CLCGB

Your journey starts here...

Cystic Fibrosis Awareness

17th - 21st July 2019

Project Brief

Prepared for: The Church Lads' & Church Girls' Brigade in conjunction with the Cystic Fibrosis Trust

Supporting

Cystic Fibrosis Trust

SUMMARY

Objective

The objective of this to raise awareness of Cystic Fibrosis and take part in a challenge to raise money.

Project Outline

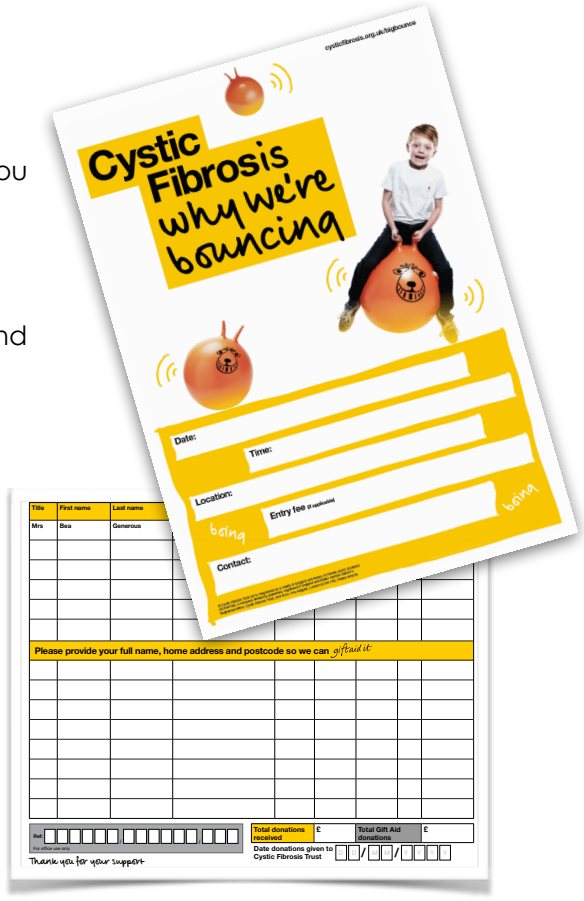
- Project encourage to take part over 2 weeks.
- **First Week:** Members to learn about the Cystic Fibrosis condition using the material provided in this brief and discuss and agree the Big Bounce challenge.
- Members to take home sponsor forms for the challenge and information to inform parent/ guardian of the project.
- **Second Week:** Big Bounce challenge to take place.

It is suggested that sponsorship is sent to to National Headquarters and will then be added up and sent to the Cystic Fibrosis Trust together. Companies to let NHQ know if they are taking part.

MATERIALS

Poster

Poster for the Big Bounce Challenge to advertise in the place you meet



Advertising

If you would like further advertising such as banners, balloons and collection tins then please contact the Cystic Fibrosis Trust at gemma.williamson@cysticfibrosis.org.uk

Equipment

Bouncy hoppers are available from the Cystic Fibrosis Trust if required

Sponsorship Form

Sponsorship form included in the pack to give out to members to take home

Certificate

Certificate can be printed for each member that took part

What is Cystic Fibrosis?

Cystic Fibrosis is a genetic condition that affects around 10000 people in the UK. It is a life limiting condition that affects the lungs and digestive systems. People with CF take a lot of medication and require a lot of treatment maintain their health.

https://youtu.be/4lGz5p4n8Fg This is a good video to show the members which sums up what Cystic Fibrosis is by someone who has CF.

https://youtu.be/WuI72eMrlQI This video is aimed at younger children

https://youtu.be/AVg24S_pSmo This video is aimed at older children

There also lots of information available at www.cysticfibrosis.org.uk

Advertising

Advertising for the CF Trust and also for CLCGB would be beneficial for both organisations. If any groups would like to advertise their project and the fundraising work they have done then you could contact local newspapers and use social media.
Please take pictures, if you have consent from members, and we can gather them together to use as a national story as well.

It is important to be seen to be raising money for other organisations as well as CLCGB. This will bring the people within your company together and be able to advertise the good work your company is doing for others.

Cystic Fibrosis what, exactly?

Cystic fibrosis (CF) is a life-shortening genetic condition that slowly damages the lungs and digestive system.

