

ALK POSITIVE LUNG CANCER (UK)

England & Wales · Charity number 1181171

Details

Status Registered

Legal form CIO

Registered 2018-12-14

Register [View on the Charity Commission register](#)

Contact

Address 1 Ethley Drive
Raglan
Usk
Monmouthshire
NP15 2FD

Phone 07975623515

Email hello@alkpositive.org.uk

Website www.alkpositive.org.uk

Activities

Objects: TO RELIEVE SICKNESS AND TO PRESERVE AND PROTECT GOOD HEALTH OF UK ANAPLASTIC LYMPHOMA KINASE (ALK) POSITIVE LUNG CANCER PATIENTS BY:-A. PROVIDING AN INFORMATION RESOURCE, IN PARTICULAR ACCESS TO INFORMATION ABOUT LATEST DEVELOPMENTS AND CLINICAL TRIALS;B. IDENTIFYING AND LOCATING UK ALK PATIENTS AND OFFERING SUPPORT AND GUIDANCE ON THE LOCATION OF UK ALK SPECIALISTS AND SERVICES;C. LIAISING WITH AND INFLUENCING DECISION MAKERS, E.G. NICE, NHS, DVLA;D. RAISING AWARENESS OF ALK LUNG CANCER, PARTICULARLY AMONGST THE MEDICAL PROFESSION SO AS TO PROMOTE THE BEST TREATMENT FOR PATIENTS;E. LIAISING WITH RELEVANT ORGANISATIONS, IN PARTICULAR ROY CASTLE LUNG CANCER FOUNDATION AND THE PHARMACEUTICAL INDUSTRY;F. RAISING FUNDS FOR THE ABOVE PURPOSES.

Activities: We provide a support network in the UK for patients with ALK-positive lung cancer and their families. We provide advice and information so that patients can be empowered to have meaningful conversations with their healthcare professionals. We advocate on their behalf at a national level so that patients receive a high level of care wherever they live in the UK

Classification

- **How:** Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£220,195	£152,874	-	-
2023-12-31	£182,857	£201,511	-	-
2022-12-31	£130,582	£114,553	-	-
2021-12-31	£164,415	£107,572	-	-
2020-12-31	£56,113	£23,560	-	-

Trustees

Name	Role	Appointed
Debra Louise Montague	Chair	2023-03-10
Andrew Thomson McKay		2023-12-01
Geoffrey Paul Otterman		2024-10-11
Graham Herbert Lavender		2023-12-01
Traceydawn White		2026-02-04

ALK POSITIVE LUNG CANCER (UK)

England & Wales - Charity number 1181171

Accounts

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2024 to 31 December 2024

The Charity was established in December 2018 and this is the Trustees' sixth Annual Report.

ALK-Positive lung cancer is a relatively rare form of lung cancer caused by a genetic malfunction and comprises about 3% of all lung cancers. Patients are, on average, much younger than most other lung cancer patients and are usually never-smokers.

1. Objectives and Activities

The objectives of the Charity are to relieve sickness and to preserve and protect good health of UK anaplastic lymphoma kinase (ALK) positive lung cancer patients by: -

- a. providing an information resource, in particular access to information about latest developments and clinical trials.
- b. Identifying and locating UK ALK-positive patients and offering support and guidance on the location of UK ALK specialists and services.
- c. Liaising with and influencing decision makers, e.g., NICE, NHS, DVLA;
- d. Raising awareness of ALK-positive lung cancer, particularly amongst the medical profession to promote the best treatment for patients.
- e. Liaising with relevant organisations, in particular EGFR Positive UK, Ruth Strauss Foundation and the pharmaceutical industry.
- f. Raising funds for the above purposes.

2. Our Vision

We want everyone in the UK who is diagnosed with ALK-positive lung cancer to thrive and live a long and fulfilling life unhindered by their disease.

3. Our Mission

Alk Positive Lung Cancer (UK) exists to

- **Support** the ALK+ lung cancer patient community
- **Empower** people affected by ALK-positive lung cancer
- **Advocate** for improvements in the diagnosis, treatment and care of ALK-positive lung cancer across the UK
- **Represent** the voice of the ALK-positive lung cancer community

4. Our Values

- We are welcoming in our approach and put the needs and interests of patients with ALK-positive lung cancer and their families first, treating them with the respect and empathy that they deserve.
- We are passionate about our work – our passion is driven by a deep personal connection to ALK-positive lung cancer which means we are highly committed and determined.
- We always act with professionalism and integrity and our activities are based on the best available evidence.

4. Achievements and Performance

A group of 18 patients and supporters came together in July 2018 with the aim of establishing a UK group of ALK-positive patients who could exchange experiences and give and receive mutual support. At our second meeting in October 2018, it was decided to form a registered charity and the Charity was registered by the Charity Commission on 14 December 2018. We started with a £1,000 loan from the Treasurer.

Our achievements and performance in our six years have greatly exceeded our expectations. The main activities undertaken in 2024 to further our objectives are set out below. In this report, “members” refers to members of the charity’s private Facebook Support Group.

