Cystic Fibrosis Trust: Access to Medicines campaign - supporting material

Link to campaign timetable https://www.cysticfibrosis.org.uk/the-work-we-do/campaigning-hard/life-saving-drugs/campaign-timeline

PRESS RELEASE

Strict embargo: 00:01hrs GMT - Thursday 7 March, 2019

CYSTIC FIBROSIS TRUST CALLS FOR IMMEDIATE ACCESS TO LIFESAVING DRUGS

The Cystic Fibrosis Trust is urging NICE, NHS England and the pharmaceutical company Vertex to reach a deal on the cost of life transforming cystic fibrosis drugs and make them available on the NHS without delay.

The House of Commons Health & Social Committee Inquiry is hearing evidence from Vertex Pharmaceuticals, NICE and NHS England regarding the ongoing and protracted negotiations for the drugs Orkambi and Symkevi* to help move discussions forward and break the stalemate between the three parties, today (Thursday 7 March).

Orkambi is the second precision medicine that targets the root cause of the disease and would benefit around half of people with Cystic Fibrosis (CF) in the UK.

It has been licensed for use for over three years, but a deal is yet to be struck that makes it available for patients in England on the NHS. During that time, a third drug to treat the root cause of the condition, Symkevi, has been approved for use but is not available on the NHS.

David Ramsden, chief executive of the Cystic Fibrosis Trust, said: 'All three parties – NICE, NHS England and Vertex - must reach a compromise and end the agonising three year wait for this these life-saving medicines. Each day that passes without a deal means the risk of more damage to the lives and prospects of thousands of children and adults with cystic fibrosis across the UK. This tragic situation must end. We hope the Committee can support efforts to find a

deal. We know from countries around the world that it is possible to reach an agreement and we remain committed to supporting all parties to find a compromise that works. We don't want to see people with cystic fibrosis once again be subjected to the anguish of the divisive public spat. No more excuses, we need action now.'

Emma Boniface, 30 from London who has Cystic Fibrosis, said: 'Knowing Orkambi is available and I am denied access to it is devastating. I've struggled to maintain my health and stayed hopeful that one day CF won't be as debilitating as it is. Knowing the outcome of my health is in the hands of strangers and, based upon a monetary value is scary, dehumanising and extremely distressing.'

Macauley Tinston, 22 from Northamptonshire, who has Cystic Fibrosis, said: 'I take drugs everyday just to tick along but taking Orkambi would double my days. It's disheartening to know that Orkambi is there, but not available to me. It's as if the battery on my clock is running out and a replacement is just a fingertip away, but I can't have it. It's upsetting that there has been such hard work and research into providing ground-breaking treatment, just for it to not be accepted due to a financial agreement.'

Jenny Agutter, Call the Midwife actor whose niece has Cystic Fibrosis, said: 'Today is a landmark in the fight for access to life-changing cystic fibrosis medicines. I hope that The Health Select Committee urge all parties involved to find common ground and end this unacceptable wait.'

-Ends-

Notes to editors

For media enquiries contact the Cystic Fibrosis Trust press office on 0203 795 2193 or pressoffice@cysticfibrosis.org.uk

*Orkambi is a combination medicine, made up of ivacaftor and lumacaftor. Lumacaftor helps get more proteins to the surface of cells in the body's organs, and ivacaftor helps the chloride channels in the cells to operate more effectively. The combination of these two things helps to keep a healthy balance of salt and water in the organs. Orkambi is manufactured by Vertex Pharmaceuticals.

**Symkevi is a new, dual combination therapy which uses two drugs together in one treatment. Symkevi combines ivacaftor with new drug compound tezacaftor, supporting chloride transfer in the body's cells. Symkevi is manufactured by Vertex Pharmaceuticals.

About Cystic Fibrosis

Cystic fibrosis is an inherited disease caused by a faulty gene. This gene controls the movement of salt and water in and out of your cells, so the lungs and digestive system become clogged with mucus, making it hard to breathe and digest food.

