease. If you receive media coverage in your area, please forward a copy to CCF to be included in CCF’s media reference list. Highlighting our media coverage to prospective outlets helps us to generate additional media interest.

Together we can make a difference and get closer to the day when every child with cardiomyopathy has the opportunity to live a full and active life.

Lisa Yue
Founder & President
Whether letting people know about cardiomyopathy in the local community or at the national level, media outlets can deliver your message to a broader audience. By sharing your story about the realities of living with cardiomyopathy, you will put a face to this disease and help the public understand what it is like to live with a chronic heart condition. This handbook serves as a how-to guide, outlining the steps involved in getting media coverage. This includes talking to reporters about your family’s story, distributing CCF press kits, and establishing relationships with the media to help us get coverage on pediatric cardiomyopathy.

GARNERING MEDIA COVERAGE FOR OUR CAUSE

**STEP 1** PLANNING: CREATE A MEDIA CONTACT LIST

The first step in media outreach is to determine whom to contact. To do this, you will need to create what’s called a media contact list. This is a list of people working in different sectors of the media industry. The list will include reporters at daily and weekly newspapers, magazines, television and radio stations.

A national media list created by CCF can be found in the Appendix. For local media, you will need to compile a list of TV and print outlets in your community. It is best to reach out to your local contacts first, but if you have a strong connection to someone who works for a national outlet, draw upon that resource as well. When contacting any national media outlet, please inform CCF so that we avoid duplicate efforts.
■ Peruse your local papers

Read your local papers and look at their mastheads for the names and titles of their editors and writers. Many mastheads will have their email address, which is a great way to make your first contact.

■ Search the web

The Internet is a great tool to gather the names of newspapers, magazines, television and radio stations in your area. Again, many will have email addresses to contact reporters directly or there may be a phone listing to add to your list.

■ Make note of reporters who cover heart-related issues and health

All media outlets have different reporters covering different sectors. Most media outlet websites have a search function that allows you to find previously printed articles or broadcast programs on a particular subject where you can find the author or producer of a health-related story. You can also find a reporter’s information by checking on the Internet or reviewing the publication directly. Search for reporters who have previously covered stories on cardiomyopathy, sudden death, heart failure or congenital heart disorders. They are among the most likely to write about cardiomyopathy.

■ Keep a record of your results

Once you start contacting the people on your media list, keep a record of the results. Include when you called and what the follow up should be. This will help you track your work and progress.

STEP 2 DRAFT A LETTER TO THE MEDIA OUTLET

Now that you have compiled the media contact list, you are ready to move onto drafting the introductory letter. You have a few choices as to how to approach your contact:

■ Tell your story in a personalized letter

Your personalized letter is crucial to getting the attention of a reporter, editor or producer. In the Appendix there are sample letters written by CCF which will help you get started. Please customize these templates to your situation and add your story. As you write, keep in mind that the outlet receives many letters so it is important to make your letter stand out from the rest. Try communicating the most impactful or newsworthy information first and balance your experience with facts about the disease, keeping your letter one to two pages. At the end of the letter, include your full name and contact information, along with any credentials or affiliations you might have.
Write a Letter to the Editor

This is a short piece (150-200 words) that focuses on a specific issue. It is sometimes in response to a particular article, and other times, more general. Here are a few suggestions for writing this letter (sample can be found in the Appendix):

- Approach community papers, radio stations, and news channels first, as they tend to run a high percentage of the stories they received. If you choose to write to a national publication, consider commenting on a story that's been written recently. Find a way to relate your letter to what has been discussed or featured.
- Focus on one main point and be concise.
- Take a look at the publication's Letter to the Editor section to get a feel for other writing styles.
- When contacted by a radio or TV producer, pay attention to past news or radio shows.
- Call or look online to find out the media outlet's procedure for submitting such a letter.
- If no response, follow up in about a month with another letter. Then follow steps 3 & 4 to secure an interview.

