



For the love of life

CYSTIC FIBROSIS QUEENSLAND LTD

Publicity Guide

31 KATE ST KEDRON QLD 4031
PO BOX 2245 CHERMSIDE CENTRE QLD 4032
PH: 07 3359 8000 FAX: 07 3359 3380

FREECALL: 1800 670 990 Email: admin@cfqld.org.au Web: www.cfqld.org.au
ABN: 97 010 549 667

PROMOTING YOUR EVENT OR FUNDRAISING INITIATIVE

Publicity is a great way to attract people to your fundraising event, or to attract donations and support.

So how do you get started?

The first thing to remember is that newspapers, radio and television stations are all in the business of telling stories and spreading news – they need interesting and fresh stories and they want to be contacted by people like you with a great one to tell! Whether a story will run in the end will depend on what other news you may be competing with on that day. The most important thing is to make contact and do your best to stir up some media interest.

In this section you will find:

- some tips for liaising with the media and preparing your media release
- a draft press release that you can modify with details of your event
- Frequently Asked Questions (FAQs) to help you respond to questions asked by media if an interview is conducted.

Here's how to get started:

1. Find out the contact details for editorial staff at your local newspapers, radio stations and television stations. These may be listed on their website, or you can call to ask. Some large news organizations may have specific editors for health or women's issues – try them all!
2. Send your media release to CFQ for approval before it is sent out. Email it to marketing2@cfqld.org.au or fax to (07) 3359 3380.
3. Send the press release to those editorial contacts by fax, email or mail. The media wants to hear your personal story because that is what is most compelling to their readers. Just share with them why you're participating and how others can make a difference by supporting you, etc. Also, give them the web address where they can read your personal profile. You might like to even attach your personal profile to the press release or fax.
4. Follow up with a phone call: The media gets bombarded every day with various requests. Call back and ensure it got in the right hands, ask if they have any questions and confirm whether or not they could do a story, save the date, request for donations--you name it!
5. Post-event: Send them a picture from your event with the results and your personal experience. Direct them again to the web page so their audience can donate to support you online!

Good luck!



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TIPS FOR LIAISING WITH MEDIA

- Always be polite.
- Thank journalists for their interest and support of your event and make it as easy and painless as possible for them to get the information they need to cover your event.
- The easier you make it for the journalist to get the information they need, the more likely they are to cover your event.
- Keep in mind, that the media are interested in what their readers are interested in reading about, which is usually something unusual or different.

One way to think about what might be interesting to the media is to think about your event in terms of what it is —is it the “biggest”, “newest”, “first”, “longest”—or in terms of who is involved, and whether they might have an interesting personal experience to tell about their involvement in the event.

- When preparing your media release, consider:
 - What is the event?
 - Why did you choose to hold this kind of event (e.g. why a business luncheon?, why a school cake stall?, why a work fun run? etc)
 - When is it being held? (day, date, time)
 - Is there any significance for this day/date/time being chosen? (e.g. birthday of loved one, new year's eve etc)
 - What made you decide to put on the event (e.g. a specific personal experience, desire to help a family member or friend, etc)
 - How much money have you raised/ are you aiming to raise?
 - What will the money be used for? (e.g. to buy new equipment, to fund a respite camp etc)
 - Any locally well known personalities attending or taking part in the event?
 - How can people get involved in your event? (e.g. volunteer their time to help out, sign up to join the fun run, enter a team in the trivia night, buy a ticket for an event, make a gold coin donation on Tuesday 3rd April, 2008 at Hilder Road State School... be specific!)
 - How can people find out more information about your event? (e.g. who should they contact if they want to buy a ticket/enter a team/ make a donation etc?)



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Tips for liaising with media (cont)

- If you don't feel comfortable answering a question or if you're uncertain of the answer to a question, don't feel obliged to come up with an answer for the sake of it. Just tell the journalist you're unsure of the answer and that you will either find the information out for them, or direct them to someone else who may be able to answer their question.
- And last but not least, remember that journalists often work to very short deadlines so if you are contacted by a journalist make sure you respond promptly or you may well miss out!



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SAMPLE MEDIA RELEASE

Date:
Contact Name:
Contact Number:

LOCAL WOMAN/MAN/TEAM TAKES UP FUNDRAISING CHALLENGE FOR CYSTIC FIBROSIS QUEENSLAND

Local woman, *Robyn Kelly of Brighton* will be to raise money for Cystic Fibrosis Queensland, a not-for-profit organisation providing emotional, practical and financial support to over 700 children, adults and teenagers living with cystic fibrosis and their families.

Cystic fibrosis (CF) is a genetic, life-threatening chronic illness that affects many of the body's systems including the lungs, digestive system, liver, reproductive system, bones and sweat glands. Currently there is no cure.

To raise money, *Robyn* has organised a on (date) at (location) starting at (time).