- Half of all people who died with Cystic Fibrosis last year were under the age of 31
- There are over 10,400 people with cystic fibrosis living in the UK and the population is growing every year
- Two million people in the UK are carrying the faulty gene without realising it. If two carriers have children, there's a one in four chance their child will have the condition, which slowly destroys the lungs and digestive system
- People with cystic fibrosis often look perfectly healthy. But it's a lifelong challenge involving a vast daily intake of drugs, time-consuming physiotherapy and isolation from others with the condition. It places a huge burden on those around them and the condition can critically escalate at any moment
- Half of people with cystic fibrosis alive today are expected to live into their forties, thanks to earlier diagnosis and ongoing developments in care and treatments

About the Cystic Fibrosis Trust

- The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited for everyone affected by cystic fibrosis
- For confidential advice, support and information on any aspect of cystic fibrosis, including help with financial support contact the Cystic Fibrosis Trust helpline on (+44) 0300 373 1000 or 020 3795 2184
- The work we do is only made possible by the generous donations from our supporters. Visit www.cysticfibrosis.org.uk to find out more about cystic fibrosis, the work of the Trust and how you can help our fight for a life unlimited.
- To support our fight for a life unlimited by cystic fibrosis text BEATCF to 70500 to give £5 to the Cystic Fibrosis Trust. Terms

Cystic Fibrosis reactive statement: 27 March 2019

We have responded to news today that the drugs company Vertex have thrown thousands of packets of the life-saving drug Orkambi in the bin as they are out of date. The news is in this letter from the drug company to the MP Sarah Wallaston MP following the evidence session at the HSC select committee hearing on 7 March 2019 - https://twitter.com/CommonsHealth/status/1110893560793055232?s=19

Statement

David Ramsden, Chief Executive at the Cystic Fibrosis Trust, said: "It's heart-breaking that packets of lifesaving drugs have been thrown away because they're out of date – what a desperate waste. Thousands of people have suffered while these drugs have been sitting on the shelf. It is vital the talks that have started deliver a real result now. All parties involved must reach a deal immediately so that we can put an end to any further unnecessary death and deterioration."

Blog: Marking three years since Orkambi

Blog - Nick Medhurst, Head of Policy and Public Affairs - 23/11/2018

This week saw the third anniversary of the precision medicine Orkambi being licensed for use in the UK, while arguments over funding mean people with CF continue to be denied access. The Trust's Head of Policy and Public Affairs, Nick Medhurst, reports back from a week of events that united the whole CF community to turn up the noise on the vital issue of access to medicines.

Marking three years of denial of <u>Orkambi</u> to people with cystic fibrosis (CF) in the UK was never going to be easy and it has been a busy and emotional week for all who have taken part.

We have been across the UK, raising the issue with decision-makers, politicians, government agencies and the manufacturer, Vertex Pharmaceuticals, and we, alongside people with CF and their families, have pressed home the tragedy of lives and health lost unnecessarily as a stand-off on price drags on interminably.

However, it has also been a week of positivity and renewed optimism, and having been to Cardiff and the Welsh Assembly, the Houses of Parliament in Westminster, and the Scottish Parliament in Holyrood in the past seven days, I know that we have powerful forces pulling with us toward a positive outcome.

In Westminster particularly, November has seen the fight for precision medicines for CF reach a new level, as Dr Sarah Wollaston MP, Chair of the Health and Social Care Committee, called upon the negotiating parties to provide evidence of their discussions, offers and counter-offers so that we can begin to unpick why people with CF are being forced to wait.

The Prime Minister comments on Orkambi



On Wednesday, Prime Minster Theresa May addressed the House of Commons, responding to a question from Heidi Allen MP, and said that she will make sure that the Department of Health and Social Care works to get the right outcome for people with cystic fibrosis.

