



**Trustees' Annual Report for the period: 4th February 2022 to 31st March 2023**

**Charity name:** ALK+ International

**Charity registration number:** 1199634

**Objectives and Activities:** To protect the lives and promote the health of the public through supporting research into nature, diagnosis, prevention and cure and advocating to improve the life expectancy of patients with Anaplastic Lymphoma Kinase Positive (ALK+) cancer. As trustees we do this by;

1. Keeping abreast of trials, breakthroughs and technologies in the oncology industry worldwide, we will advocate for patients and help accelerate the introduction of lifesaving ALK-positive cancer advances. Whereby we can make criteria-driven trustee decisions on the best research programmes to help fund.
2. Awarding grants for research which fulfils the criteria in our Grant Policy and a completed grant application.
3. Advocating for improvements to treatment and clinical trial availability by liaising with government, pharmaceutical companies, regulatory bodies and other organisations.
4. Embedding ourselves into relevant organisations, we will effect change among decision makers using our knowledge and experience of ALK-positive cancers.
5. Working with other charities and organisations to create campaigns for raising awareness and identifying new patients who may be in need of information and support.
6. Providing resources such as a website and social media support groups. Whereby, we will be connecting patients and educating the wider general public, keeping them informed of the most up-to-date developments on the advancement of treatments and research.
7. Fundraising for the above.

**Summary of the purposes of the charity as set out in its governing document:**

To relieve the sickness and to preserve and protect the good health of patients with Anaplastic Lymphoma Kinase Positive (ALK+) cancer in particular, but not exclusively, by:

- a. Awarding grants for research into the nature, diagnosis, prevention and cure for ALK-positive cancer, the useful results of which will be published.
- b. Working with other charities and organisations to create campaigns that will raise public awareness of ALK-positive cancer;
- c. Advocating for improvements to treatment and clinical trial availability, by liaising with government, pharmaceutical companies, regulatory bodies and other organisations;
- d. Identifying and locating ALK-positive patients and offering them information and support;
- e. The provision of resources such as a website and social media support groups that will connect patients and educate the general public and keep them informed of the most up-to date developments on the advancement of treatments and research, and;
- f. Raising funds for the above purposes.

**Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.**

1. This year the trustees have been working hard, keeping up to date with clinical trials. In particular the long awaited ALKOVE-1 trial that is now recruiting at the Royal Marsden hospital, London. There are many ways in which the trustees keep up to date with these breakthroughs and technologies including but not limited to
  - keeping contact with pharmaceutical companies through face to face meetings; remote meetings
  - attending conferences
  - networking with other like minded organisations
  - following the medical oncology industry on social media like Twitter and LinkedIn
2. The trustees have yet to award a research grant in the 2022/2023 financial year, however the trustees are in talks with a very prominent institute located in the UK, and are looking to award a substantial grant for research, providing it fulfils the criteria in our Grant Policy and a completed grant application is submitted.
3. 2022, saw two trustees of ALK+ International appear on BBC radio on three separate occasions to talk about the importance of liquid biopsies and the role it plays when being diagnosed with ALK-positive cancer. Advocating for improvements to treatment and clinical trial availability are high on the list of priorities for our trustees and our community. By liaising with pharmaceutical companies, trustees have been invited to attend conferences and speak.
4. The trustees have formed affiliations with the following relevant organisations;  
Institute for Cancer Research, British Thoracic Oncology Group (BTOG), ALK Positive Inc. (USA based), LUCE (Lung Cancer Europe), Every Breath Lung Cancer Support Group, The Ruth Straus Foundation, BBC radio 4, Charities Aid foundation, The Charity Excellence Framework, Liberating Research and pharmaceutical companies such as Pfizer, Roche and Takeda.

ALK+ International provides a useful links page on our website ([www.alkinternational.org/usefullinks](http://www.alkinternational.org/usefullinks)) that directs ALK-positive patients to further supportive charities: Roy Castle Lung Cancer Foundation, Children with Cancer UK, NCRI, Mind, Willow, Treatment bag, Cancer Support UK, The Bike Network, The Fitness Support Network and Something to Look Forward To.