4.1 Support and Empowerment

Conference

We held our third national conference for ALK-positive patients and their families. 148 delegates attended the conference which was held in London and they heard from and questioned some of the UK’s leading ALK-positive experts. The conference was the largest gathering of ALK-positive patients and their families in the world, outside the USA. It was funded, in part, by grants from pharmaceutical companies. The conference was a huge success and videos of all sessions are on our website along with a vox pop of what the delegates thought. We received very positive feedback about the venue, organisation and quality of the speakers.

Life Coach

We offered a Living With ALK+ Lung Cancer Coaching Service, providing 6-week online group sessions. A cancer diagnosis can cause loss of identity and self. Through self-management, individuals are empowered to regain control of their lives by understanding thoughts and emotions, strengthening mental resilience, identifying challenges, exploring different perspectives and setting goals. We have had very positive feedback from participants.

Regional Ambassadors

Twelve of our members from many parts of the country have volunteered to be Regional Ambassadors to arrange local meet-ups for members. The Charity believes that these social gatherings are important for the mental well-being of patients and, for this reason, the charity subsidises the cost of meals.

We produced guidelines for the Ambassadors to equip them in delivering what has become a key component of our service to members.

Website

Additional information was added to the website which provides information about the Charity and is a source of information for members to be better informed about ALK-positive lung cancer. One of our principal aims is to empower patients to enable them to ensure that they get the best possible care.

We developed two animated videos – the first explaining what ALK-positive lung cancer is and the second is about good practice. Both animations have been used in our social media output and are available on the website.

We place considerable importance on the mental wellbeing on patients and we provide several resources on the website.

Visits to the website have increased from about 500 per month in 2020 to 2000 per month in 2024.

A working party of members was established to review the website and prepare a brief for its redesign to focus on newly diagnosed patients. We asked newly diagnosed patients how we could make the website easier for them to find the information that they were looking for.

Facebook Page

The Facebook page is a great success and the number of members increased from 638 to 748 during the year. Each day, there are postings by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% of respondents would recommend the group to other ALK-positive patients.

Newsletters

We produced newsletters in Spring, Summer and Autumn which inform members of developments in the treatment of ALK-positive lung cancer and the activities of the charity.

Medical & Scientific Advisory Panel

We had a Medical & Scientific Advisory Panel comprising two retired GPs and a Professor Emeritus of Molecular Oncology, all ALK-positive patients. The Panel produced guidance on the NHS rules concerning extended breaks of treatment.

During the year, the Panel was reconstituted and now comprises working lung cancer oncologists and members of relevant allied professions.

DVLA Panel

The Panel of three members continued to interact with the DVLA with the objective of amending their rules which we consider to be unreasonably harsh for our members. The Panel is able to give advice to members on the application of these rules.

During the year, the Panel produced an authoritative guidance for members on the DVLA rules on driving and brain tumours.

4.2 Advocacy

Surveys

For six years, we have conducted surveys of our members to ascertain real-world data on all aspects of their diagnosis, treatment and care. The data produced enables us to identify deficiencies and variations in the level of services our members receive, including regional variations. We use this information at meetings with oncologists and nurses and at conferences to advocate for best practice. During the year, we conducted a survey of patients' experiences of their treatment for blood clots.

We attended the national conferences of

- British Thoracic Oncology Group
- Lung Cancer Nurses UK
- All Ireland Lung Cancer Coalition
- Cambridge Rare Diseases Conference

We also attended other meetings with healthcare professionals where we raised awareness of the Charity and of ALK-positive lung cancer and advocated on behalf of patients. It is important that healthcare professionals are aware of the Charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

We had abstracts published at key stakeholder conferences –

- British Thoracic Oncology Group
- Lung Cancer Nurses UK
- British Oncology Pharmacists Association
- European Lung Cancer Conference

We continued to work with the Christie Hospital on the development of an Educational Portal for oncologists, their teams and patients and we are supporting the development of the patient Resources section.

We continued to campaign for early diagnosis of lung cancer and a fourth phase of our “See Through the Symptoms Campaign with EGFR Positive UK and the Ruth Strauss Foundation was launched. This campaign is targeted at primary care.

We were members of

- UK Lung Cancer Coalition
- Lung Cancer Europe
- Cancer52
- European Lung Foundation
- Genetic Alliance

To coincide with Lung Cancer Awareness Month in November and again in collaboration the EGFR UK and Ruth Strauss Foundation, we launched “All You Need is Lungs” campaign aimed at the general public and social media users.

We have continued to grow our use of social media and are active on Twitter, LinkedIn and Instagram, TikTok and BlueSky

4.3 Representation

We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products relevant to ALK-positive lung cancer and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients’ perspective.

We continued to collaborate with several pharmaceutical companies on the development of resources for patients and participated in other working groups and advisory boards.

Working with these organisations and groups gives us access to information about latest developments and raises the Charity’s profile with key clinicians.

We developed links with organisations in the Scottish, Welsh and Northern Ireland regions. We registered with the Scottish Charity Regulator and joined the Scottish Cancer Coalition. We have appointed one of our Trustees who lives in Scotland our representative. We have become members of the Wales Cancer Coalition and the Northern Ireland Cancer Charities Coalition. We joined with other organisations in lobbying the NI Health Executive about the lack of resources in NI for diagnosing and treating lung cancer.

