

# KLINEFELTER'S SYNDROME ASSOCIATION

England & Wales · Charity number 1058319

## Details

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**Other names** K.S.A.

**Status** Registered

**Legal form** Other

**Registered** 1996-09-27

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

## Contact

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**Address** Engineers Cottage  
Homesford  
Whatstandwell  
Matlock  
DE4 5HJ

**Phone** 07814915722

**Email** [Contact@ksa-uk.net](mailto:Contact@ksa-uk.net)

**Website** [www.ksa-uk.net](http://www.ksa-uk.net)

## Activities

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**Objects:** TO PRESERVE AND PROTECT THE HEALTH AND PROMOTE THE WELFARE OF PERSONS AFFECTED BY KLINEFELTER'S AND RELATED SYNDROMES. TO ADVANCE THE EDUCATION OF THE MEDICAL PROFESSION, OTHER PUBLIC AND PRIVATE BODIES AND THE GENERAL PUBLIC ON THE SUBJECT OF KLINEFELTER'S AND RELATED SYNDROMES AND THEIR IMPLICATIONS FOR THE FAMILY. TO PROMOTE RESEARCH INTO KLINEFELTER'S AND RELATED SYNDROMES AND TO PUBLISH THE RESULTS THEREOF AND TO SUPPORT ORGANISATIONS PROMOTING RESEARCH INTO KLINEFELTER'S AND RELATED SYNDROMES.

**Activities:** Information on Klinefelter's Syndrome is provided via: website ([www.ksa-uk.net](http://www.ksa-uk.net)) which has a 'Members Only' section Helpline 0300 111 4748. Subsidised Activity Weekends and Conference are held annually. Member meetings are held throughout the year in various locations. Access is available to private Facebook groups. Membership is worldwide.

## Classification

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- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability, Other Charitable Purposes
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Defined Groups

## Geography

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- Australia
- Bahrain
- Brazil
- Canada
- Croatia
- Egypt
- France
- Germany
- Guernsey
- India
- Ireland
- Japan
- Malta
- Netherlands
- New Zealand
- Nigeria
- Northern Ireland
- Scotland
- United Arab Emirates
- United States
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£28,151	£30,694	-	-
2024-03-31	£35,911	£20,965	-	-
2023-03-31	£24,513	£21,616	-	-
2022-03-31	£18,854	£14,130	-	-
2021-03-31	£11,782	£6,500	-	-

## Trustees

Name	Role	Appointed
ALISON EDITH BRIDGES		
Claire Harkin		2020-03-21
Kenneth Iain Scott		2014-06-28
Lexi BREEN		2023-05-13
Melanie Perrins		2024-05-18
Paul Dutton		2024-05-18
Philippa Reed		2024-05-18
Sarah Gordon		2023-10-21
Sasha Steventon		2026-01-17
Sylvia James-Yates		2023-06-17

**KLINEFELTER'S SYNDROME ASSOCIATION**

England & Wales - Charity number 1058319

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# Accounts

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Registered Charity No. 1058319

**KLINFELTER'S SYNDROME ASSOCIATION (KSA)**

**TRUSTEES ANNUAL REPORT & ACCOUNTS**

**FOR THE YEAR ENDED 31 MARCH 2025**

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**KLINEFELTER'S SYNDROME ASSOCIATION****Reference and administrative information****Year Ended 31 March 2025**

Registered charity number: 1058319

**TRUSTEES:**

Mr Paul Dutton (Chair)  
Ms Lexi Breen (Vice Chair & Social Media)  
Mrs Sarah Gordon (Treasurer)  
Mrs Sylvia James-Yates (Secretary)  
Mrs Alison Bridges (Activity Weekend Organiser)  
Mrs Claire Harkin (Research Coordinator)  
Mrs Melanie Perrins (Membership Secretary)  
Mr Kenneth Scott  
Mrs Phillipa Reed

**ADDRESS:**

Engineers Cottage Homesford  
Matlock  
Derbys.  
DE4 5HJ

**BANKERS:**

TSB  
PO Box 1000 BX4 7SB

Co-operative Bank plc  
PO Box 250  
Skelmersdale  
WN8 6WT

**Report of the Trustees**

The trustees present their report and financial statements of the charity for the year ended 31 March 2025.