5. This year's Lung Cancer Awareness Month campaign (November 2022), saw ALK+ International partner with ALK Positive inc. and share the tagline #MoreResearchMoreLife. The campaign that was spread across all social media platforms, saw 130 participating patients from all over the world and over 40 of the world's leading oncologists/prominent figures from the ALK community.
6. Trustees have created and subsidised resources such as a website and various social media platforms ([www.alkinternational.org](http://www.alkinternational.org) /Facebook/Instagram/Twitter/LinkedIn/YouTube) where we have been able to connect patients and educate the wider general public about rare ALK-positive cancers, keeping them informed of the most up-to-date developments on the advancement of treatments and research.
7. The following fundraisers took place this year between February 2022 and March 2023;
  - Community building "£5 for 5K". Our intention to launch ALK+ International was announced on 4th February 2022, where our first community building fundraiser was launched. We challenged ALK-positive cancer patients, and their families and friends to run, walk or cycle 5k and donate £5 so that we could reach our £5,000 target to prove the need for an ALK-positive cancer research charity. In approximately two weeks we far surpassed our target and by the end of the month-long campaign, we had just over £12,000. With hundreds of donors via the initial JustGiving page, Including other patient support groups like "EveryBreath" and prominent lung cancer "advocates" like Instagram influencer "Jog for Georgie".

- In the same month we saw prominent London based cosmetic business Luna Lash, donate 10% of their sales.
- Cyber security company Digital Shadows held a quiz night and sponsored chair of trustees Jamie Gibbard to cycle 5k a day throughout the month of February.
- April saw friend of the charity Kirsty Barnes take part in a skydive in aid of ALK+ International and then host a Charity fun day in Darwin, complete with raffle and DJ and personalised ALK+ International cake.
- In May, friend of ALK+ International Aeron Charnley held a black tie fundraiser evening in Southport where they had live music, buffet, and raffle with top prizes all donated by local businesses.
- In August 2022, fellow ALK+ cancer patient Hayley Adams and friends held their annual rounders match at Bruce Castle Park Tottenham, and chose ALK+ International as this year's beneficiary.
- In September we saw Margaret Gibbard hold a coffee morning and book shop.
- October was a busy month with Andy Gibbard running a marathon, Sarah Sharman's birthday fundraiser, November saw trustee Yvonne Diaz create a JustGiving fundraiser in aid of Lung Cancer Awareness Month and sister to ALK-positive cancer patient Benthany Entwistle skydive in our honour.
- In December friend of the charity, Christie pledged to run 1KM for every pound donated to her JustGiving page.
- The station public house held a charity waxing and announced they will be holding a regular quiz night in honour of ALK+ International
- Popular Poole based teashop Heathers Tearoom, held a bake off on our behalf in January 2023.
- The Knit & Natter group of Hadlow Library, Kent, designated ALK+ International their charity of the year also in January.
- We had two Legacies this year, from David Asquith and Eric Ballard

## Patient Survey 2022

With overwhelming support we continued to hit the ground running and released a European wide ALK-positive patient survey entitled 'What do patients want'. We had an astonishing response of over 130 surveys completed, to-date the largest ALK-positive patient-wide survey completed in both the UK and Europe. Findings were presented at the World Lung Cancer Conference in July 2022, held in Vienna, where the world's leading experts in lung cancer saw the data extrapolated from our survey in the form of graphs. The survey was held on the platform "Survey Monkey".

## Social Media

We have continued to grow our social media following by firstly introducing 'Fact Friday' posts on Instagram and Facebook explaining in laymans terms "what is ALK?" & "What is a liquid biopsy" etc. The trustees together built and paid privately to host a website ([www.alkinternational.org](http://www.alkinternational.org)) and started an ALK stories page showcasing that anyone can be diagnosed with ALK-positive cancers regardless of age, gender or any other defining factor. To date there are 14 ALK patient stories on the website including a neuroblastoma patient and a bowel cancer patient which ties in with our 'all ALK cancers' ethos.

Alk\_international Instagram followers: 1510

<https://www.facebook.com/alkinternational> Facebook page: 465

Facebook support group:383

(@ALKpositiveInt) Twitter followers: 590

<https://youtube.com/@alkinternational> YouTube views:283

<https://www.linkedin.com/company/alk-international/> LinkedIn followers:646

**Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit**

The trustees of ALK+ International have had regard to the guidance issued by the Charity Commission on public benefit as well as in the trust deed, the many policies and procedures installed to run the charity and role descriptions alike.

ALK+ International is part of the charity excellence framework and prides itself on keeping as up to date as possible with charity law as well as taking opportunities to learn more, attend courses etc. Each trustee had also completed a DBS check.

### **Research Grant Criteria Policy**

ALK+ International will only assign grants to medical researchers or organisations affiliated with medical researchers in the field of ALK-positive cancers to further extend the lives of ALK-positive cancer patients.

ALK+ International uses the following criteria to select individuals or organisations for grants.

All or some may apply depending on the individual circumstance that will be determined by a unanimous decision by the Trustees and under the advice of the Patient Advisory Board.

The proposed research benefits all ALK-positive cancer patients, not just those of a particular type (eg. ALK-positive lung cancer). We believe anyone with an ALK-positive Cancer should be included and not just the most common. Many are overlooked including but not limited to ALK Kidney, ALK Breast and ALK Lymphoma.