We have developed links with relevant organisations throughout Europe. Our Chair is Vice-president of Lung Cancer Europe, a Board member of ALK Positive Europe and a member of the European Lung Cancer Foundation Patient Advisory Committee.

5. Financial Review

Our members undertook a wide range of activities which, together with those activities organised by the charity, raised over £70,000. We are very grateful to these members.

We have registered with the Fundraising Regulator and this requires us to comply with their fundraising standards.

We are also very grateful to all those members who are now making regular monthly donations.

The Charity had £ 177,023 in its bank account at the end of the year, a year-on-year increase of £68K. The principal reasons for the surplus were increased fundraising and donations. With uncertainty about funding of future conferences and the need to employ a part-time CEO, it is expected that we will draw on balances in future years.

The Charity is risk averse and we ensure that we have sufficient funds in hand before committing ourselves to expenditure.

6. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation and the governing document is its Constitution which provides that there shall be between three and eight Trustees.

During the year, the trustees had two face-to-face meetings, an AGM at the start of the year and a half-year review, and eighteen meetings held electronically, by email or Zoom. The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

Three new trustees were appointed and one left at the end of the year – details at paragraph 8.

Day-to-day management is delegated to the Senior Leadership Team comprising the Chair, Treasurer, Secretary and Chief Officer.

Following a review of administration, we appointed a part-time Manager who is tasked with reviewing our administrative arrangements, implementing our PIF Tick obligations and putting the charity on a sustainable basis.

We started to use Monday.com as a project management tool and we are making greater use of Google Share to store and share documents.

Following our successful Strategic Planning meeting towards the end of 2023, we adopted a 10-point Action Plan for 2024.

Our first official complaint was received at the end of 2023 and resulted in a review of attendance by bereaved relatives at regional lunches.

The Charity has policies in place concerning –

- Code of Conduct
- Equality and Diversity
- Privacy
- Use of Images & Quotes
- Complaints Procedure
- Financial Control
- Trustee Expenses
- Conflicts of Interest
- Fundraising
- Whistle-blowing

7. Reference and Administrative Details

Charity Name	ALK Positive Lung Cancer (UK)
Other names the charity uses	ALK Positive UK and ALK+UK
Registered charity number	1181171
Charity's principal address	1 Ethley Drive Raglan Monmouthshire NP15 2FD

8. Names of the Charity Trustees who Managed the Charity in 2024

Trustee Name	Office (if any)	Dates Acted if not for whole Year
Debra Montague	Chair	
Graham Lavender	Secretary	
Rebecca Stebbings		To 29/12/24
Angela Field		
Andy McKay	Treasurer	
Kathy Redmond		From 15/2/24
Geoff Otterman		From 11/10/24
Callum Cobb		From 4/12/24

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil.

9. Declarations

The Trustees declare that they have approved the Trustees' Report as above.

Signed on behalf of the Charity's Trustees

Signatures	G H Lavender	D L Montague
Full Names	Graham Herbert Lavender	Debra Louise Montague
Positions	Secretary	Chair
Date	17 September 2025	17 September 2025

Income	2024
Old Account	79,923
New Account	19,779
Opening Balance	109,702
Donations	28,488
Events	2,214
Fees (Deb's appearance payments)	11,592
Conference	3,411
Grants (Restricted)	64,416
In Mem	30,669
Our Fundraising Events (including Gift Aid)	22,595
Members' Fundraising (including Gift Aid)	49,056
Standing Orders	6,949
Other	805
	220,195
	329,897

Expenditure	2024
Admin	9,086
National Conference	70,186
Attendance at Conferences	7,249
Events	8,738
Life Coach	2,370
Local Meet-ups	4,664
PIFTIK	3,463
Printing & Publicity	8,620
Website	2,470
Staffing	16,252
Social Media	17,194
Trustee Expenses	1,328
Other	1,254
	152,874
Closing Balance	177,023
Old Account	19,409
New Account	157,614
Closing Bank Balance	177,023



Section A

Independent Examiner's Report

Report to the trustees

ALK Positive Lung Cancer (UK)

On accounts for the year ended

2024

Charity no

1181171

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/11/2024**.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.


Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:



Date:

13/09/2025

Name:

Philip Collins

Address:

19 Wye Crescent

Chepstow

NP16 5DW

ALK POSITIVE LUNG CANCER (UK)

England & Wales - Charity number 1181171

Accounts

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2022 to 31 December 2022

The Charity was established in December 2018 and this is the Trustees' fourth Annual Report.

ALK-Positive lung cancer is a relatively rare form of lung cancer caused by a genetic malfunction and comprises less than 4% of all lung cancers. Patients are, on average, much younger than most other lung cancer patients and are usually never-smokers.

1. Objectives and Activities

The objectives of the Charity are to relieve sickness and to preserve and protect good health of UK anaplastic lymphoma kinase (ALK) positive lung cancer patients by: -

- a. providing an information resource, in particular access to information about latest developments and clinical trials.
- b. Identifying and locating UK ALK-positive patients and offering support and guidance on the location of UK ALK specialists and services.
- c. Liaising with and influencing decision makers, e.g., NICE, NHS, DVLA;
- d. Raising awareness of ALK-positive lung cancer, particularly amongst the medical profession to promote the best treatment for patients.
- e. Liaising with relevant organisations, in particular Roy Castle Lung Cancer Foundation and the pharmaceutical industry.
- f. Raising funds for the above purposes.