The charity is registered with the Charity Commission, the Regulator for Charities in England & Wales. The Trustees have adopted the provisions of the Charities Act 2011 and with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014.

**Objectives and activities of the KSA**

The KSA exists to offer support and information to all affected by, or having an interest in, Klinefelter's Syndrome (KS)/XXY which is a relatively common, but hugely under-diagnosed genetic condition caused by the presence of an extra sex chromosome. The KSA provides information and support via its website, Helpline, annual conferences, social media, newsletters and publications. It hosts and encourages various social activities to provide a support network.

The KSA works to raise the profile of the condition with the medical profession, other public and private bodies and the general public and to help all to understand its implications, not only for the individual affected, but also for all those with whom they have contact during their lives. The KSA exhibits at medical conferences to raise awareness of KS/XXY. It offers free membership to professional people with an interest in KS/XXY.

The KSA works to promote and support research into the condition. The KSA promotes relevant research projects in newsletters, on our website, by email and by via social media.

The Trustees confirm that they have referred to the guidance contained in the Charity Commissions general guidance on public benefit when reviewing the Charity's aims and objectives and in planning future activities.

The trustees have had regard to the Charity Commission's public benefit guidance when exercising any powers or duties to which the guidance is relevant.

**Achievements and Performance****Raising Awareness**

To help raise awareness of KS/XXY, KSA trustees have exhibited and / or spoken at several medical and related Conferences and Awareness/Information Days throughout the year.

Of particular note (\*) Alison Bridges has made contact with a group of Forensic Psychologists at the University of Derby who are interested in helping to produce guidelines on the treatment of KS/XXY people who come into contact with the Justice Systems of the UK.

<b>Dates</b>	<b>Event</b>	<b>Attendees</b>
May 2024	University & College Union LGBT Conference	Lexi Breen - Speaker
June 2024	iDSD Conference Stockholm	Ken Scott - Steering Group member & Lexi Breen (costs borne by organisers).
June 2024	British Psychological Society Conference	Claire Harkin

**Report of the Trustees Cont/d**

<b>Dates</b>	<b>Event</b>	<b>Attendees</b>
September 2024	*Celebrating Psychology in the Midlands	Alison Bridges
October 2024	Royal College of GP's Conference, Liverpool	Lexi Breen Paul Dutton
November 2024	University & College Union Equalities Conference	Lexi Breen - Speaker
November 2024	British Association of Gender Identity Specialists (BAGIS)	Lexi Breen - Speaker
November 2024	European Society for Paediatric Endocrinology	Lexi Breen - Delegate
February 2025	Safeguarding Leads UK	Lexi Breen - Speaker
February 2025	MSc International Social workers	Lexi Breen - Speaker
February 2025	LGBT Health Professionals Network	Lexi Breen - Speaker
February 2025	Rare Diseases Day at St Thomas KS/XXY clinic	Sylvia-James Yates
February 2025	Rare Diseases Day at the Glasgow Children's Hospital	Ken Scott
March 2025	BES Conference, Harrogate	Lexi Breen Ken Scott
March 2025	Genetic Alliance Rare Diseases Day at Scottish Parliament with MSP's.	Ken Scott
March 2025	Liverpool Medical School training video	Paul Dutton
March 2025	BES Clinical Update, Birmingham	Lexi Breen
March 2025	European Association for Urology Congress	Claire Harkin (A European Patient Advisory Group Advocate) - Speaker (co-presenting with Mr Tet Yap).

**Podcasts and Webinars**

Lexi Breen has taken part in a podcast in April 24 that is very specific to KS/XXY - Understanding "Klinefelter Syndrome: The Chromosome Anomaly"

<https://podcasts.apple.com/gb/podcast/understanding-klinefelter-syndrome-the-chromosome/id1657370014?i=1000653683578>

**KS/XXY Awareness Day**

Trustee AJ Howard designed the 2024 Awareness Day Advert which featured a series of posts and a short video. The KSA are planning for the Awareness Day to become an annual occurrence with events to compliment it.