The Trustees will make an assessment of the proposed research projects maturity, or expected time to reach a clinical setting. This will be carried out by extensive research of the proposed research project. Research projects will submit an initial research grant application form and then the trustees will hold subsequent interviews for successful projects.

An assessment of the viability of the researcher or research organisation to produce a successful research project. Trustees will carry out due diligence and background checks if necessary to assess the viability of the researchers within the projects proposed.

Trustees will consider the infrastructure, and other resources that are or may be available to the researchers and their proposed projects, as well as the researchers personal competence, experience and background.

To assess the feasibility of a research project providing a clinical benefit to ALK+ cancer patients. This will include but not be limited to risk assessment and solutions, control efficiency, timeline and estimations and resources available. Trustees may also consider economic, technical, scheduling and operational feasibility in this instance.

The methodology proposed is scientifically sound. This will include but not be limited to the above in relation to feasibility, but also applying to the methodology in which the proposed research will commence.

Any ethical or legal considerations such as the Human Rights Act should be carefully considered when looking at a proposed research application.

The proposed cost for the research project, how viable our grant participation would be, and if other organisations/charities would likely be awarding or investing into the proposed research project, if such information is easily discernible.

In addition, the individual researcher or proposed research project would be subject to an assessment by Trustees to validate their business and its appropriateness in relation to the charity. Background checks may be carried out at the discretion of the Trustees and or upon the advice of the Patient Advisory Board.

In addition to the medical criteria above, the Trustees will ensure the proposed project is well understood by all, particularly:

What will be delivered and how,

- What exactly is the project
- How easy will it be to monitor its delivery
- Whether the proposed researcher or research project can deliver what is required
- If the proposed researchers or project has the capability and capacity to deliver
- If the proposed researchers have the capability to efficiently adhere to a time frame.

- The individual researchers expertise and skills in this specific area - what history and track record do they personally and professionally have? A CV or something of equal calibre will be required.
- Whether the individual researcher or employee within the proposed research project has the management and technical capability and capacity to undertake this project along with its existing commitments.
- The cost of the project, what ALK+ International's funds will go towards and how it is going to be used. An itemised breakdown and or budget may be requested at this point.

### **Contribution made by volunteers**

Volunteer contributions in the year 2022 were all exclusively through fundraising and the running of personal fundraising events through Kindlink or JustGiving, we had 12 volunteers in total hosting a wide range of events.

Risk assessments/ public liability insurance was taken into consideration within the locations of events by property owners externally and ALK+ International had no matters arising regarding this.

### **Press release**

This year the charity has made great strides in connecting/networking with like minded companies and organisations. ALK+ international has opened up doorways of communication via various social media/media groups/ channels to talk about research and advocate on important topics. This has directly led us to our main goal - to fund research.

### **Financial Review**

Review of the charity's financial position at the end of the period

Money in: £59,202.03

Money out: £0

The trustees have chosen to externally sponsor certain administrative costs for the running of the first year of the charity, these costs include website hosting of £110.40 as the website was built by the trustees, costs were at a minimum. Trustees also chose to subsidise their own travel expenses while attending conferences.

No reserves are held for ALK+ International. The reason for this is that we currently have zero overheads and in the future intend to access grants to expand our core administration costs IE we would like to subscribe to the fundraising regulator and pay for the website etc. The trustees generously sponsored our first year of core funding as a gauge to how much we would need to secure through grants in the future. The trustees understand that long term this is unsustainable and acquiring funding would reinforce the charity's aims, credibility and the '100% of funds raised will go towards research' ethos.

This year, the charity principal sources of funds have come solely from fundraising from the public.

ALK+ International is constituted with a trust deed.

Methods of trustee selection include but are not limited to:

- Being an invested part of the ALK-positive community
- Having a firm belief that research will extend the lives of ALK+ cancer patients
- Can bring something to our trustee group that will help to forward the charity. IE; fundraising/media backgrounds.
- Trustees must unanimously agree to appoint new trustees and uphold the values set out in our objectives and activities.

## Reference and Administrative details

Charity name: ALK+ International

Other name the charity uses: ALK International

Registered charity number: 1199634

Charity's principal address:

4 PEEL STREET

HASLINGDEN

ROSSENDALE

BB4 5DZ

## Names of the charity trustees who manage the charity

1. Joanna Jonathan
2. James Gibbard
3. Catherine Gibbard
4. Yvonne Diaz - appointed 13.08.22
5. Jan Clark - appointed 13.08.22

All trustees work remotely from their homes throughout the UK negating the need for travel expenses, office space & public liability insurance?