Respond to a news article or a television program

If you read or see a heart-related article or television program, use the opportunity to get your story out to the media by writing an editorial response letter. The key in this situation is to have a "news hook." In other words, the issue you are commenting on should be relevant to the week's news story. Here are a few tips for composing your letter (sample can be found in the Appendix):

- Write the body of the letter in advance so that you can move quickly when a heart-related news story or event occurs.
- Speak in your own voice and use facts and examples to support your points.
- Limit the article to 750 words. Make your strongest point first and use short sentences and paragraphs so it is easier to read.
- Include a few sentences on your background along with your full contact information.
- Check the submission guidelines of the publication you plan to contribute.

Whatever option you choose, CCF is available to assist in proofing and editing your final letter.
After sending the letter, follow up in a week with a phone call to request a commitment for a piece or an interview. Here is an example of what you can say:

“Hello (REPORTER’S NAME). My name is (NAME) from (YOUR CITY, STATE). I recently sent you a letter about my son/daughter (NAME) who has a chronic heart disease called cardiomyopathy. I am very interested in getting a story about pediatric cardiomyopathy out to your viewers/readers because it is such a neglected disease and often undiagnosed. I’d like to share my son/daughter’s story with your audience to educate others about pediatric cardiomyopathy and what they can do to recognize it and screen for it. Would you be interested in such a story?”

If they don’t answer or you are unable to reach them after several attempts, you can try leaving a message emphasizing your interest in his or her help. Here is an example of something you can say:

Hello (REPORTER’S NAME). This is (YOUR NAME) from (CITY, STATE). I’m calling to follow up on my letter dated (DATE OF LETTER) about doing a story on pediatric cardiomyopathy. As I mentioned in the letter, cardiomyopathy is the leading reason for sudden cardiac arrest and heart transplants in children under 18 years. I feel it’s important to educate the public about the disease and inform them of what to watch for. If you could kindly let me know your thoughts by calling (YOUR TELEPHONE). Thank you.

What if I don’t hear back?

Try again a few days later or in a week. If you still hear nothing, you can assume the reporter is not interested or unable to do the story. Call or write them again in a few months restating your interest in a story. Add any updates since last contacting them.
What if I hear back, but the reporter says no?

Don’t be discouraged; it may not be the right fit. Some reporters are only interested in newsworthy information on the disease (such as a genetic discovery or new therapy), while others prefer more special interest stories about individuals or families. If possible, ask the reporter for feedback and whether there may be another reporter who may be better suited to your story.

ENSURING A SUCCESSFUL INTERVIEW

Interviews give a personal face to the disease and help the reader or viewer understand the effects of the disease. If you decide to participate in an interview, here are some details on what’s involved as well as a few tips for ensuring a successful interview.

Be on time

As a common courtesy, be on time when they need to interview you.

Know your talking points

Outline three, short, memorable messages you want to convey. Practice them aloud ahead of time with a spouse or trusted friend.

Be concise when answering questions

Everyone who works in the media is on a tight deadline. Be clear and to the point when responding to questions. If you’ve sent materials in advance, do not assume a reporter has read it so highlight your key messages and facts about the disease during the interview.
Be honest & don’t speak “off the top of your head”

If you don’t know the answer, tell the reporter that it is not your area of expertise. If the reporter wants detailed information or questions you in a controversial way, offer to send them written background information on the topic after the interview and once you have checked your facts or sources. You can also direct the reporter to CCF for disease statistics.

There is no such thing as “off the record”

Be sure not to say anything you would not want to read in the newspapers. What you say today could appear in tomorrow’s news!

Keep in mind photo opportunities

A picture is worth a thousand words. Before and after the interview, offer your suggestions to the photographer and remember to provide or verify the captions.