## **KLINEFELTER'S SYNDROME**

### **Report of the Trustees Cont/d**

#### **Research**

<b>Research topic</b>	<b>Institution</b>	<b>Researchers</b>
Gender Incongruence: Assessing the perspectives of people with Klinefelter Syndrome (KS), healthcare professionals and KS experts to improve clinical practice and treatment/support policy	University of Derby	Athina Tripli Professor James Elander Dr Eliana Taylor
A systematic review of evidence about gender identity and Klinefelter syndrome/XXY: prevalence, beliefs, attitudes and experiences	University of Derby	Athina Tripli Professor James Elander Dr Eliana Taylor
The experience of having Klinefelter syndrome/XXY diagnosed during investigation of infertility: A qualitative exploration	University of Derby	Professor James Elander Claire Harkin Dr Bryan Woodward
Experiences of professionals who have worked with individuals with Klinefelter's Syndrome in contact with the criminal justice system.	University of Derby	Henrietta Bergstrom Harry Evans
What are the perceived impacts of school-based counselling on the educational experiences and emotional well-being of students aged 8-11 diagnosed with Klinefelter Syndrome in mainstream schools, as reported through qualitative interviews?	University of Exeter	Ellie Crisp Oliver Bridge
KS/XXY qualitative experiences of infertility	De Montfort University	Dr Kristine Fearon
KS Quality of Life	City, University of London	Brien Mehmet Sofia Llahana
KS/XXY and Autism	Autism Research Centre, University of Cambridge	Sir Simon Baron-Cohan Alexander Tsompanidis

#### **RedCap Database**

The KSA continues to support financially the setup of a RedCap Database, which is situated at the KS Clinics at Guy's and St Thomas'. This holds anonymised data about KS/XXY patients at the clinic which will inform the clinicians and help them to see trends. The KSA will continue to fund the management of the database going forward.

**Report of the Trustees Cont/d**

**Support and Information**

**Website**

The main source of information provided by the KSA is our website which is often praised by people who contact us. It contains The Members' Handbook, information about events and recordings from previous KSA Conferences and webinars.

**Newsletter**

The KSA sends out frequent mailings to its members via Mail Chimp. These contain information about events which have been organised by the KSA, news about current research, updates about fund raisers, opportunities to take part in research and any other information about the KS/XXY world which is likely to be of interest to our members. These mailings are very useful because they can be sent at short notice – unlike a printed newsletter. An annual compilation is made available on the website for members who like to have a printed copy. A limited number of printed copies are sent to members who are unable to access the internet.

**Helpline and website contact form**

In the last year the KSA have received and responded to nearly 250 Helpline calls and contacts through the website. The subjects of these vary enormously and include seeking a diagnosis, questions about behaviour or an elderly parent worried about how their adult son will manage when they can no longer support him. Often calls will take an hour or more because people are so grateful to find a sympathetic and supportive listener. Website contacts also often precipitate calls. A single contact can often result in multiple conversations. Alison Bridges and Ken Scott respond to the Helpline. Alison replies to website-initiated contacts but may involve other trustees as appropriate.

**Activity Weekends**

KSA Activity Weekends were introduced in 2001 as a way of getting people who are affected by KS/XXY together in a relaxed environment. They provide a unique opportunity to meet others, of all ages, who are affected by KS/XXY. By the end of the weekend people seem to have grown in confidence and self-esteem and many say that they feel part of the wider KS/XXY community. 40 people attended in April 2024 plus 33 people in September 2024 including members living in France.

**Social events**

Because our members are scattered across the country (and, indeed, the world) it is difficult to organise social events. To help plug this gap, several regular virtual chats have been arranged. Members who join in have said that they value the opportunity to 'meet' and chat with others who understand their experiences. In-person meetings are arranged when possible and may feature pub lunches or country walks.

**KSA AGM and Conference**

This was again a hybrid 'in-person'/virtual event. It was held in May 2024 at the Kent's Hill Park training centre in Milton Keynes. The location of rooms and refreshment arrangements coupled with poor wifi meant that we couldn't consider rebooking for 2025.

Despite the venue drawbacks the Conference was very enjoyable. Amongst the speakers were representatives from Guy's London KS/XXY clinics. Three workshops were run by a variety of medical professionals and others. The Conference helps to educate members while developing peer support.