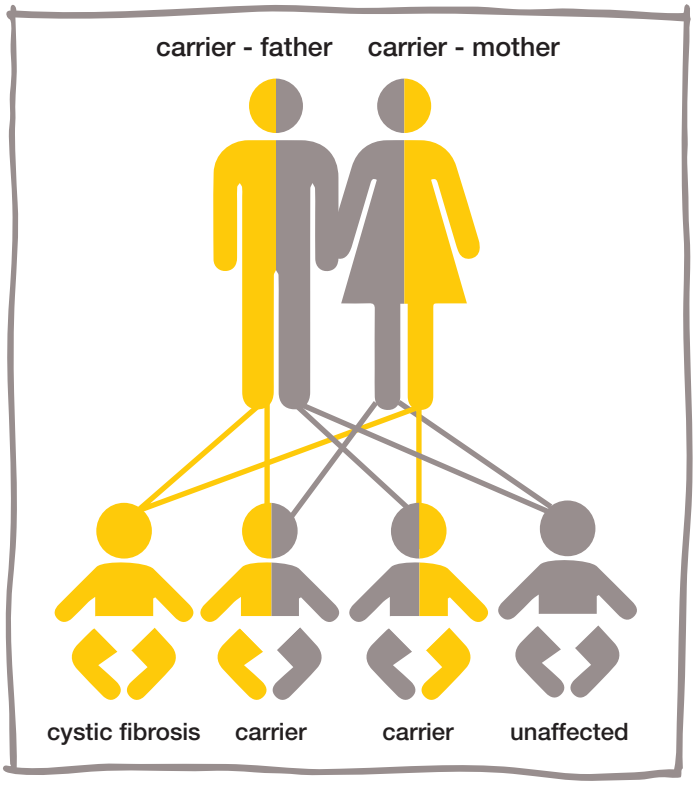
How do you get cystic fibrosis?

Cystic fibrosis is an inherited condition caused by a faulty gene. You can't catch cystic fibrosis, or develop it later in life. For someone to have CF, they must inherit two copies of the faulty gene – one from each of their parents.

The faulty gene is carried by 1 in 25 people.

A carrier does not have cystic fibrosis, they just carry one copy of the faulty gene that causes it. If two people who carry a copy of the gene (carriers) have a baby, there is:

- **a 25% chance the baby will have cystic fibrosis**
- **a 50% chance the baby will be a carrier of the faulty cystic fibrosis gene**
- **a 25% chance the baby will neither be a carrier nor have cystic fibrosis**



How does cystic fibrosis affect the body?

The faulty gene disrupts the movement of salt and water in the body's cells, causing the mucus that naturally occurs in the body to be thicker and stickier than in people without cystic fibrosis. This sticky mucus causes problems, particularly in the lungs and digestive system, but can also affect other parts of the body. The small airways in the lungs can get clogged up with the mucus, causing infection and, over time, damage to the lungs. For many people with CF, blockages in the pancreas mean a lifelong need for enzyme supplements and a special diet.

People with cystic fibrosis often have some or all of these symptoms:

- frequent chest infections
- a severe or prolonged cough
- wheezing or shortness of breath
- abnormal bowel movements
- difficulty gaining weight, and
- for most men, infertility.

How many people have cystic fibrosis?

There are more than 10,400 people living with cystic fibrosis in the UK.

Each week in the UK five babies are diagnosed with the condition.

Who gets cystic fibrosis?

The vast majority of people with cystic fibrosis are Caucasian. However the condition is found in many different ethnic groups.

How is cystic fibrosis diagnosed?

Cystic fibrosis is usually diagnosed soon after birth through the routine heel prick test. Older children and adults who were not screened at birth may be diagnosed with cystic fibrosis later in life.

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Can I be screened to see if I am a carrier of the faulty gene?

A simple blood test can establish if someone is a carrier of the CF gene. Carrier testing may be available on the NHS if a relative has cystic fibrosis.

How is cystic fibrosis treated?

A range of daily treatments is needed to tackle cystic fibrosis effectively, including:

- antibiotics to fight infection in the lungs
- physiotherapy to help shift the mucus that builds up around the organs
- enzyme capsules with food
- a special diet to ensure the body gets the nutrients it needs
- drugs to thin mucus, and
- if conventional treatments are no longer effective, a lung transplant might be needed.

People with CF can spend a long time each day doing their treatments.

Is there a cure?

There is currently no cure for cystic fibrosis.

Each week in the UK two people die of the condition.

However, understanding and treatment of cystic fibrosis are improving all the time.

What is the life expectancy?

