

Winter 2024

Butterfly
Trust

Cystic Fibrosis
support for Scotland



little magazine



Asiah

A 'Hair-Raising' Idea!

Ten-year-old Asiah lives on the beautiful island of Tiree and has always been proud of her lovely, long hair, so long, she could even sit on it. So, when Asiah came home from school one day and told her mum she wanted to cut her hair off for charity, it came as a huge surprise.

Just weeks later, minus 15 inches of her hair, Asiah was left with a gorgeous, stylish bob.

She smashed her initial fundraising target of £500 within 24 hours, with her final donation totalling an incredible £2,300.

Thank you Asiah, a truly inspiring young girl.

A catchup and message from our Managing Director

Dear supporters

After my 20 years with the Trust, I can still say there are exciting times ahead supporting Scotland's Cystic Fibrosis Community. We develop our specialised services to adapt to the changes people with Cystic Fibrosis face and strive to make access to our support easier.

We continue to discuss, with our stakeholders, what are the future challenges our service users face and how we can provide support to overcome them.

At the forefront of that is developing our one-to-one psychosocial support for both adults and young people affected by Cystic Fibrosis and the vital support after diagnosis.

To develop and continue to provide the broad range of services we currently offer, we need your help. We need people to volunteer to provide direct support in the community. People to get involved with our fundraising initiatives, organising their own events and nominating us as corporate partners with employers and local community groups.

I'd like to take this opportunity to thank all of our volunteers and supporters, as without your support, none of what we do would be possible!



Taxi!!!

The staff at NHS Forth Valley had organised a special day out for Callum, but required transportation.

The Butterfly Trust co-ordinated Glasgow Taxis to provide the transport needed.

We have it on good authority that Callum thoroughly enjoyed his excursion with the generous support of Glasgow Taxis.



International Teamwork

Thomas, a Physiotherapist from the Cystic Fibrosis Centre in Lyon (France), set off from London on Thursday May 30th to cycle to the European Cystic Fibrosis Conference in Glasgow.

Thomas was raising awareness for the Butterfly Trust on the way and arrived in Scotland, June 3rd.



ECFC, Glasgow 2024

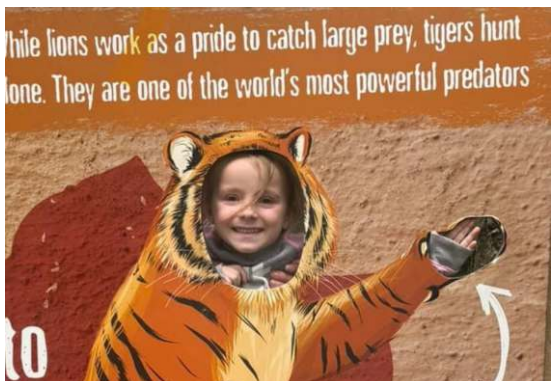
We were thrilled to attend the European Cystic Fibrosis conference in Glasgow this year, as an exhibitor.

These conferences are invaluable for expanding professional relationships, sharing knowledge, discussing best practice, and learning from one another, leading to improved patient care and advancements in the field.



Wild adventures

We recently assisted a family in planning a day at Edinburgh Zoo. With its wide variety of attractions and accessibility, the zoo offered something for everyone. The whole family had a fantastic day out and as you can see from the photo, the 'BIG CATS' were a hit!





Paul's story – life with Cystic Fibrosis

Paul was born in 1953, at a time when little was known about Cystic Fibrosis. His older brother had died in 1952 and his mother, Betty, noticed Paul exhibited similar symptoms. Determined to help her son survive, she wrote to doctors in Harley Street, America, and Australia. However, they offered no medical advice—only sympathy and prayers.

In the early 1960s, Betty worked tirelessly to raise awareness about the condition and was a cornerstone for creating support for people living with Cystic Fibrosis.

Despite the challenges, Paul was doing well and growing into a mischievous little boy. As a teenager, he had to visit children's hospitals to see doctors since there were no clinics for adults with the condition at the time. Paul saw many of his friends lose their battle with Cystic Fibrosis, which left him feeling isolated.

In the mid-1970s, Dr Brian Stack opened an adult clinic for those with Cystic Fibrosis, and his exceptional care greatly benefited Paul. Undergoing two bowel surgeries in his 20s due to blockages, Paul experienced ongoing issues that persisted into his late 50s. In the mid-2000s, lung problems worsened, requiring IV treatments, hospital stays, and recovery at home.