**Report of the Trustees Cont/d**

**Virtual and in-person support at Guy's and St. Thomas' KS Clinic**

KSA trustees have joined the team at Guy's and St Thomas' to virtually (and, when possible, in-person) to support patients and families at the Adults and Young Person's KS Clinics. They talk to patients and signpost them to support available outside of the clinics.

**KS/XXY as an intersex condition**

Intersex people are born with primary and secondary sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns or chromosomal patterns) that do not fit typical binary notions of male or female bodies (UN Human Rights Commission).

Experts estimate that up to 1.7 percent of the population are born with intersex traits. Other terminology may be used (such as Variations in Sex Characteristics, Differences or Disorders of Sex Development or the name of a particular condition). Intersex people may have any gender identity or sexual orientation.

People who are KS/XXY are neither XX - typical female nor XY – typical male and we often have bodily differences from more typical people. Because of this KS/XXY is classed as an intersex condition, though it's a matter of personal choice whether we choose to use this label at all. Our bodily differences to more typical XX/XY people can have serious ramifications when it comes to healthcare (for example we have a higher risk of breast cancer than an XY male) but that is often not understood by those affected, or their medical professionals.

When the KSA was first set up many of our advising medical professionals at the time were confident that every XXY person was male, but as knowledge has advanced it has become clear that there are other factors (such as androgen insensitivity for example), which mean that some XXY people have female bodies. KSA is therefore today aware that our members and potential members represent a very broad range of experience yet we still seek to support all KS/XXY people and our work for the KSA and in liaison with other organisations reflects that.

**Membership of other organisations**

- Ken Scott is a patient representative on the I-DSD steering committee and on the Rare Conditions Patient Advisory Group.
- Lexi Breen is a member of Mental Health Partnership Network for Rare Diseases.
- Claire Harkin is a patient representative on the NICE\* forum, discussing the proportionate approach to technology appraisals and improvements to the NICE\* guidance concepts.
- the National Council for Voluntary Organisations (NCVO)
- the Prescription Charges Coalition
- EURORDIS-Rare Diseases Europe
- ENDO European Reference Network
- UROGEN European Reference Network
- Genetic Alliance and Rare Disease
- Rare Conditions Network
- Interconnected (ICON) UK
- LGBTIQ+ Scotland (The Equality Network).
- the KSA is affiliated to the British Endocrine Association which gives it some authority when corresponding with medical professionals.
- the KSA has representation on the planning board for the new KS Paediatric Clinic at Guy's and St Thomas'.
- the UK Men's Health Network.

**Report of the Trustees Cont/d**

**Structure, Governance and Management**

The KSA has been a charity since 1996 and is run by trustees who form the National Executive Committee (NEC). They are elected at the AGM or can be co-opted at any time. The KSA generally recruits from its membership but would be happy to recruit from outside if the opportunity presented itself.

**Trustees**

There were a number of trustees changes at the AGM in May 2024. Paul Dutton took over as Chair from Alison Bridges who had been acting Chair since the death of Barry Duplock. Alison continues her role as trustee focusing on organising our popular activity weekends. Lexi Breen was elected Vice Chair at the AGM in addition to their Social Media responsibilities. Melanie Perrins has taken over the Membership Secretary role from Jim Harkin. Mike Green has decided to step down from his trustee role and Phillipa Reed joined the NEC at the AGM.

As at 31<sup>st</sup> March 2025 there were nine trustees.

**Volunteers**

We now have a small group of volunteers who can't commit to being trustees but who help in the everyday running of the KSA. Their support really makes a difference.

I would like to thank everyone who made a donation, told someone else about the KSA (or KS), fund raised, organised a meeting, contributed to the Newsletter or helped the KSA community in any way. A little help from a lot of people adds up to a great deal.

**Financial Review**

For a review of the financial performance please refer to the Statement of Financial Activities and Balance Sheet for the year ended 31<sup>st</sup> March 2025.

The Charity holds sufficient reserves to fulfil its policy objectives. We aim to maintain a minimum of 4 months' worth of expenses in the charity's bank accounts. If reserves fall below 8 months' worth of expenses an agenda item must be included at the next National Executive Committee meeting to discuss ways of increasing Charitable income in order to prevent cash reserves getting close to the 4 month minimum.