Cystic fibrosis affects everyone differently, so it's hard to say what an individual's life expectancy is. The most recent figures suggest that half of people with CF will live past their 47th birthday, but it's thought that a baby born today with cystic fibrosis could live longer as life expectancy continues to increase with advances in treatment and care.

Can people with cystic fibrosis live a normal life?

Cystic fibrosis is a serious condition that needs careful management. However, with the right care and treatment, people with cystic fibrosis can lead a full life, albeit with compromises and challenges. Many people with CF are able to work, travel and have families.

I've heard people with cystic fibrosis cannot meet each other – is that true?

People with cystic fibrosis are prone to lung infections that can be very harmful to others with the condition. Each person may carry different bugs in their lungs, which can be passed on by being around each other. To avoid the risk of cross-infection, people with cystic fibrosis are advised not to mix with each other at all.

How do we help?

As well as working hard to create a brighter future for people with CF, the Cystic Fibrosis Trust is supporting people affected by CF in the here and now.

Our helpline offers a confidential information and listening service for all worries or questions, big or small. Peer-to-peer support is available through our CF Connect service and on the online forum; both offering support through sharing with others affected by cystic fibrosis.

The Cystic Fibrosis Trust can also provide financial assistance in times of need or even to help with the cost of holidays. Contact our helpline on **0300 373 1000** for more information about these services.

How can you help us?

Supporters of the Cystic Fibrosis Trust generously donate their time, money and voices to help us fight for a life unlimited by cystic fibrosis. There are lots of ways you can help, for example:

- Spare some time and **organise a fundraising event**
- **Make a donation** – either personally or get your workplace involved
- **Lend your voice** to our campaigns or to raise awareness of the condition

Take a look at **cysticfibrosis.org.uk/get-involved** for more information on getting involved with the Trust. To make a donation please visit **cysticfibrosis.org.uk/donate**.

What does the Cystic Fibrosis Trust do?

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited by cystic fibrosis for everyone affected by the condition. We invest in cutting-edge research to develop improved treatments, drive up standards of clinical care at specialist CF centres and clinics across the UK, provide trusted information, advice and support to those affected, and campaign hard on the issues that matter.

How can I find out more about cystic fibrosis?

Visit our website **cysticfibrosis.org.uk**

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cysticfibrosis.org.uk/bigbounce

Cystic Fibrosis why we're bouncing

Date:

Time:

Location:

boing

Entry fee (if applicable)

Contact:

boing

Cystic Fibrosis why we're fundraising

Cut out each of the pieces of bunting along the dotted lines. Use a hole-punch to cut out two small circles at the top of each flag. Thread the shapes onto a piece of string.

Cystic Fibrosis why we're fundraising

cysticfibrosis.org.uk

Fighting for a Life Unlimited

Cystic Fibrosis why we're fundraising

cysticfibrosis.org.uk

Fighting for a Life Unlimited

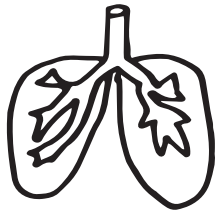
Cystic Fibrosis a fight we must win

How to organise a Big Bounce event

Spring into action with Big Bounce fundraising in aid of the Cystic Fibrosis Trust.

Events and fundraising enquiries:
t: 020 3795 2176 or e: events@cysticfibrosis.org.uk

1



Clear lungs

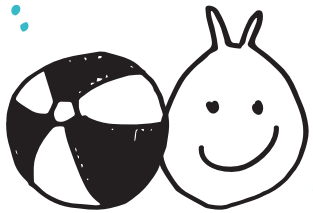
Bouncing is a fun way for people with cystic fibrosis to help clear the mucus from their lungs.

2

Raise awareness

Organising your own bouncing event is a great way of raising awareness of cystic fibrosis.

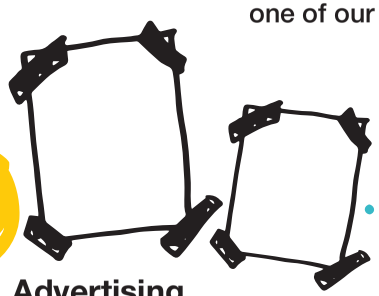
3



We can help

We at the Cystic Fibrosis Trust can provide you with a space hopper or beach ball.

4



Advertising

We can also provide you with posters, banners, stickers, and leaflets.

5

How would you like to bounce?

You could use a trampoline, bouncy ball, pogo sticks, a bouncy castle or even one of our space hoppers.

6

Create your own

Remember to get creative you can even come up with your own way of bouncing and set everyone challenges.