2. Our Vision

We want everyone in the UK who is diagnosed with ALK-positive lung cancer

- to receive the best care possible
- to live their best lives possible
- to live for as long as possible

To achieve this, we

- **Support** patients by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment
- **Empower** patients by providing information that enables them to demand a high level of care
- **Advocate** on behalf of patients to ensure that they receive the best care wherever they live in the UK

3. Achievements and Performance

A group of 18 patients and supporters came together in July 2018 with the aim of establishing a UK group of ALK-positive patients who could exchange experiences and give and receive mutual support. At our second meeting in October 2018, it was decided to form a registered charity and the Charity was registered by the Charity Commission on 14 December 2018. We started with a £1,000 loan from the Treasurer.

Our achievements and performance in our first four years have greatly exceeded our expectations. The main activities undertaken in 2022 to further our objectives were –

3.1 Support and Empowerment

Conference

We held our first national conference for ALK-positive patients and their families. 110 delegates attended the conference which was held in Birmingham and they heard from and questioned some of the UK's leading ALK-positive experts. The conference was a huge success and videos of all sessions are on our website along with a vox pop of some of the delegates. The conference was the largest gathering of ALK-positive patients and their families in the world, outside the USA. It was funded by grants from pharmaceutical companies.

Life Coach

We launch a Living With ALK+ Lung Cancer Coaching Service providing 6-week online group sessions. A cancer diagnosis can cause loss of identity and self. Through self-management, individuals are empowered to regain control of their lives by understanding thoughts and emotions, strengthening mental resilience, identifying challenges, exploring different perspectives and setting goals. We have had very positive feedback from participants.

Regional Ambassadors

Towards the end of the year, twelve of our members from many parts of the country volunteered to be Regional Ambassadors to arrange local meet-ups for members. The Charity believes that these social gatherings are important for the mental well-being of patients and, for this reason, the charity subsidises the cost of meals.

Other social events have included a speedboat down the Thames and a Thames-side walk.

Website

Additional information was added to the website which provides information about the Charity and is a source of information for members to be better informed about ALK-positive lung cancer. One of our principal aims is to empower patients to enable them to ensure that they get the best possible care.

Facebook Page

The Facebook page is a great success and the number of users increased from 450 to 543 during the year. Each day, there are postings by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% of respondents would recommend the group to other ALK-positive patients.

Medical & Scientific Panel

We established a Medical & Scientific Advisory Panel comprising two retired GPs and a Professor emeritus of Molecular Oncology, all ALK-positive patients. The panel will provide advice to the Trustees and ensure that all our publications reach a high standard. Medical advice will not be provided to members.

Surveys

We carry out surveys of our members to ascertain real-world data on all aspects of their diagnosis, treatment and care. The data produced enable us to identify deficiencies and variations in the level of services our members receive, including regional variations. We use this information at meetings with oncologists and nurses and at conferences to advocate for best practice. During the year, we gathered data on

- Brain Metastases
- Alectinib
- Side effects
- Membership details
- Brigatinib
- Fatigue
- Lorlatinib
- Demand for social gatherings

Online Activities

We hold weekly exercise sessions which are recorded and placed on the website and monthly coffee mornings.

3.2 Advocacy

We attended the national conferences of

- British Thoracic Oncology Group
- Lung Cancer Nurses UK
- Cancer Research UK

The LCNUK was their first face-to-face conference since the pandemic. Over 300 lung cancer nurses from throughout the UK attended and we spent a very busy two days talking to them.

We also attended other meetings with healthcare professionals where we raised awareness of the Charity and of ALK-positive lung cancer and advocated on behalf of patients. It is important that healthcare professionals are aware of the Charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

We had abstracts published at key stakeholder conferences –

- British Thoracic Oncology Group
- Lung Cancer Nurses UK
- World Conference on Lung Cancer
- International Association for the Study of Lung Cancer

We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients' perspective.

We worked with several pharmaceutical companies on the development of resources for patients.

We worked with other organisations to raise awareness of rare lung cancers and were members of

- UK Lung Cancer Coalition
- Cancer52
- Genetic Alliance
- International Association for the Study of Lung Cancer
- European Lung Foundation
- Lung Cancer Europe

We published several resources –

- Mental health poster
- Biomarker testing
- Molecular Mechanisms and Treatment Strategies.
- Need for National Guidelines (published in medical press)
- Importance of Oncogene-Driven LC support Groups
- Charity Brochure

Our DVLA panel was active in lobbying the DVLA to amend their rules about driving with brain metastases.

We have opened up channels of communications with LC oncologists and nurse specialists in all hospitals throughout the UK so that we can tell them about the support that the charity can offer to their patients.

We have continued to grow our use of social media and are active on Twitter, LinkedIn and Instagram.

Our “See Through the Symptoms” early diagnosis campaign, developed with EGFR Positive UK and the Ruth Strauss Foundation, was taken up by Gateway C, the leading GP education provider, and they now provide an online never-smoker lung cancer course as part of their curriculum.