The KSA Trustees believe that the charity is a going concern as bank balances of £90,218 (£30,000 of which was paid to the KSA as a bequest but intended for Tet Yap's research team. The KSA is currently holding these funds on his behalf), are well in excess of annual expenditure of £30,694. There are no post balance sheet events to the date of this report to change the assessment that the KSA is a going concern.

Approved by the trustees and signed on their behalf by:



**Mrs Sarah Gordon      November 2025**

**Independent Examiner's Report to the Trustees  
of Klinefelter's Syndrome Association ("KSA")**

I report to the charity trustees on my examination of the accounts of the KSA for the year ended 31<sup>st</sup>  
March 2025.

**Responsibilities and basis of report**

As the charity trustees of the KSA, 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 KSA's accounts carried out under section 145 of the Act. In carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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:

accounting records were not kept as required by section 130 of the Act; or  
the accounts do not accord with those records; or  
the accounts do not comply with the applicable requirements concerning the format 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 confirm that there are no other matters to which your attention should be drawn to enable a proper understanding of the accounts to be reached.

Signed: 

Date: 30/11/25

Name: Lindsay Brett

Address: 6 St Andrews Close, Fearnhead, Warrington WA2 0EJ

Relevant professional qualification(s) or membership of professional bodies:

**KLINEFELTER'S SYNDROME**

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**Statement of Financial Activities****For the Year Ended 31 March 2025**

<b>Year Ended</b>	<b>31/03/25</b>	<b>31/03/24</b>
	<b>£</b>	<b>£</b>
<u>Incoming Resources</u>	<b>28,151</b>	<b>35,911</b>
Donations & Legacies	14,735	22,342
Charitable Activities	13,061	10,626
Investment Income	0	0
Other	355	2,943
<u>Resources Expended</u>	<b>30,694</b>	<b>20,965</b>
Charitable Activities	26,639	13,465
Other	4,055	7,502
<b><u>Net Income / (Expenditure)</u></b>	<b>(2,543)</b>	<b>14,946</b>
Total Fund Balances Brought Forward	62,761	47,815
Total Fund Balances Carried Forward	60,218	62,761

**Statement of Assets and Liabilities****As at 31 March 2025**

	<b>31/03/25</b>		<b>31/03/24</b>
	<b>£</b>		<b>£</b>
<b>CURRENT ASSETS</b>			
Prepayments and Accrued Income	0		0
TSB Bank	24,053		21,131
Co-Operative Bank	65,637		71,220
PayPal Account	528		410
	<b>90,218</b>		<b>92,761</b>
<b>CURRENT LIABILITIES</b>			
Creditors	0		0
Accruals and Deferred Income	0		0
Research Liability	30,000		30,000
	<u>30,000</u>		<u>30,000</u>
<b>NET ASSETS</b>	<b>60,218</b>		<b>62,761</b>
<b>RESERVES</b>			
<b>Unrestricted Funds</b>			
Reserves Brought Forward	54,824		41,556
Surplus of Income over Expenditure for the Year	2,835	57,659	13,268
			54,824
<b>Restricted Funds</b>			
Reserves Brought Forward	7,937		6,259
Surplus / (Deficit) for the Year	(5,378)	2,559	1,678
	<u>60,218</u>		<u>62,761</u>

**Notes to the accounts at 31 March 2025****1. Accounting policies****Basis of accounting**

The financial statements have been prepared on a cash accounting basis in accordance with the **Receipts and Payments** method, as permitted for small charities under **Section 133 of the Charities Act 2011** and the accompanying guidance issued by the Charity Commission for England and Wales.

Income is recognized when received, and expenditure is recorded when paid, rather than when incurred. As a result, the accounts do not reflect outstanding income or expenses at the balance sheet date. This basis of accounting is considered appropriate for the charity given its size and straightforward operations.

The accounts present a 'true and fair' view and the accounting policies adopted are those outlined in this note.

**Fund accounting**

Unrestricted funds are funds which are available for use at the discretion of the Committee in furtherance of the general objectives of the Charity and which have not been designated for other purposes. The restricted funds are to be used as per individual donors' wishes. These are usually to help fund shortfalls in activity weekends.