Heidi Allen's question was prompted by listening to the Cystic Fibrosis Trust's Lynsey Beswick at an event in Parliament (pictured) hosted by Ian Austin MP on Monday, which was attended by 63 MPs.

Lynsey, our Public Affairs and Advocacy Manager, spoke powerfully and heartbreakingly of her personal experience of living with the condition and the struggles of watching her fragile health decline over the last few years. She fought back tears as she spoke of watching her friends with the condition dying and feeling helpless to do anything, whilst knowing that there is a drug out there that could help.

The room was hushed, and Lynsey's voice and message carried all the way to the Prime Minster two days later.



The Westminster event was attended by another 20 people from the CF community, families representing loved ones back home – and we were (unexpectedly!) joined by a young man living with CF who works in the office of a Member of Parliament.

People in Northern Ireland were represented by three families who joined the event and met with five Northern Irish MPs (pictured), who committed to represent their interests in Belfast, while the Stormont Assembly remains suspended.

Petition for Orkambi reaches Vertex



It was a very special event in a very special day that also saw the CF community march to Vertex Pharmaceuticals headquarters in Paddington and hand in a petition of 70,000 signatures asking them to make their medicines affordable for the NHS, before heading to NHS England's London Headquarters, where a small group met with officials to discuss the issue.

At 6pm, after a very long day, we all gathered in Parliament Square (pictured), as rain fell on a cold, dark night, to reflect on lives lost to CF, in a vigil of remembrance.

Campaigning for access to medicines across the UK

This flurry of activity had followed a cross-party meeting at the Senedd in Cardiff. David Rees AM chaired a meeting that took evidence from the Welsh Government, Vertex Pharmaceuticals and the Cystic Fibrosis Trust, including the testimony of a woman with CF and a young mother of a child with the condition. Assembly Members present spoke of how moved they had been by the stories and pleas of their constituents and committed to a series of actions that they hope will put Wales and Welsh people with CF back in the driving seat on pushing for access to new medicines.

David and his cross-party colleagues will meet privately with Cabinet Secretary for Health and Social Services, Vaughan Gething AM, and have offered their support and assistance with Sarah Wollaston MP's Westminster inquiry.

On Wednesday night, Jackie Baillie MSP hosted us alongside representatives of Scottish government, a dedicated group of supportive, crossparty MPs (including Anas Sarwar MSP, Alex Neil MSP, Alexander Cole-Hamilton MSP and Miles Briggs MSP), and more than a dozen families.

People with CF were represented by their mothers, fathers, aunts, uncles, grandparents, husbands, partners, brothers, sisters, and a son and daughter.

It brings home the shattering cruelty of the disease that the only person with CF who was due to and could attend (because of the risk of cross-infection), Kelli Gallagher of Glasgow, was too unwell, as she starts a new course of IV antibiotics.

Why Orkambi and Symkevi matter

We heard stories from families where Orkambi is transforming lives, and we heard the heartbreaking story of Stewart Kelly, from his mother and aunt, for who Orkambi and latterly <u>Symkevi</u>, were granted on compassionate grounds, far too late to save the life he lost in June this year, aged just 30.

It was a hugely poignant and engaging session as MSPs looked for every way they can work together to move the situation forward and collectively support the Cabinet Secretary, Jeane Freeman MSP, to find the right outcome. They agreed a plan of action and we have offered all our support to help them take the issue forward.

Attention turns now to Vertex Pharmaceuticals as we call on them to make full submissions relating to all their licensed medicines to both the Scottish Medicines Consortium (SMC) and National Institute for Health and Care Excellence (NICE), the bodies responsible for advising governments of investment in medicines.

We need access to medicines now

We understand that Vertex is speaking to both bodies, but talk is cheap. All parties must find the compromise and flexibility to end the wait and give so many families more than just hope, but the guarantee that they will be able to benefit from the latest advances in CF care.

To be crystal clear, we want Orkambi now, we want Symkevi now and we want the next generations of drugs on the very first day they are available.