7

Contact us

For help with your event and to order your materials simply contact the events team on **0203 795 2176** or e-mail us at **events@cysticfibrosis.org.uk**

“ Our Big Bounce took place with the help of the local primary school, Ysgol Bro Dewi in St. Davids. The sixth form helped to organise it and they came up with the idea of having a race track around the football pitch. All of the classes had great fun taking part and they raised £800.”

Mother with two daughters with CF, Pembrokeshire branch

cysticfibrosis.org.uk/howto

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Title	First name	Last name	Home address	Postcode	Amount pledged £	Date received	Gift Aid?	Gift Aid amount £ (for office use only)
Mrs	Bea	Generous	123 Street, My Town	ABC 123	£10.00	01/10/2103	√	

Please provide your full name, home address and postcode so we can *giftaid it*

Ref: ☐☐☐☐☐☐/☐☐☐☐☐☐/☐☐☐☐

For office use only

Total donations received	£	Total Gift Aid donations	£

Date donations given to Cystic Fibrosis Trust D D / M M / Y Y Y Y

Thank you for your support

Sponsors: please print clearly in block capitals

In order for Gift Aid to be claimed, sponsors must complete the form in their own handwriting.

Please photocopy this form if you need more space, but please return to us all forms written on by sponsors so that we can process Gift Aid.

Name of participant: _____ Event: _____

Record of pledges and gift aid declarations

Cystic Fibrosis counting on your support

Sponsorship form

Event:

Date of event:

Full name:

Home address:

Postcode:

Phone (daytime):

Phone (mobile):

Email:

Would you be happy to hear from us about:

Other events and activities you can get involved in?
☐ yes ☐ no

The Trust's work and other ways you can make a difference? ☐ yes ☐ no

How would you like us to stay in touch?
Mail ☐ yes ☐ no **Email** ☐ yes ☐ no **Phone** ☐ yes ☐ no

Please note that we aim to send emails where possible to save money, but will sometimes contact you by mail or phone.

Once your fundraising is complete, please return this form together with all the money you raise.

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cysticfibrosis.org.uk

Cystic Fibrosis invisible. But not invincible

40

Around half of people with cystic fibrosis will not live to celebrate their 40th birthday.

You can't catch cystic fibrosis – it's a genetic condition you're born with – and there's currently no cure.

More than two million people carry the faulty gene that causes cystic fibrosis, most without knowing it.

With your help we can develop better treatments to stop cystic fibrosis in its tracks.

cysticfibrosis.org.uk/donate

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Cystic Fibrosis a lifelong challenge

60

is the average number of tablets that people with cystic fibrosis have to take every day.

People with cystic fibrosis, like David, soon learn it's a lifelong challenge: vast daily intakes of drugs, time-consuming physiotherapy and isolation from others with the condition, just to stay healthy.

Despite this, it can critically escalate at any moment.

We're here to shout louder and make a daily difference to people with cystic fibrosis and those who care for them, but we need your help.

cysticfibrosis.org.uk/donate

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Cystic Fibrosis what, exactly?

Cystic fibrosis (CF) is a life-shortening genetic condition that slowly destroys the lungs and digestive system.

10,400+ people are living with cystic fibrosis in the UK, and each week five babies are diagnosed with the condition.

There is currently no cure for cystic fibrosis, and each week in the UK two people die of the condition.

What does the Cystic Fibrosis Trust do?

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited by cystic fibrosis for everyone affected by the condition. We invest in cutting-edge research to develop improved treatments, drive up standards of clinical care at specialist CF centres and clinics across the UK, provide trusted information, advice and support to those affected, and campaign hard on the issues that matter.

Find out more by visiting cysticfibrosis.org.uk

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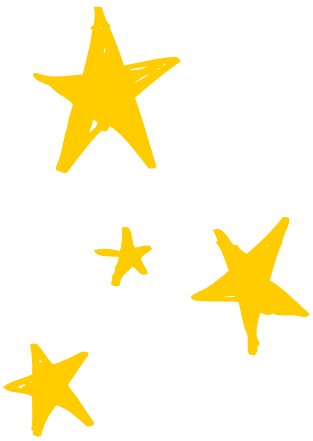
Cystic Fibrosis is grateful for your support



presented to

_____

for

_____

_____

Thank you for your contribution, which will help us invest in cutting-edge research, drive up standards of care, offer support for everyone affected by cystic fibrosis, and campaign for change. With your support, cystic fibrosis is beatable.

date_____

Thank you!

cysticfibrosis.org.uk

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