QUICK TIPS FOR THE BROADCAST INTERVIEW

- Relax: Speak at a normal pace.
- Act natural: Look at the reporter, not the camera!
- Dress for success: Solid fabrics come across better on camera than prints.
- Avoid white clothing and flashy jewelry: These might reflect light into the camera.

STEP 5 ESTABLISH A LONG-TERM WORKING RELATIONSHIP

One of the best ways to secure ongoing news coverage is by building a good relationship with key reporters. Here is what one organization of a successful media outreach campaign had to say:

“For us, the secret has been relationship-building with reporters. We communicate things that they might consider covering and they appreciate the scoops and suggestions. Right now, we’re in regular communication with many reporters, providing “leads” they might be interested in pursuing. The key is 1) relationship-building and 2) staying in communication.”
Send a Thank You Letter

A letter shows your appreciation for the reporter’s time, while reminding him or her about what else can be done. Send something out within two days of your interview. Re-emphasize key message points or facts/statistics about cardiomyopathy from your interview, and stress the need for the story to be told. Ask if they need any additional information and offer to fact check or view the article/footage before it is published or broadcast.

Contact them again a few months after the story has come out to share any updates on cardiomyopathy and let them know about the positive outcome of their media coverage.

Keep in Touch

Write the reporters on your list periodically to tell them about new developments on cardiomyopathy. Send them a CCF newsletter and any other current information.

SUMMARY

With persistence and patience, you can make a real difference. Your story will give strength to those dealing with cardiomyopathy, and educate those who are not familiar with the disease yet. Here’s a quick review of the steps:

- Create a list of your local media contacts using the phone book, Internet and knowledge of your area.
- Draft a personalized letter to send to the people on your media list.
- Follow up with a phone call to request an interview.
- Once an interview is secured, send a press kit along with a follow-up note confirming the date and time.
- Prepare key message points for your interview.
- After the interview, send a thank you letter.
- Continue to build a relationship with reporters with updates on CCF or new developments in the field of pediatric cardiomyopathy.

CCF can help with all of the steps outlined in the handbook and share with you our media knowledge. Please call Lisa Maher at 866-808-2873 ext 902) who will walk you through the steps, share our resources and help you come up with a plan of approach. We also have plenty of additional forms and templates that you may find useful in your media outreach.
APPENDIX

- Facts About Pediatric Cardiomyopathy and CCF
- Personalized Letter to Editor or TV Producer
- Letter to TV Producer in Response to a Heart-Related TV Program
- Letter to Editor in Response to a Heart-Related Article
- Post Interview Thank You Letter
- National Media List
FACTS ABOUT PEDIATRIC CARDIOMYOPATHY AND CCF

ABOUT PEDIATRIC CARDIOMYOPATHY

- Pediatric cardiomyopathy is a rare and underdiagnosed disease of the heart muscle that can lead to heart failure and sudden death in the very young.
- Cardiomyopathy affects 1 per 100,000 children, which is similar to the incidence of such childhood cancers such as lymphoma, Wilms tumor and neuroblastoma.
- Approximately 30,000 children under the age of 18 suffer from some form of cardiomyopathy. This is compared to the number of people with cystic fibrosis in the U.S.
- Considered “an orphan disease” because of its rarity, pediatric cardiomyopathy is often overlooked, and research continues to be underfunded by federal agencies and pharmaceutical companies.
- The disease knows no boundaries; it affects all races, genders and cultures regardless of socio-economic background.
- To date, there is no cure that can repair the damaged heart or stop the progression of the disease.
- The percentage of children with cardiomyopathy who receive a heart transplant has not declined in the past 14 years, and cardiomyopathy remains as one of the leading causes of transplantation for children over one year of age.
- More than 75 percent of diagnosed children do not have a known cause, yet genetic causes are likely to be present in most. In some cases, pediatric cardiomyopathy can also be acquired through a viral infection to the heart.