Our campaign ends when we've beaten CF for good. Until then, we're not going away.

Be the first to hear about the latest campaign actions in your area by signing up to our campaigning mailing list today.

Life Saving Drugs Now Campaign Communications Evaluation for 6th-8th March 2019











Top NHS doctor questions 'moral compass' of drug firm boss

Chris Smyth, Health Editor

5.00pm, Thursday March 7 2019









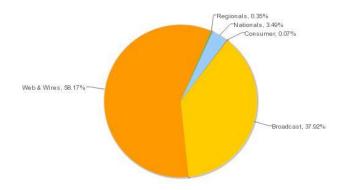
Total clips – 160 pieces Circulation of 49.5 million people Ave - £500,000

National Broadcast - 4
(including BBC Breakfast Wales and Scotland)
National Print - 12
Regional Broadcast - 51
Regionals print - 11
Web &Wires - 77
Consumer - 1

Audience

The majority of our audience heard about the campaign key messages calling for life-saving drugs now from viewing the news online (58.17%) and through TV and radio (37.92%) The highlights included BBC Breakfast (England, Scotland and Wales) with over 4 million viewers, Sky News Sunrise with 2 million viewers and Sky News watched by 5.5 million.

TOTAL CIRCULATION, SUMMARISED BY MEDIA TYPE Date Range: 06/03/19 to 08/03/19 - Total Clips: 158



MEDIA TYPE TOTAL NUMBER OF CLIPS TOTAL CIRCULATION PERCENTAGE

Note: Circulation figures were unavailable for 5 clips.

Broadcast	55	18,648,412	37.92%
Consumer	1	35,637	0.07%
Nationals	12	1,716,780	3.49%
Regionals	11	170,312	0.35%
Web & Wires	77	28,608,872	58.17%
X: USA Web & Wires	2	0	0.00%

BREAKDOWN

Broadcast

1. BBC Breakfast 8.15am (David Ramsden from the Trust and Lucy Baxter)

- 2. Sky Sunrise at 7.15am (Rebecca Cosgriff form the Trust and Rebecka Bowe a case study from Wales attending the demo)
- 3. BBC Kent, ITV Regional and Sky News all covered the demo (David Ramsden was interviewed for BBC Kent)
- 4. Our spokesperson Ollie Lewington also featured on BBC Radio Cumbria (7.05am) and BBC Radio Surrey (8.05am) and BBC Parliament covered the select committee hearing

CF sufferer and case study Lucy Baxter, 21 from Preston, on BBC Breakfast sofa with David Ramsden, Chief Executive of The Cystic Fibrosis Trust on BBC Breakfast down the line.







Rebecca Cosgriff form the Cystic Fibrosis Trust with case study Rebecka Bowe, 39 from Wales, on the Sky Sunrise sofa. Rebecka's 9 year old daughter Sophia is eligible for Orkambi



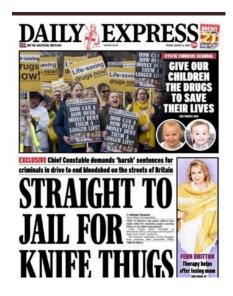


Three outlets covered the demo outside Parliament including Sky News, BBC Kent and ITV Regional (Below David Ramsden, Chief Executive of The Cystic Fibrosis Trust on BBC Kent, TV)



National Print & Online breakdown

- o **Daily Express** covered the story as their front page on both the 7th and 8th March 2019 with a total of 7 articles over the two days including a comment piece penned by **MP Crispin Blunt**
- o The Guardian covered the story on the 6th and the 7th (Sarah Boseley). While Jane Kirby's article in PA featured in The Independent.
- o **Polly Toynbee** wrote an opinion piece for comment is free in the **Guardian online** and **Chris Smythe** at **The Times** also reported on the scandal.
- o **The Daily Telegraph** featured the story on p2. While <u>ITV Online</u>, <u>Sky News online</u> and the **New York Times International** also reported on the demo and select committee hearing.