We led on the development of the Oncogene-Driven Lung Cancer Patient Alliance, which leading ALK experts are supporting. This will be the platform where we engage with policy makers to ensure that never-smoking lung cancer is included in all lung cancer strategies. Professor Alastair Greystoke agreed to be the honorary Clinical Lead. We commissioned an animated video on the role of support groups and the benefits they offer patients.

3.3 Fundraising

We hit the ground running at the beginning of the year with the Sapphire Ball. 115 people had an amazing night and an incredible total of over £15,000 was raised for the charity.

Our members undertook a wide range of activities which, together with those activities organised by the charity, raised £55,000. We are very grateful to these members whose activities included

- Zip Wire in North Wales
- Rollerblading
- Marathons
- Charity Gig
- Walking
- Sky Dive
- Sale of cakes
- Abseil
- Half Marathons
- 60s/70s evening
- Race night
- Mountain climbing
- Playing bridge
- Cycling

We launched a “Many More” Standing Order campaign. We chose this name as we want patients to

- Enjoy many more birthdays
- Take many more holidays
- Go on many more walks
- Make many more memories
- Do the things that they like many more times

We are very grateful to all those members who are now making regular monthly donations.

4. Financial Review

The Charity had £128,120 in its bank account at the end of the year, including £4,477 of restricted funds. This was a year-on-year increase of £16,029 due to the high level of fundraising. In October, the Trustees held a strategic planning meeting to determine actions to ensure that the charity has a sustainable base and to develop it to “the next level”.

We do not occupy premises and we do not currently employ staff, although we commission services. We have a very low level of fixed costs, e.g., website maintenance, subscriptions to other organisations, insurance, and our end of year balances are largely available to promote the Charity’s objectives.

5. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

We have policies in place concerning –

Code of Conduct
Complaints Procedure
Conflicts of Interest
Equality and Diversity
Financial Control
Fundraising
Privacy
Trustee Expenses

We sought advice on the General Data Protection Regulations to ensure that we are compliant.

We were delighted that Jackie Fenemore, a leading lung cancer nurse specialist, agreed to join our panel of Honorary Clinical Advisors

6. Reference and Administrative Details

Charity Name	ALK Positive Lung Cancer (UK)
Other names the charity uses	ALK Positive UK and ALK+ UK
Registered charity number	1181171
Charity's principal address	Old Carw Farmhouse Carrow Hill St Brides Netherwent Caldicot Monmouthshire NP16 3AU

7. Names of the Charity Trustees who Managed the Charity in 2022

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Debra Montague	Chair		
Graham Lavender	Secretary & Treasurer		
Rebecca Stebbings			
Susan Eastwood		Until 31/07/2022	
Angela Field			

Tessa Rust		Until 20/02/2022	
Lynne Murtha			
Paula Tully		From 20/02/2022	

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil.

8. Declarations

The Trustees declare that they have approved the Trustees' Report as above.

Signed on behalf of the Charity's Trustees

Signatures	G H Lavender	D L Montague
Full Names	Graham Herbert Lavender	Debra Louise Montague
Positions	Secretary	Chair
Date	16 September 2023	16 September 2023

Income & Expenditure 2022

Income

Opening Balance		112,091
Amazon + easyfunding	530	
Conference registration	1,179	
Donations	5,115	
Early Diagnosis Campaign	2,550	
Fees charged	3,450	
Gift Aid	596	
Grants	29,216	
In Mem	13,353	
Our Fundraising Events	15,387	
Private Funraising	40,139	
Regional Meet-ups	636	
Sapphire Ball	15,405	
Standing Orders	2,325	
Other	701	
Total Income		130,582
		242,673

Expenditure

Administration	4,614	
Annual Conference	31,792	
Communications Strategy	4,800	
Conferences	7,418	
Early Diagnosis Campaign	9,056	
Events	5,826	
Fitness Classes	2,150	
Fundraising	5,124	
HCP communications	1,411	
Just Giving fee	468	
Newsletter (2021)	1,567	
Oncogene-Driven LC Alliance	921	
Patient Material	4,756	
Patient Information Forum	540	
Publications	9,686	
Publicity	6,363	
Regional Meet-ups	1,611	
Sapphire Ball	2,744	
Social Media	8,673	
Trustee Expenses	454	
Video	4,046	
Other	533	
Total Expenditure		114,553
Closing Balance		128,120
Restricted (Early Diagnosis Campaign)		4,477
Unrestricted Balance		123,643



Section A

Independent Examiner's Report

Report to the trustees

Charity Name: ALK POSITIVE LUNG CANCER (UK)

On accounts for the year ended

31st DECEMBER 2022 Charity no (if any) 1181171

Set out on pages

1 and 2 (remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended DD / MM / YYYY.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

[The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of [insert name of applicable listed body]]. Delete [] if not applicable.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below *) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
• the accounts did not accord with the accounting records; or
• the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

* Please delete the words in the brackets if they do not apply.