ABOUT THE CHILDREN’S CARDIOMYOPATHY FOUNDATION

The Children’s Cardiomyopathy Foundation (CCF) is a national nonprofit organization dedicated to finding causes and cures for pediatric cardiomyopathy. An underdiagnosed and incurable heart disease, cardiomyopathy is the leading cause for sudden deaths and heart transplants in children under age 18.

CCF started in 2002 with one family’s desire to call attention to a poorly understood heart disease and to take action on the lack of medical progress and public awareness. Since then, CCF has grown into a global community of families, physicians, scientists and pediatric professionals focused on improving diagnosis, treatment and quality of life for children affected by cardiomyopathy.
CCF has committed close to $10 million to research and treatment initiatives in the U.S. and Canada.

- CCF’s research grant program and international scientific workshops bring together experts from the medical and research fields to advance knowledge on the disease and accelerate the development of new therapies.

- CCF’s funded research has resulted in more than 76 scientific publications and presentations, and the establishment of a multi-center biologic specimen repository.

- CCF’s educational materials are now distributed in more than 70 hospitals in the U.S. and Canada.

- CCF serves as an access point for information, resources and guidance to more than 2,640 families from 73 countries.

- CCF’s networking opportunities such as local support groups, family matching and online-support community have empowered parents to advocate for the best medical care for their child.

CCF’s hope for the future is that more lives will be saved, and every affected child will have a chance to live a full and active life.

**MEDICAL ADVISORS**

Wendy Chung, MD, PhD, Columbia University Medical Center  
Daphne Hsu, MD, Children’s Hospital at Montefiore  
Steve Lipshultz, MD, Children’s Hospital of Michigan  
Steve Colan, MD, Children’s Hospital Boston  
Jeff Towbin, MD, Le Bonheur Children’s Hospital  
Shelley Miyamoto, MD, University of Colorado  
Joseph Rossano, MD, MS, University of Pennsylvania Perelman School of Medicine  
James Wilkinson, MD, MPH, Vanderbilt University School of Medicine

For more information about CCF, please visit www.childrenscardiomyopathy.org
Dear MEDIA CONTACT NAME,

You may have heard of a student who collapsed from sudden cardiac arrest while playing sports or of a baby who died without explanation in his/her sleep. Chances are pediatric cardiomyopathy was the cause. I had never heard about pediatric cardiomyopathy until August 6, 2006 – this was the day physicians at Duke University told me that my 7-year-old son, Kyle, had dilated cardiomyopathy and was in heart failure.

What I learned was that cardiomyopathy is the leading cause of sudden deaths and heart transplants in children under the age of 18. Kyle had never been sick before and always appeared completely healthy. Yet he died 15 days after he was diagnosed. It is too late for Kyle, but it is not too late for the thousands of families whose children are at risk or diagnosed with this disease.

Substitute your story instead:
- Briefly describe your child and your family’s experience with cardiomyopathy
- Your child’s diagnosis – at what age and how severe
- Any significant milestones since diagnosis
- Treatment and hope for the future

There is a great need to increase awareness of pediatric cardiomyopathy and educate others so that this life-threatening heart disease can be detected earlier and appropriately treated. That is why I am reaching out to you today. I hope that you will consider WRITING/PRODUCING a story on pediatric cardiomyopathy and help us spread this important message to a wider audience.

In the past, cardiomyopathy was erroneously thought to not strike young children. But it does, affecting approximately 1 out of every 100,000 children. According to a study in the New England Journal of Medicine, children under the age of one are 10 times more likely to develop cardiomyopathy than those aged 2 to 18 combined. The cause is unknown in more than two-thirds of these cases. Many do not have a family history, and because the disease may present without symptoms, it can often go undiagnosed. In Kyle’s case, he lived with cardiomyopathy for years until it was finally detected by a chest x-ray. By then the disease had advanced, and it was too late to treat him.
Pediatric cardiomyopathy has received little media coverage, and it remains severely underfunded by federal sources and pharmaceutical companies given the severity of the disease. Fortunately, a foundation now exists – the Children’s Cardiomyopathy Foundation (CCF) – that is trying to fill the void in research and education. Founded by a determined mother who lost two children to the disease, CCF has committed nearly $10 million to research and treatment programs, distributes patient education materials to over 70 hospitals in North America, and offers support services to affected families worldwide. I have been involved with CCF the past 3 years raising funds for research (INDICATE YOUR CCF INVOLVEMENT).