THE TIMES





Top NHS doctor questions 'moral compass' of drug firm boss

Chris Smyth, Health Editor

5.00pm, Thursday March 7 2019

KEY NATIONAL COVERAGE

6th March 2019

Daily Express

• Tweet raises fears of 'no change' over vital drugs (print only, p14)

The Guardian (online)

o Firm in NHS row paid no UK tax

7th March 2019

Daily Express (Front page story continued on p6 and p14)

Chris Riches

Showdown in fight for drug to save children (p6)

Make deal or my brave lad will die far too soon (print only, p6)

o Crispin Blunt, Tory MP for Reigate

COMMENT, (print only, p6)

Independent

Jane Kirby at PA,

Cystic fibrosis patients 'at their wits' end' (print only, p4)

The Guardian

Sarah Boseley,

Drug firm that charges £105,000 a patient pays no corporation tax (print only, p14)

8th March 2019

The Guardian (online)

Polly Toynbee, Comment is Free,

Sick children denied cystic fibrosis drugs is grim forecast for post Brexit NHS

The Times

o Chris Smyth

Top NHS doctor questions moral compass of drug firm (print only)

Daily Telegraph

NHS deadlock over cost of cystic fibrosis drugs (p2)

Daily Express (Front page story continued on p4, p5, p12)

o Chris Riches

Drug boss hides in limo as families beg for help (p4)

o Martyn Brown

'Pay up and you can have Orkambi in just four weeks (p5)

Has this man no shame? (print only, p12)

Digital and social media breakdown

Traffic to our website was up by almost one third (31.75%) in comparison to last year and almost three quarters (75.45%) were organic visitors suggesting the media coverage helped to drive the increase.

2019 – 9,056 users (up by 31.75%)

2018 – 6,883 users

2019 channels

Organic – 75.45%

Direct - 9.81%

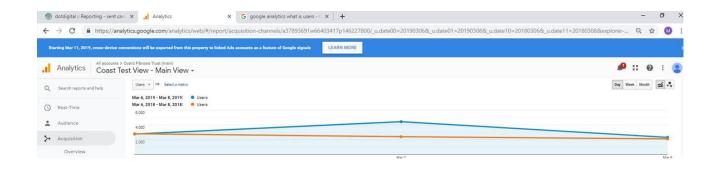
Paid Search – 4.99%

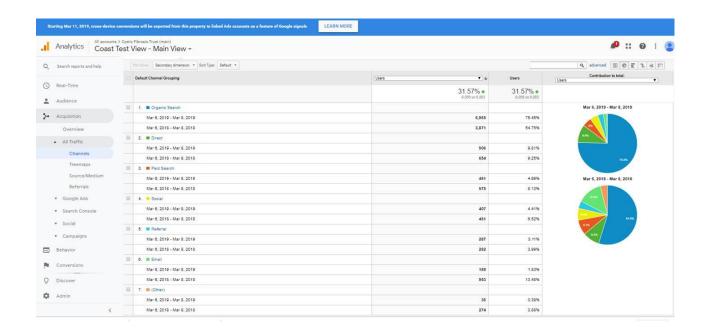
Social – 4.41%

Referral – 3.11%

Email – 1.83%

Other – 0.39%





Cystic Fibrosis on social
Demonstration - MPs
We received lots of great mentions across all social channels, including MPs who joined the demo.
<u>Twitter</u>
<u>Twitter</u>
<u>Twitter</u>
Demonstration – TV Coverage
Community have picked up on coverage from BBC Breakfast & Sky News
<u>Twitter</u>

Demonstration – Community

Amazing turn out from our community yesterday, using #LifeSavingDrugsNow #OrkambiNow

<u>Twitter</u>

<u>Twitter</u>

Interview with Lynsey & James MP was recorded live on <u>Instagram</u> as well as video capturing our community was also shared!