Signed: [Signature]

Date: 11/9/23

Name: ANDREW EVANS

Relevant professional qualification(s) or body

-

(if any):

--

Address:

4 CURLEY HILL RD
LIGHTWATER
GU18 5YG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

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ALK POSITIVE LUNG CANCER (UK)

England & Wales - Charity number 1181171

Accounts

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2021 to 31 December 2021

The Charity was established in December 2018 and this is the Trustees' third Annual Report.

ALK-Positive lung cancer is a relatively rare form of lung cancer caused by a genetic malfunction and comprises less than 4% of all lung cancers. Patients are, on average, much younger than most other lung cancer patients and are usually non-smokers.

1. Objectives and Activities

The objectives of the Charity are to relieve sickness and to preserve and protect good health of UK anaplastic lymphoma kinase (ALK) positive lung cancer patients by: -

- a. providing an information resource, in particular access to information about latest developments and clinical trials.
- b. Identifying and locating UK ALK patients and offering support and guidance on the location of UK ALK specialists and services.
- c. Liaising with and influencing decision makers, e.g., NICE, NHS, DVLA;
- d. Raising awareness of ALK lung cancer, particularly amongst the medical profession to promote the best treatment for patients.
- e. Liaising with relevant organisations, in particular Roy Castle Lung Cancer Foundation and the pharmaceutical industry.
- f. Raising funds for the above purposes.

2. Our Vision

We want everyone in the UK who is diagnosed with ALK-positive lung cancer

- to receive the best care possible
- to live their best lives possible
- to live for as long as possible

To achieve this, we

- **Support** patients by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment
- **Empower** patients by providing information that enables them to demand a high level of care
- **Advocate** on behalf of patients to ensure that they receive the best care wherever they live in the UK

3. Achievements and Performance

A group of 18 patients and supporters came together in July 2018 with the aim of establishing a UK group of ALK-positive patients who could exchange experiences and give and receive mutual support. At our second meeting in October 2018, it was decided to form a registered charity and the Charity was registered by the Charity Commission on 14 December 2018. We started with a £1,000 loan from the Treasurer.

Our achievements and performance in our first three years have greatly exceeded our expectations. Despite many of our planned activities for 2021 being severely curtailed by the Covid-19 pandemic, we still achieved a great deal. The main activities undertaken to further our objectives were –

3.1 Support and Empowerment

Website

The website was upgraded during the year. It provides information about the Charity and is a source of information for members to be better informed about ALK-positive lung cancer. One of our principal aims is to empower patients to enable them to ensure that they get the best possible care.

Facebook Page

The Facebook page is a great success and the number of users increased from 343 to 450 during the year. Each day, there are posting by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% would recommend the group to other ALK-positive patients.

Surveys

We carried out surveys of our members to ascertain the availability of MRI scans and to assess the prevalence and severity of the side effects of the various prescribed treatments. The data produced enables us to identify variations in the level of services our members receive and regional variations. We use this information at meetings with oncologists and nurses and at conferences.

Online Activities

Because of the pandemic, we took to Zoom and provided

Seven "ASK THE EXPERT" presentations, available on our YouTube Channel
a weekly exercise session, also available on YouTube
a monthly coffee morning

3.2 Advocacy

In partnership with EGFR+ UK and Ruth Strauss Foundation we launched a £100,000 and award-winning campaign to raise awareness amongst primary healthcare professionals of the need for early diagnosis. The campaign had the support of the British Thoracic Oncology Group, the British Lung Foundation, the Taskforce for Lung Health, Macmillan Cancer Support, Gateway C and the Primary Care Respiratory Society as well as leading Respiratory Consultants and Oncologists.

As a result of our campaign, there were 1.2M impressions across the social media platforms utilised, with 10,000 views of the microsite (our target based on national data for click through rates was 4.3k). Following the campaign in April, we held a UK wide GP training webinar in collaboration with the PCRS (Primary Care Respiratory Society) where non-smoking lung cancer was the topic with several speakers endorsing our messages.

We were also asked to be a panel member for the final Q&A session. Gateway C, the leading UK on-line GP education platform, has developed a module of Non-smoking Lung Cancer as a result of our campaign and we gave them permission to use our assets. We have also shared the campaign with two Cancer Alliance Groups, who were keen to utilise our material in one of their public health campaigns.

We attended meetings with healthcare professionals where we raised awareness of the Charity and of ALK-positive lung cancer and advocated on behalf of patients. It is important that healthcare professionals are aware of the Charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients' perspective.

We worked with other organisations to raise awareness of rare lung cancers and were members of

- UK Advanced Cancers Coalition
- Cancer52
- Genetic Alliance
- International Association for the Study of Lung Cancer
- European Cancer Patient Coalition
- Lung Cancer Europe
- National Council for Voluntary Organisation

We lobbied the DVLA to amend their rules about driving with brain metastases. We formed a DVLA panel and prepared a Frequently Asked Questions document.

We introduced an award for Lung Cancer Nurse Specialists and 36 nurses were nominated by 28 members.

In conjunction with the EGFR+ Group, we published in the medical press a report on the role of UK oncogene-focused patient groups in supporting and educating patients with oncogene driven non-small cell lung cancer.

We submitted an abstract on “The Importance of Support Groups” to the British Thoracic Oncology Group and another abstract on “The Importance and benefits of having a named nurse” at the Lung Cancer Nurse UK Conference.