Robyn Kelly said of her challenge:

"I have chosen to support Cystic Fibrosis Queensland by because....."

Jane Anderson, CEO of Cystic Fibrosis Queensland said:

"We are delighted that Robyn Kelly is (organising the event/running etc) for Cystic Fibrosis Queensland. Every contribution makes a difference and funds raised will go towards ensuring we can continue to provide vital support to the growing number of people living with cystic fibrosis in Queensland."

Cystic Fibrosis Queensland enhances the lives of Queenslanders affected by CF and their families through provision of counseling and support services. It relies on community support to continue its valuable work with only six per cent of income received from government funding. Over the past four years, demand for Cystic Fibrosis Queensland's services has increased by 27 per cent

ENDS

For more information on Cystic Fibrosis Queensland and our services, visit our website www.cfqld.org.au or call us on (07) 3359 8000.



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HANDLING QUESTIONS FROM MEDIA

One of the situations that may arise as part of your involvement in a community fundraising event is the opportunity to speak with representatives of the media about the event. To help you prepare for this situation, we have prepared the following list of Frequently Asked Questions about cystic fibrosis and the Cystic Fibrosis Queensland organisation that you may like to refer to when speaking with the media.

By using these FAQs as your guidelines when talking with the media you will be helping to ensure we are sending a strong, consistent and positive message to the community about the value of Cystic Fibrosis Queensland's services and doing your part to encourage a greater awareness and understanding of the need to continue to provide support to Queenslanders living with cystic fibrosis.

Cystic Fibrosis Queensland FAQs

Who is Cystic Fibrosis Queensland?

Cystic Fibrosis Queensland (CFQ) is a not-for-profit organisation dedicated to enhancing the lives of Queenslanders living with cystic fibrosis and their families.

Our motto is "For the love of life" – because we believe every person diagnosed with cystic fibrosis deserves the very best possible quality of life they can and we are committed to providing the support to make that possible.

Is Cystic Fibrosis Queensland government funded?

Less than seven percent of its income comes from government funding. This means CFQ relies heavily on the support and generosity of the general public and corporate sponsorships to enable it to provide and extend the services it offers to its clients.

What does Cystic Fibrosis Queensland do?

CFQ provides assistance to Queenslanders living with cystic fibrosis and their families through the provision of:

- medical equipment (e.g. respiratory equipment);
- hospital and clinic transfers;
- physiotherapy services;
- away from home accommodation for families during hospital stays;
- counseling services;
- respite programs (e.g. Mothers' Respite Weekends, Sibling Camps etc); and
- advocacy and education programs.

CFQ also plays a major role in raising public awareness of cystic fibrosis, and the daily challenges faced by Queenslanders diagnosed with the life-threatening disease.



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Where does Cystic Fibrosis Queensland operate?

CFQ services the whole of Queensland and some areas of northern NSW and the Northern Territory via its network of support staff. CFQ has its headquarters in Brisbane but also has an office in Cairns, with plans to open an additional office on the Sunshine Coast in October 2008.

How many people have Cystic Fibrosis in Queensland?

CFQ provides services and support to over 800 Queenslanders living with cystic fibrosis and their families.

Why is there a need to raise funds for Cystic Fibrosis Queensland?

Over the past four years, demand for CFQ's services has increased by 27 percent yet only six per cent of income is received from government funding. Without the donations and support of the community, CFQ cannot provide these much needed services to Queenslanders who face the daily challenges of living with CF, and the stresses it brings to them and their families.

What is cystic fibrosis?

Cystic fibrosis (CF) is the most common life-threatening, recessive genetic condition affecting Australian children. There are over 3000 Australians who have CF at any one time. CF affects the lungs and digestive system however with improved medication and treatment, life expectancy has been extended considerably.

How do people get cystic fibrosis?

CF is an inherited condition. For a child to be born with CF both parents must be genetic carriers for CF. They do not have cystic fibrosis themselves. One in every 2,500 Australian children is born with CF. One in every 25 people, often unknowingly, carries the cystic fibrosis gene. Every four days a child is born with cystic fibrosis. More than one million Australians carry the faulty CF gene. 80% of parents who have a child with CF were unaware they were carriers.

Is Cystic Fibrosis contagious?

CF is not contagious and is strictly genetic. Coughing is a frequent symptom of CF. Because of this, some people are afraid they may catch it, but CF is an inherited condition which is present at birth. You cannot 'catch' CF and you cannot give it to anyone else.



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How is CF diagnosed?

In Australia, all babies are screened at birth for CF. A blood spot test is applied and if this test proves to be positive, a sweat test will be done to measure the amount of salt in the sweat and it is with this test that a final diagnosis is made.

What happens?

In cystic fibrosis there is a problem with the protein that controls the movement of salt in and out of the cells. Too much salt in the cells causes mucus to be very thick and stick and to build up in organs like the lungs. The mucus clogs the tiny air passages in the lungs and traps bacteria.