No trustees hold property belonging to the charity. Similarly no funds or assets held as custodian trustees.

## Additional Information

A medical committee is still in the process of being formed but will be formalised in the coming months. We currently have 4 highly prominent figures in the ALK oncology field and they will be announced in due course.

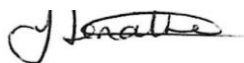
## Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Full name(s)

Joanna Jonathan - Community Fundraiser/ Co-Treasurer



Catherine Gibbard -Community Fundraiser/ Co-Treasurer



James Gibbard - Secretary/Communications...



Date: 1st December 2023

**Financial Statements**  
**for the Period Ended 31 March 2023**  
**for**  
**ALK+ International**

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**Statement of Financial Activities  
for the Year Ended 31 March 2023**

	Unrestricted fund £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	59,202	-	59,202
	<u>          </u>	<u>          </u>	<u>          </u>
<b>Total</b>	<u>59,202</u>	<u>-</u>	<u>59,202</u>
<b>EXPENDITURE ON</b>			
Charitable activities	-	-	-
	<u>          </u>	<u>          </u>	<u>          </u>
<b>Total</b>	<u>-</u>	<u>-</u>	<u>-</u>
<b>NET INCOME/(EXPENDITURE)</b>	59,202	-	59,202
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	-	-	-
	<u>          </u>	<u>          </u>	<u>          </u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>59,202</u>	<u>-</u>	<u>59,202</u>

**Balance Sheet**  
**31 March 2023**

	Unrestricted fund £	Restricted funds £	Total funds £
<b>FIXED ASSETS</b>			
Tangible assets	-	-	-
<b>CURRENT ASSETS</b>			
Cash at bank and in hand	<u>59,202</u>	<u>-</u>	<u>59,202</u>
	<b>50,937</b>	<b>-</b>	<b>59,202</b>
<b>CREDITORS</b>			
Amounts falling due within one year	-	-	-
	<u>-</u>	<u>-</u>	<u>-</u>
<b>NET CURRENT ASSETS</b>	<u>59,202</u>	<u>-</u>	<u>59,202</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>	<u>59,202</u>	<u>-</u>	<u>59,202</u>
<b>NET ASSETS</b>	<u>59,202</u>	<u>-</u>	<u>59,202</u>
<b>FUNDS</b>			
Unrestricted funds			59,202
Restricted funds			<u>-</u>
<b>TOTAL FUNDS</b>			<u>59,202</u>

The financial statements were approved by the Board of Trustees and authorised for issue on .12/01/2024. and were signed on its behalf by:

J Jonathan - Trustee

## 1. ACCOUNTING POLICIES

### Basis of preparing the financial statements

The Trustees have chosen to adopt the Update Bulletin 1 issued by the Charities Commission in February 2016, which exempts the charity from the need to prepare a statement of cash flows.

The board of trustees have considered the charity's going concern position for a period which extends beyond 12 months from the date of approval of the financial statements.

### Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

### Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

### Taxation

The charity is exempt from tax on its charitable activities.

### Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

## 2. DONATIONS AND LEGACIES

Donations	£
	<u>59,202</u>
	<u><u>59,202</u></u>

### 3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or benefits for the period ended 31st March 2023.

#### Trustees' expenses

There were no trustees' expenses paid for the period ended 31st March 2023.

### 4. STAFF COSTS

The average monthly number of employees during the year was as follows:

Staff	<u>Nil</u>
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No employees received emoluments in excess of £60,000.

### 5. MOVEMENT IN FUNDS

	At 1.4.22 £	Net movement in funds £	At 31.3.23 £
<b>Unrestricted funds</b>			
General fund	<b>59,202</b>	<b>59,202</b>	-
<b>Restricted funds</b>			
Restricted funds	-	-	-
	-	-	-
<b>TOTAL FUNDS</b>	<u><b>59,202</b></u>	<u><b>59,202</b></u>	<u>-</u>

### 6. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2023.

**Detailed Statement of Financial Activities  
for the Year Ended 31 March 2023**

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	£
<b>INCOME AND ENDOWMENTS</b>	
<b>Donations and legacies</b>	
Donations	<u>59,202</u>
	59,202
<b>Total incoming resources</b>	59,202
<b>EXPENDITURE</b>	-
	<hr/>
Total resources expended	<hr/> -
<b>Net income</b>	<u><u>59,202</u></u>

## **Independent Examiner's Report to the Trustees of ALK+ International**

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### **Independent examiner's report to the trustees of ALK+ International**

I report to the charity trustees on my examination of the accounts of ALK+ International for the period ended 31 March 2023.

### **Responsibilities and basis of report**

As the charity 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 accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all 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 giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do 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.

Nicola Lewis ACA

Date: .12/01/2024