Our Chair addressed the British Thoracic Oncology Group Conference where she presented the results of some of our surveys, including delays in diagnosis, frequency of scans and treatment of bone metastases. She also addressed the Women Against Lung Cancer in Europe Conference where she shared examples of the work ALK Positive UK has done to support patients across the UK.

We regularly posted on Twitter.

3.3 Fundraising

Despite the restrictions of the pandemic, our members undertook a wide range of activities which, together with those activities organised by the charity, raised £38,000. One of our fundraisers said “I was diagnosed with Stage 4 ALK-positive lung cancer a few weeks before my 40th birthday. The ALK Positive support group has inspirational and amazing members who provide invaluable advice and are a great source of knowledge and comfort. Having been reasonably active throughout my life, I decided to take part in a challenge every 6 months to raise awareness that anyone with lungs can get lung cancer”

4. Financial Review

The Charity had £112,121 in its bank account at the end of the year, including £37,942 of restricted funds. This was a year-on-year increase of 56,843 due, on the one hand, to a sharp reduction in our expenditure resulting from having to cancel some of our planned activities and, on the other hand, our income holding up as a result of successful fundraising events.

We do not occupy premises and we do not employ staff, although we commission services. We have a very low level of fixed costs, e.g., website maintenance, subscriptions to other organisations, insurance, and our end of year balances are largely available to promote the Charity’s objectives.

5. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation, and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

We have policies in place concerning –

Code of Conduct

Complaints Procedure

Conflicts of Interest

Equality and Diversity

Financial Control

Fundraising

Privacy Trustee Expenses

6. Reference and Administrative Details

Charity Name	ALK Positive Lung Cancer (UK)
Other names the charity uses	ALK Positive UK and ALK+ UK
Registered charity number	1181171
Charity's principal address	164 Guildford Road Lightwater Surrey GU18 5RL

7. Names of the Charity Trustees who Managed the Charity in 2021

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Debra Montague	Chair		
Graham Lavender	Secretary & Treasurer		
Rebecca Stebbings			
Susan Eastwood			
Angela Field			
Tessa Rust		From 4 April 2021	
Lynne Murtha		From 4 April 2021	
Catherine Gibbard		From 4 April 2021	

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil

8. Declarations

The Trustees declare that they have approved the Trustees' Report as above

Signed on behalf of the Charity's Trustees

Signatures	<i>G H Lavender</i>	<i>D L Montague</i>
Full Names	Graham Herbert Lavender	Debra Louise Montague
Positions	Treasurer	Chair
Date	19 th April 2022	19 th April 2022

Income & Expenditure 2021

Income

Opening Balance		55,279
Donations	4,391	
Grant (Conference)	11,850	
Sale of goods	48	
Gift Aid	975	
Fees Charged	3,608	
In Mem	2,940	
Amazon + easyfunding	314	
Our Fundraising Events	17,053	
Private Funraising	21,237	
Early Diagnosis Campaign	101,942	
Other	58	
		164,415
		219,694

Expenditure

Patient Materials & Postage	3,962	
Website	444	
Trustee Expenses	57	
Events	2,149	
Fitness classes	2,305	
Q&A Sessions	4,200	
Early Diagnosis Campaign	91,145	
Nurse Awards	228	
Just Giving	187	
Admin	2,423	
Other	473	
		107,572
Closing Balance		112,121
Restricted		37,942
Unrestricted Balance		74,179



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity name
ALK Positive Lung Cancer (UK)

On accounts for the year
ended

31/12/21

Charity no
(if any)

1181171

Set out on pages

1 & 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/21

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

24/07/22

Name:

Andrew Evans

Relevant professional
qualification(s) or body
(if any):

Address:

4 Curley Hill Road, Lightwater, GU18 5YG

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

ALK POSITIVE LUNG CANCER (UK)

England & Wales - Charity number 1181171

Accounts

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2020 to 31 December 2020

The Charity was established in December 2018 and this is the Trustees' second Annual Report.

ALK-Positive lung cancer is a relatively rare form of lung cancer caused by a genetic malfunction and comprises less than 4% of all lung cancers. Patients are, on average, much younger than most other lung cancer patients and are usually non-smokers.

1. Objectives and Activities

The objectives of the Charity are to relieve sickness and to preserve and protect good health of UK anaplastic lymphoma kinase (ALK) positive lung cancer patients by:-

- a. providing an information resource, in particular access to information about latest developments and clinical trials;
- b. Identifying and locating UK ALK patients and offering support and guidance on the location of UK ALK specialists and services;
- c. Liaising with and influencing decision makers, e.g. NICE, NHS, DVLA;
- d. Raising awareness of ALK lung cancer, particularly amongst the medical profession so as to promote the best treatment for patients;
- e. Liaising with relevant organisations, in particular Roy Castle Lung Cancer Foundation and the pharmaceutical industry;
- f. Raising funds for the above purposes.

2. Achievements and Performance

A group of 18 patients and supporters came together in July 2018 with the aim of establishing a UK group of ALK-positive patients who could exchange experiences and give and receive mutual support. At our second meeting in October, it was decided to form a registered charity and the Charity was registered by the Charity Commission on 14 December 2018. We started with a £1,000 loan from the Treasurer.