**Incoming resources**

Income is included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. Legacies are included in the Statement of Financial Activities when receipt is probable, that is, the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gift Aid is included in income when the claim has been received from HMRC.

Membership subscriptions are always treated as subscriptions. If a member adds an additional amount at the time of paying the subscription this is classified as a donation.

Grants and donations are only included in the SoFA when the general income recognition criteria are met. In the case of performance related grants, income is recognised to the extent that the charity has provided the specified goods or services as entitlement to the grant only occurs when the performance related conditions are met.

The restricted funds are used solely for the purposes of the Activity Weekend Subsidies given to members who attend this activity. Every year the excess of costs over Activity Weekend income reduces the amount of restricted funds.

**Resources expended**

All expenditure is accounted for on a cash basis and has been classified under headings that aggregate all costs related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with use of the resources.

The expenditure categorisations in the Statement of Financial Activities for the year ended 31<sup>st</sup> March 2025 are stated in line with SORP FRS102

**2. Transactions with Trustees and Related Parties****Trustee Remuneration and Benefits**

**KLINEFELTER'S SYNDROME**

For the years ended 31<sup>st</sup> March 2024 and 31<sup>st</sup> March 2025, none of the trustees have been paid any remuneration or received any other benefits from an employment with their charity or a related entity.

**Trustee Expenses**

Expenses were reimbursed to 6 trustees for the year ended 31<sup>st</sup> March 2025 amounting to £3,307.

The majority of these expenses related to trustees' attendance of exhibitions and external conferences as well as travel, food and accommodation for the Annual KSA conference. This was a modest decrease compared to £5,227 in the year ended 31<sup>st</sup> March 2024.

**Transaction(s) with Related Parties**

There were no related party transactions for the years ended 31<sup>st</sup> March 2024 and 31<sup>st</sup> March 2025.

**KLINEFELTER'S SYNDROME****Detailed Statement of Financial Activities**

<b>Year Ended</b>	<b>31/03/25</b>	<b>31/03/24</b>
	<b>£</b>	<b>£</b>
<b><u>INCOME</u></b>		
Membership	1,723	1,818
Online Membership - PayPal	4,031	4,747
Donations and Sponsorships	8,980	15,277
Grants and Awards	0	500
AGM and Conference	4,635	3,146
Activity Weekend	8,426	7,480
Interest Received	0	0
Miscellaneous Income	0	65
Legacies and Bequests	278	1,264
Gift Aid	78	1,614
	<b>28,151</b>	<b>35,911</b>
<b><u>EXPENDITURE</u></b>		
AGM Conference	11,980	6,807
NEC Meetings	0	147
Newsletter	0	21
Exhibition and Related Travel Expenses	3,349	3,544
Postage and Stationery	55	468
Activity Weekend Costs	13,804	5,802
Helpline Phone	568	531
Website & IT Costs	313	1,295
DBS Checks	199	0
Accountancy	131	131
Insurance Costs	96	96
PayPal Charges	98	116
KSA Clothing	71	0
Miscellaneous Expenses	0	321
Advertising and Marketing	0	222
Database	0	1,417
Cost of raising funds	30	48
	<b>30,694</b>	<b>20,965</b>
<b>Net Surplus (Deficit) for the Year</b>	<b>(2,543)</b>	<b>14,946</b>

**KLINEFELTER'S SYNDROME ASSOCIATION**

England & Wales - Charity number 1058319

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# Accounts

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Registered Charity No. 1058319

**KLINFELTER'S SYNDROME ASSOCIATION (KSA)**

**TRUSTEES ANNUAL REPORT & ACCOUNTS**

**FOR THE YEAR ENDED 31 MARCH 2024**

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**KLINEFELTER'S SYNDROME ASSOCIATION****Reference and administrative information****Year Ended 31 March 2024**