I would be interested in speaking to you further about this story possibility. I can provide you with access to CCF’s founder and medical advisors as well as other affected families for interviews. You can reach me directly at (YOUR PHONE).

I look forward to hearing from you, and thank you again for your time and consideration.

Sincerely,

YOUR NAME (mother to YOUR CHILD’S NAME, CHILD’S AGE)
YOUR ADDRESS
YOUR TELEPHONE
YOUR EMAIL
Dear MEDIA CONTACT NAME,

I recently viewed your program, “The Mysterious Human Heart,” (NAME PROGRAM) and I want to commend you on such an informative piece. I am writing to you today to share my story and to ask for your help in raising awareness of pediatric cardiomyopathy, a life threatening heart disease. For many years, cardiomyopathy in children has been an unrecognized disease with many misconceptions. It has mistakenly been perceived as a disease that doesn’t affect young children. However, this is far from the truth, as I know first hand.

My first son, Dillon, was diagnosed with hypertrophic cardiomyopathy at only 2 months old after a visit to the pediatrician for a mild cold. He has had many ups and downs fighting this heart disease and is now being considered for a heart transplant (INSERT YOUR STORY). I never thought I would be in a position to appeal to you or to be an advocate for cardiomyopathy. But Dillon’s story and my personal struggles with pediatric cardiomyopathy have led me to write this letter to you. I hope you will consider producing a story on pediatric cardiomyopathy, which can help inform and educate the public about the realities of this serious heart disease.

Cardiomyopathy is the leading cause of sudden deaths and heart transplants in children under the age of 18. There is a great need to increase awareness of pediatric cardiomyopathy and educate others so that this life-threatening heart disease can be detected earlier and appropriately treated.

A few other things to point out about cardiomyopathy:

- In over two-thirds of cases the cause is never known.
- It affects 1 out of every 100,000 children, which is comparable to the incidence of such childhood cancers as lymphoma, Wilms’ tumor and neuroblastoma.
- The disease knows no boundaries; it affects all races, genders and cultures regardless of socio-economic background.
- Cardiomyopathy has affected several well-known people: Boston Celtics’ Reggie Lewis, NY Knicks Cuttino Mobley, Olympic skater Sergei Grinkov, Dr. Atkins, Ashton Kutcher’s twin brother, singer Rick James, Backstreet Boys singer Nick Carter, PGA golfer Erik Compton and Chicago Bears Charles Tillman’s daughter.
Pediatric cardiomyopathy has received little media coverage, and it remains severely underfunded by federal sources and pharmaceutical companies given the severity of the disease. Fortunately, a foundation now exists – the Children’s Cardiomyopathy Foundation (CCF) – that is trying to fill the void in research and education. Founded by a determined mother who lost two children to the disease, CCF has committed nearly $10 million to research and treatment programs, distributes patient education materials to over 70 hospitals in North America, and offers support services to affected families worldwide. I have been involved with CCF the past 3 years raising funds for research (INDICATE YOUR CCF INVOLVEMENT).

I hope that you or someone else at (MEDIA OUTLET) will find value in doing a story on cardiomyopathy. I, along with CCF’s founder and medical advisors, are available for interviews. I can also provide access to other families with diagnosed children.

I look forward to speaking with you, and thank you for your time and consideration.