Our achievements and performance in our first two years have greatly exceeded our expectations. Despite many of our planned activities for 2020 being severely curtailed by the Covid-19 pandemic, we still achieved a great deal. The main activities undertaken to further our objectives were –

2.1 Support of Patients

Website

The website was upgraded during the year. It provides information about the Charity and is a source of information for members to be better informed about ALK-positive lung cancer.

Facebook Page

The Facebook page is a great success and the number of users increased from 245 to 343 during the year. Each day, there are posting by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% would recommend the group to other Alk-positive patients.

Patients' Forum

Eighty members attended the Forum meeting in London where they heard presentations from ALK+ expert and were able to ask questions.

Publications

We published "Good Practice from the Patients' Perspective" and this was endorsed by three leading ALK+ experts.

We also published "Living with ALK+ Lung Cancer" which contains valuable information for patients and their families.

Online Activities

Because of the pandemic, we took to Zoom and provided

a weekly diet club

a monthly Alkie Arms – informal meeting with a glass in the hand

a weekly exercise session

a monthly coffee morning

2.2 Advocacy

We attended meetings with healthcare professionals where we raised awareness of the Charity and of ALK-positive lung cancer and advocated on behalf of patients. These meeting were in person in the first quarter of the year and then online thereafter. It is important that healthcare professionals are aware of the Charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients' perspective.

We worked with other organisations to raise awareness of rare lung cancers and were members of

- UK Advanced Cancers Coalition
- Cancer52
- Genetic Alliance
- International Association for the Study of Lung Cancer
- European Cancer Patient Coalition
- Lung Cancer Europe
- National Council for Voluntary Organisation

We lobbied the DVLA to amend their rules about driving with brain metastases.

An Abstract about our MRI data was accepted by the International Association for the Study of Lung Cancer for their annual conference in Singapore.

We contributed to Lung Cancer Europe's report on the Psychological and Social Impact of Lung Cancer and to Roy Castle Foundation's "I'm Still Here" campaign

We conducted a major survey of members to ascertain information about their treatment. The data obtained will inform our advocacy at meetings with health care professionals.

2.3 Fundraising

We participated in Cancer52's 20for20 fundraising event. 35 of our members took part and over £15,000 was raised.

We received a grant of £11,850 for half the cost of our planned Patients' Weekend Conference and a grant of £7,000 towards Breathe For Life's End to End cycle ride.

3. Financial Review

The Charity had £55,279 in its bank account at the end of the year, including £11,850 of restricted funds. This was a year-on-year increase of £32,553 due, on the one hand, to a sharp reduction in our expenditure resulting from having to cancel some of our planned activities and, on the other hand, our income holding up as a result of the successful 20for20 fundraising event.

We do not have premises and we do not employ staff. We have a very low level of fixed costs, e.g. website maintenance, subscriptions to other organisations, insurance, and our end of year balances are largely available to promote the Charity's objectives.

4. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees and there were five throughout 2020.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

5. Reference and Administrative Details

Charity Name	ALK Positive Lung Cancer (UK)
Other name the charity uses	ALK+ UK
Registered charity number	1181171
Charity's principal address	164 Guildford Road Lightwater Surrey GU18 5RL

6. Names of the Charity Trustees who Managed the Charity in 2020

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Debra Montague	Chair		
Graham Lavender	Secretary & Treasurer		
Rebecca Stebbings	Communications		
Susan Eastwood	Research		
Angela Field	Fundraising		

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil

7. Declarations

The Trustees declare that they have approved the Trustees' Report as above

Signed on behalf of the Charity's Trustees

Signatures	G H Lavender	D L Montague
Full Names	Graham Herbert Lavender	Debra Louise Montague
Positions	Treasurer	Chair
Date		

Income & Expenditure 2020

Income	2020
Opening Balance	22,726
Donations	4,611
Grant (Takeda) Patients Forum	11,850
Grant (Takeda) End2End cycle ride	7,011
Sale of goods	457
Gift Aid	2,363
Forum registrations	840
Fees (Deb's appearance payments)	2,185
In Mem	8,975
20four20 fundraising	13,232
Abseil registration	600
Amazon	176
Our Fundraising Events	2,453
Private Funraising	1,360
Other	
	<u>56,113</u>
	78,839
Expenditure	
Merchandise	557
Patient Materials & Postage	4,874
Patient Forums	3,250
Printing & Publicity	1,276
Website	3,992
Trustee Expenses	0
Events	8,836
Fitness classes	650
Other	125
	<u>23,560</u>
Closing Balance	55,279
Restricted (Takeda Forum grant)	<u>11,850</u>
Unrestricted Balance	43,429

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
ALK Positive Lung Cancer (UK)

On accounts for the year
ended

31/12/20

Charity no
(if any)

1181171

Set out on pages

1 and 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended DD / MM / YYYY.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

* Please delete the words in the brackets if they do not apply.

Signed: Andrew Evans

Date: 9 August 2021

Name: Andrew Evans

Relevant professional
qualification(s) or body
(if any):

Address: 4 Curleyhill Road, Lightwater GU18 5YG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

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