Registered charity number: 1058319

**TRUSTEES:**

Mr Barry Duplock (Chair) (Deceased 18<sup>th</sup> June 2023)  
Mrs Alison Bridges (Vice Chair & Activity Weekend Organiser)  
Mr Michael Green (Treasurer until 20<sup>th</sup> October 2023)  
Mrs Sarah Gordon (Treasurer from 21<sup>st</sup> October 2023)  
Mrs Sylvia James-Yates (Secretary)  
Mr Christopher Breen (Social Media)  
Mrs Claire Harkin (Research Coordinator)  
Mr Jim Harkin (Membership Secretary)  
Mr Kenneth Scott  
Mr Jim Howard

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DE4 5HJ

**BANKERS:**

TSB  
PO Box 1000 BX4 7SB

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PO Box 250  
Skelmersdale  
WN8 6WT

## **KLINEFELTER'S SYNDROME ASSOCIATION**

### **Report of the Trustees**

The trustees present their report and financial statements of the charity for the year ended 31 March 2024.

The charity is registered with the Charity Commission, the Regulator for Charities in England & Wales. The Trustees have adopted the provisions of the Charities Act 2011 and with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014.

### **Objectives and activities of the KSA**

The KSA exists to offer support and information to all affected by, or having an interest in, Klinefelter's Syndrome (KS)/XXY which is a relatively common, but hugely under-diagnosed genetic condition caused by the presence of an extra sex chromosome. The KSA provides information and support via its website, Helpline, annual conferences, social media, newsletters and publications. It hosts and encourages various social activities to provide a support network.

The KSA works to raise the profile of the condition with the medical profession, other public and private bodies and the general public and to help all to understand its implications, not only for the individual affected, but also for all those with whom they have contact during their lives. The KSA exhibits at medical conferences to raise awareness of KS/XXY. It offers free membership to professional people with an interest in KS/XXY.

The KSA works to promote and support research into the condition. The KSA promotes relevant research projects in newsletters, on our website, by email and by via social media.

The Trustees confirm that they have referred to the guidance contained in the Charity Commissions general guidance on public benefit when reviewing the Charity's aims and objectives and in planning future activities.

The trustees have had regard to the Charity Commission's public benefit guidance when exercising any powers or duties to which the guidance is relevant.

### **Achievements and Performance**

#### **Raising Awareness**

##### **Exhibiting at Conferences**

To help raise awareness of KS/XXY, KSA trustees have exhibited at several medical conferences and awareness / information days throughout the year. These include:

- British Endocrine Society (BeS) conference in Glasgow (November) and Royal College of General Practitioners (RCGP) conference in Glasgow (October) attended by Chris Breen and Ken Scott.
- Endocrine Clinical Update in Birmingham (April) attended by Chris Breen and Alison Bridges.
- European Society of Paediatric Endocrinology in the Hague (September) attended by Chris Breen.
- Rare Diseases Day (February) at St Thomas KS/XXY clinic attended by Sylvia-James Yates and at the Glasgow Children's Hospital attended by Ken Scott.
- Information Day at Glasgow University attended by Ken Scott.

## **KLINFELTER'S SYNDROME ASSOCIATION** **Report of the Trustees Cont/d**

### **Podcasts and Webinars**

Chris Breen has taken part in two very interesting podcasts. The first in April 23 is Genetic diagnosis of azoospermia: from chromosomes to whole exome analysis webinar:

<https://endo-ern.eu/event/webinar-genetic-diagnosis-of-azoospermia-from-chromosomes-to-whole-exome-analysis/>

The second, in April 24 is more specific to KS/XXY - Understanding Klinefelter Syndrome: The Chromosome Anomaly:

<https://podcasts.apple.com/gb/podcast/understanding-klinefelter-syndrome-the-chromosome/id1657370014?i=1000653683578>

### **KS/XXY Awareness Day**

Our first KS/XXY Awareness Day campaign on 11th May 2023 was organised by trustee AJ Howard with assistance from trustee Ken Scott and volunteer Ed Dobie. Another trustee managed to get a little airtime on local radio to talk about the Awareness Day. AJ also designed the 2024 Awareness Day Advert which featured a series of posts and a short video. The KSA are planning for the Awareness Day to become an annual occurrence with events to compliment it.