People who meet Paul are often amazed by his positive outlook on life and his tremendous sense of humour, which has occasionally landed him in trouble! Paul's wife, Anne Marie, like his mother, has been a strong source of support throughout their marriage.

Despite his health challenges Paul worked for the Glasgow City Council Housing Department for 32 years. He has a great love for cars, music, and football. He attended his first gig in the 70s and continues to enjoy live music today.

Befriending with Bethan

In this video Bethan shares why she volunteers with the Butterfly Trust, providing on-to-one support for young people, and what it means to her.

If you want to gain new skills, experience working in a professional setting and give something back to your community, please get in touch.



Massage Therapy Service

Massage is available to adults during hospital admission. Qualified therapists attend at a time convenient to you, free of charge.

Previous clients have shared this experience, describing physical relaxation, relief from mental stress and being able to better cope with their medical treatment.



Fiona's story

The Butterfly Trust must raise its own funds to meet the financial needs of the organisation; vital for us to continue the essential work we do.

We rely on our supporters to assist us, whether by participating in our events, projects, and appeals, or by organising your own fundraising activities.



The Breathe Easy Ball



In May, we were privileged to attend the Breathe Easy Ball in Glasgow, remembering a beautiful young lady, Chloe. An evening of reflection, but also vast amounts of fun and laughter. Chloe's mum, Yvonne, her family, and friends raised over £13,000 for the Butterfly Trust.

Ayrshire Beard & Moustache Championships

Fundraiser Muir organised Ayrshire's first-ever Bear and Moustache Championships in August this year. This unique event happened as a result of the hard work and dedication of Muir, his family, and friends. Their efforts truly paid off, donating £1030 to the Butterfly Trust. A huge thank you to everyone involved.



The Kiltwalk



Amazing supporters took part in the Glasgow and Edinburgh Kiltwalks this year. Thank you - we really do appreciate your efforts.

As a charity these fundraised monies make a real difference to help us continue the important work we do.

Cystic Fibrosis Scotland Golf Day 2025



Save the date! The Cystic Fibrosis Scotland Golf Day 2025 is set for June 6th, 2025.

Watch our video for a sneak peek at what's in store. If you have a team of four ready to take on the Texas Scramble format, we'd love to hear from you - reach out to sign up.

Support Scotland's Cystic Fibrosis Community



Without your support none of what we do is possible!

Here's Anne, our Fundraising Manager, telling you what's happening with our community fundraising programme and how you can get involved.

Raffles and Auctions for the Trust

Enter our Winter Raffle for a chance to win fantastic prizes, with all proceeds supporting people living with Cystic Fibrosis in your community. Prizes include a 2-night holiday let in Anstruther, afternoon tea at Tigerlily, lots of NEXT goodies, and loads more!

Get in contact to purchase tickets, or even better, sell some for us.



Cystic Fibrosis Firewalk 2025

Step into 2025 with a daring challenge - walk across hot embers for charity! This experience goes beyond putting one foot in front of the other; it's about overcoming personal obstacles and achieving what you set your mind to. Click on the photo to register your interest.



Standing order form



Your Personal Details

First Name: _____

Surname: _____

Address: _____

Postcode: _____

Tel Number: _____

Your Bank Details

Account No: _____

Sort Code: _____

Bank: _____

Branch: _____

Instructions to your bank

Please pay to **The Butterfly Trust** the sum of: £ _____

Amount in words: _____ (pounds)

Every month with effect from ___/___/___ until further notice

Account Type: **Trustees Account**

Bankers: **Bank of Scotland**

Bankers Sort Code: **80-02-78**

Account No: **00584054**

Declaration

I pay UK income tax and would like THE BUTTERFLY TRUST to reclaim the tax on my gifts

Signature: _____

Date: _____

Please take this form to your bank and return a copy to:

Fundraising Team, The Butterfly Trust, Swanston Steading, 109/3 Swanston Road, Edinburgh, EH10 7DS

Our vision is that people affected by Cystic Fibrosis have the opportunity for personal choice and access to support that enables them to fulfil potential and realise aspirations.



Contact details

109/3 Swanston Road
Edinburgh
EH10 7DS
info@butterflytrust.org.uk

butterflytrust.org.uk
facebook.com/butterflytrust
justgiving.com/butterflytrust
Registered Scottish Charity No SC 033174