Jenny Agutter Video

On Facebook the video reached nearly 35,000 people, 11.8k views and 428 likes, with our community sharing their own stories and getting ready to go the



Ahead of the Demonstration today, here is a message from Jenny Agutter who is fighting with us for #OrkambiNow and #LifeSavingDrugsNow for cystic fibrosis. If you're joining us at the demonstration, make sure share your stories with us or if you can't make it, watch it live on our website at: https://www.cysticfibrosis.org.uk/.../s.../7-march-demonstration



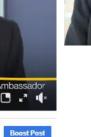
3,405

Engagements

34,806

C 2 428

People reached



16 Comments 286 shares 11K views





cftrustuk • Following



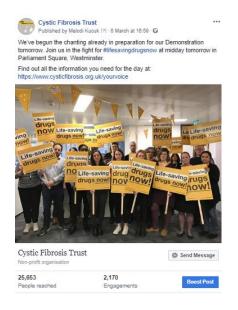
Impressio ns	Reach	Likes	Saves	Comments	Video Views	
5,021	3,455	313	14	2	1,439	26

Reach	Likes	Shares	Engagements	Comments	Views
34,806	428	286	3,405	16	11,834

Demonstration at HQ

The post at HQ received good engagement, encouraging supporters to talk about the great work the Trust have been doing.







Impressio ns	Likes	Retweets	Engageme nts	Link Clicks
4,770	81	45	281	26

Impressions	Reach	Likes	Saves	Comment s	Pr Vi
7,691	4,734	667	8	15	27

Reach	Likes	Shares	Engagements	Comments
25,653	469	190	2,170	31

Video from the protest

The video from the protest really engaged with our followers on Instagram with 49 profile visits increasing our Instagram followers to 8,400. Thus we received positive comments thanking the good work from everyone at the protest.



Impressio ns	Reach	Likes	Saves	Comments	Video Views	Profile Visits
6,348	4,408	481	11	14	1,758	49

TV Coverage – Becca C & Mrs Bow

Great engagement from our tweet on Sky News interview with Rebecca C & Mrs Bow with celebrity presenter.



Impressions	Likes	Retweets	Engagement s	Link Clicks
3,268	30	19	120	13

Wonder drug pleas grow as victims hit record high

THE need for cystic fibrosis drugs on the NHS is more urgent than ever, due to record numbers of sufferers. New statistics reveal there are now 10,509 people in Britain with CF, compared to 10,469 last year. Dr Janet Allen, director of strategic innovation at the Cystic Fibrosis Trust, said that if the number of sufferers continues to grow, the NHS "may struggle to cope". "This new SmartCare technology could make all the difference," she said. "Our hope is to predict when someone's health is in decline and act early to prevent further damage."

Express

Stars give a yellow bellow for UK's cystic fibrosis sufferers

Daily Express https://www.express.co.uk/news/uk/1143853/cystic-fibrosis-yellow-celebrities-mps

Cystic Fibrosis Week: 'I am one of the lucky ones' - CF patient reveals experience

Sky News https://news.sky.com/story/cystic-fibrosis-week-i-am-one-of-the-lucky-ones-cf-patient-reveals-expeirence-11743481

Could this be the answer in the battle to beat the superbugs? Experts - and these families - believe viruses found in the most bizarre places may be the answer

Daily Mail https://www.dailymail.co.uk/health/article-7151359/Experts-believe-viruses-answer-beating-superbugs.html

"We gave our son a life sentence before he took his first breath"

The Daily Telegraph https://www.telegraph.co.uk/health-fitness/body/giving-son-cystic-fibrosis-gene-feels-like-life-sentence/

Relative Values

The actress Jenny Agutter and her niece Georgina, a florist, on the Call the Midwife 'facelift' and their families battle with cystic fibrosis. **Sunday Times**Magazine, 26 May 2019

<u>September – October 2019, deal coverage</u>

Topline media coverage for deals for Orkambi and Symkevi in Scotland, England, NI and Wales