Repeated infections and blockages can cause irreversible lung damage and death. Mucus can also cause problems in the pancreas preventing the release of enzymes needed for the digestion of food. This means that people with CF can have problems with nutrition.

Can CF be diagnosed before birth?

Yes, if there is already a child with CF in the family then testing can be carried out at 10 weeks of pregnancy. Parents of a child with CF are encouraged to have genetic counselling before planning a further pregnancy.

Is CF carrier testing available?

Following the discovery of the CF gene in 1989 it is now possible to offer carrier testing. However, this is not a simple matter as whilst there is one most common gene for CF, there are over 900 mutations of the gene. Because of this, carrier testing is usually offered only to those people who have a family history of CF. However the availability of testing varies from state to state in Australia. Further information is available from CF Associations or genetic counselors.

What are the symptoms of CF?

People with CF may have the following symptoms:

- persistent cough, particularly with physical effort
- some difficulty in breathing or wheezing with effort
- tiredness, lethargy or an impaired exercise ability
- frequent visits to the toilet
- salt loss in hot weather which may produce weakness
- poor appetite.



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How is CF treated?

Treatment for CF can be intensive and time consuming. At present there is no cure for CF and treatment is therefore aimed at slowing progression of the condition.

Treatment has improved greatly in recent years and advances continue to be made. Studies have provided that regular attendance at a major CF centre or clinic is beneficial. This enables people to experience the expertise of the CF team which includes doctors, physiotherapists, dietitians, social workers and nurses.

Lungs

Treatment for lung problems includes:

- chest physiotherapy
- antibiotics
- inhalations via compressed air pump and nebuliser

Most people will require this treatment on a regular daily basis and some may require aerosol medications to assist breathing.

Exercise is encouraged on a regular basis to maintain a healthy lung capacity. Sport and aerobic exercise are recommended for all age groups of people with CF.

It is common for people with CF to encounter some difficulties with their lungs. A combination of airway clearance techniques and medication can help control lung infections and prevent lung damage. To avoid the risk of cross infection, people with CF need to ensure they do not come into close contact with others with CF.

Digestion

CF affects the pancreas (which produces the enzyme needed to digest food) and makes it difficult for people with CF to absorb food. This can cause malnutrition, which can lead to poor growth, physical weakness and delayed puberty. There is medication that can compensate for the failure of the pancreas.

To improve absorption of food, most people with CF require enzyme replacement capsules with meals and snacks.

To improve nutrition and maintain body weight a well balanced diet high in protein, fat and calories is required.

Some people may also require supplementary vitamins.

In older patients, insulin production can become deficient due to increasing pancreatic disease.



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Some develop CF related diabetes and their blood sugar levels are no longer controlled. However, this rarely happens to children with CF. Common symptoms of diabetes include thirst, hunger, weight loss and excessive need to urinate, but some people do not show obvious symptoms of diabetes.

Sweat glands

Salt supplements and additional fluids are required in hot weather, during strenuous exercise and in cases of fever.

Other affected organs

In every 10 babies born with CF, one is ill in the first few days of life with a bowel obstruction called meconium ileus. In these cases, the meconium (a thick black material present in the bowels of all newborn babies), is so thick that it blocks the bowel instead of passing through. Babies with meconium ileus often need an urgent operation to relieve and bypass the blockage.

People with CF are prone to osteoporosis (thin, brittle bones) due to the nutritional and other problems involved with the disease. Adults with CF are at an increased risk of osteoporosis because of the adverse effects of steroids taken to control lung disease.

Although CF does not cause sexual impotency it can lead to fertility problems. In most men with CF, the tubes that carry sperm are blocked, which causes infertility. Because underweight women are more likely to have irregular menstrual cycles, the nutritional problems associated with CF may affect fertility. However, women with CF do produce healthy, fertile eggs so effective contraception is necessary.

CF can cause the blockage of small ducts in the liver. This only happens to approximately 8% of people who have CF.

Is diabetes related to CF?

A small percentage of people with CF may also develop diabetes (another function of the pancreas is the production of insulin). However, this is not common before the teenage years.

What is the life expectancy for people who have CF?

CF is no longer just the childhood disease it was years ago when most children did not survive their teen years. Today life expectancy for many people with CF has increased to their 30s and 40s and they are leading active and productive lives.

Will CF affect a child's schooling?

CF does not impair intellectual ability in any way. Most students with CF have a good attendance record but will require time off for clinic appointments and possible hospital admissions.



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Does a lung transplant cure CF?

The transplanted lungs come from people who do not have CF, so the new lungs do not have and will not develop CF. However, after transplant, the person still has CF in the pancreas, sweat glands, sinuses and reproductive tract. The person still has to take enzymes with food and to help absorb the anti-rejection medications.