Sincerely,
YOUR NAME (mother to YOUR CHILD’S NAME, CHILD’S AGE)
YOUR ADDRESS
YOUR TELEPHONE
YOUR EMAIL
Dear Editor,

I’d like to commend your recent article on “Children & Heart Disease” (NAME OF ARTICLE AND DATE OF ISSUE). Four years ago, my family’s life was turned upside down, when my son, (NAME), was diagnosed with dilated cardiomyopathy, a chronic disease of the heart muscle (INSERT YOUR STORY). Little is known about this heart condition when it affects a child. Everyday we live with the fear that (CHILD’S NAME) may need a heart transplant or that HE/SHE might collapse from a sudden cardiac arrest. With more than 30,000 children affected in the U.S., many families face these same anxieties and uncertainties about their child’s future.

That is why I am reaching out to you today. I hope you will consider running a story on pediatric cardiomyopathy and help me inform the public about the realities of this devastating heart disease.

Each year, there are nearly 1,000 new cases - three times the number of U.S. children born with AIDS. What many do not realize is that cardiomyopathy is the leading cause of sudden deaths and heart transplants in children under the age of 18. Although considered one of the most severe pediatric heart diseases, there has not been much medical progress in the field and there are still gaps in knowledge on how to accurately diagnose or properly treat this chronic heart disease.

Pediatric cardiomyopathy has received little media coverage, and it remains severely underfunded by federal sources and pharmaceutical companies given the severity of the disease. Fortunately, a foundation now exists – the Children’s Cardiomyopathy Foundation (CCF) – that is trying to fill the void in research and education. Founded by a determined mother who lost two children to the disease, CCF has committed nearly $10 million to research and treatment programs, distributes patient education materials to hospitals in North America, and offers support services to affected families worldwide. I have been involved with CCF the past 3 years raising funds for research (INDICATE YOUR CCF INVOLVEMENT).
I hope that you or someone else at (MEDIA OUTLET) will find value in doing a story on cardiomyopathy. I, along with CCF’s founder and medical advisors, are available for interviews. I can also provide access to other families with diagnosed children. It is my hope that through increased awareness and research, more lives will be saved, and every affected child will have the chance to live a full and active life.

I look forward to speaking with you, and thank you for your time and consideration.

Sincerely,

YOUR NAME (mother to YOUR CHILD’S NAME, CHILD’S AGE)
YOUR ADDRESS
YOUR TELEPHONE
YOUR EMAIL
Dear NAME,

It was a pleasure to meet with you on (DAY OF MEETING). Thank you for taking the time to talk with me and for your interest in my SON/DAUGHTER’s, (NAME) story.

As I mentioned during our interview, pediatric cardiomyopathy is a chronic disease of the heart muscle. There are an estimated 30,000 children in the U.S. affected by the disease, which is comparable to the number of people with cystic fibrosis. For years, cardiomyopathy has been a misunderstood disease not well known among the general public. This is why media coverage on the disease is so important. Your story can educate many people about the importance of reviewing their family’s heart history, recognizing signs that could lead to an earlier diagnosis, and the need for family screening.

Please let me know if you can provide any additional information for your ARTICLE/BROADCAST. If after reading the press kit materials you have any questions about pediatric cardiomyopathy or the Children’s Cardiomyopathy Foundation (CCF), please do not hesitate to call me. I can also put you in touch with CCF’s founder and medical advisors, as well as other affected families for additional interviews.

Thank you for helping us to share the facts about cardiomyopathy with your audience.

Sincerely,

YOUR NAME
YOUR ADDRESS
YOUR PHONE
YOUR E-MAIL
# NATIONAL MEDIA LIST

## NATIONAL MAGAZINES

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## NATIONAL NEWSPAPERS

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<td><a href="http://www.npr.org">www.npr.org</a></td>
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<tr>
<td>WABC</td>
<td><a href="http://www.abcradio.com">www.abcradio.com</a></td>
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<tr>
<td>WCBS</td>
<td><a href="http://www.wcbs880.com">www.wcbs880.com</a></td>
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