Scotland (12 September 2019)

National: 19 articles Regional: 24 articles Broadcast: 77 clips

England (24th-1st October)

In total – 116 articles Broadcast clips: 19 Regional: 15 articles National: 16 articles

Northern Ireland (30th Sept – 7 October)

In total - 36 articles Regionals: 7 articles Broadcast: 3 clips

Wales (13 - 20 November 2019)

In total – 104 articles Broadcast: 6 clips Regional: 20 articles

Scotland coverage

BBC news at Six – from 12:10mins Rebecca C is interviewed in this piece BBC One

BBC News at Ten – from 22:50mins

BBC One

Newsnight - from 26:00 mins

This piece follows up on the CF 'Buyers Club' and updates on the positive the news in Scotland. Michael Naylor and Sarah Wollaston MP are quoted

'Life-changing' cystic fibrosis drug deal for Scotland is welcomed BBC News Online

Health Secretary Matt Hancock calls in pharma bosses to break four-year deadlock over cost of cystic fibrosis drugs

This piece covers the ongoing deadlock in England, Wales and Northern Ireland - Nick M is mentioned in this piece

Cystic fibrosis patients to get new drug after price deal

dailymail.co.uk

Hancock's bid to end cystic fibrosis drug row
The above piece featured in print as well as online
Daily Mail

Cystic fibrosis patients to get new drug after price dea The Times

Scots to get 'unaffordable' cystic fibrosis drug denied

The Guardian

Cystic Fibrosis patients to receive 'wonder drug'

The i

Pressure piles on Hancock as Scots say 'yes' to vital drugs **Daily Express**

'We want justice for sufferers across Britain'

Maggie Gallacher, who campaigned for access in Scotland, is quoted here **Daily Express**

Scotland and Vertex strike CF drug deal



Cystic fibrosis

Scotland agrees deal for 'unaffordable' cystic fibrosis drug Orkambi





PharmaTimes

Vertex strikes deal for Orkambi and Symkevi in Scotland, ramping up pressure on holdout England Fierce Pharma

Scottish government step in to help cystic fibrosis sufferers **Metro Scotland**

Scots patients to get cystic fibrosis drugs

David R is quotes here, as is Ludovic Fenaux, Senior Vice President at Vertex Scottish Daily Express (attached)

Scots with cystic fibrosis win drug access

The Daily Telegraph Scotland

Hundreds of Scottish cystic fibrosis patients to get Orkambi on NHS heraldscotland.com

'LANDMARK MOMENT' AS CF PATIENTS IN SCOTLAND GET ACCESS TO ORKAMBI DRUG **PA News Wire**

Vertex Announces New Access Agreement with Scottish Government for ORKAMBI (lumacaftor/ivacaftor) and SYMKEVI (tezacaftor/ivacaftor) pressreleasepoint.com

'Landmark moment' as CF patients in Scotland get access to Orkambi drug **uk.yahoo.com**

Patients' joy as deal is struck on life-saving drug

Keli Gallacher, who has CF, is featured in this piece

Daily Record

Cancer care shame as UK survival rates slump

The positive Orkambi news from Scotland is mentioned in a 'box-out' alongside this piece

Scottish Daily Mail

New drugs for cystic fibrosis **Scottish Daily Mail**

Social Media

Following the BBC Newsnight piece, Jeremy Corbyn tweeted the following:



England coverage

Broadcast

Lorraine, Richard Madeley interview

BBC News

ITV News

CF Trust director, Rebecca Cosgriff was interviewed on ITV and live on the BBC News Channel.
CF Trust Oli Lewington was interviewed by Matthew Wright on Talk Radio
The story was also covered on Radio 4's 'Today programme', 'The Victoria Derbyshire show' and ITVs 'This Morning'

<u>Print</u>

The Independent

The Daily Mail

The Sun

The Daily Express

The Telegraph

The Metro

The i

The Guardian

The Mirror