### **Research**

#### **Gender Identity and KS/XXY Research, University of Derby**

PhD Studentship - Following Claire Harkin's Psychology MSc that focused on Gender Identity and KS/XXY, the University of Derby was able to secure funding for a PhD studentship on gender identity among people with Klinefelter syndrome (KS/XXY). Athina Tripli was the successful candidate and will be conducting the PhD research, with members of the KSA NEC sitting on the Advisory Panel, as well as other key medical professionals in KS/XXY from across the globe supporting Athina on this journey. The research will assess the perspectives of people with KS/XXY, healthcare professionals and KS/XXY experts to improve clinical practice and treatment/support policy.

#### **Systematic Review – The School of Psychology, University of Derby**

This is a systematic review of evidence about gender identity and KS/XXY. The proposed review question is: How does gender identity develop among people with Klinefelter syndrome/XXY? The members of the team conducting the review are Professor James Elander, Claire Harkin, Dr Elaina Taylor and Athina Tripli.

#### **Fertility Conference 2024, Edinburgh, Scotland**

Claire presented a Rapid-Fire Poster Presentation on “Experiences of infertility among people with Klinefelter syndrome/XXY” to 50 fertility specialist delegates. The abstract was co-authored with Professor James Elander and Dr Bryan Woodward (Scientific Director, X&Y Fertility and Executive Committee Member of the British Fertility Society).

#### **BPS Health Division Conference 2024, Stirling Scotland**

In June Claire will be delivering a Poster Presentation on "Klinefelter syndrome (XXY) and infertility: qualitative insights into the experiences of those affected". The abstract was co-authored with Professor James Elander and Dr Bryan Woodward.

#### **UK Fertility Preservation Conference, Edinburgh, Scotland**

Having seen Claire's presentation in Edinburgh, Dr Bryan Woodward will be presenting a Poster Presentation on “Diagnosing the XXY karyotype: an audit of the profiles of people referred to the endocrinology department of an NHS state-funded hospital in the UK”. The abstract was co-authored with Dr AlJumaah (Higher Specialist Doctor), Dr Levy (Consultant Physician and Endocrinologist), Joella Wormleighton (Admin Manager), Dr Narendra

## **KLINFELTER'S SYNDROME ASSOCIATION** **Report of the Trustees Cont/d**

(Consultant Physician and Endocrinologist), Dr Masato (Higher Specialty Doctor), Claire Harkin, and Professor James Elander, Dr Bryan Woodward to talk more about this at the KSA Conference.

### **THANKS Study – Huddersfield University**

At the 2022 KSA Conference we were lucky to have Dr Jenny Retzler talking about Executive Function problems often associated with KS/XXY. She is now hoping to conduct some research to understand the interplay between fatigue, cognition and neurodiversity, and the role of testosterone. Dr Retzler is currently applying for a grant to conduct this study and once this is approved the KSA will support the study with Claire representing the KSA as co-researcher for Public and Patient Involvement (PPI).

### **Autism and XXY, Autism Research Centre, University of Cambridge**

The Autism Research Centre are particularly interested in the role of biological sex and steroid hormones in brain development. This research is being led by Dr Alexandros Tsompanidis and Professor Simon Baron-Cohan.

### **RedCap Database**

The KSA continues to support financially the setup of a RedCap Database, which is situated at the KS Clinics at Guy's and St Thomas'. This holds anonymized data about KS/XXY patients at the clinic which will inform the clinicians and help them to see trends. The KSA will continue to fund the management of the database going forward.

## **Support and Information**

### **Website**

The main source of information provided by the KSA is their website which is often praised by people who contact us. It contains The Members' Handbook, information about events and recordings from previous KSA Conferences and webinars.

### **Newsletter**

The KSA sends out frequent mailings to its members containing information about events which have been organised by the KSA, news about current research, updates about fundraisers, opportunities to take part in research and any other information about the KS/XXY world which is likely to be of interest to our members. An annual compilation is made available on the website for members who like to have a printed copy. A limited number of printed copies are sent to members who are unable to access the internet.

### **Helpline and website contact form**

In the last year the KSA have received and responded to nearly 250 Helpline calls and contacts through the website. The subjects of these vary enormously and include seeking a diagnosis, questions about behaviour or an elderly parent worried about how their adult son will manage when they can no longer support him. Often calls will take an hour or more because people are so grateful to find a sympathetic and supportive listener. Website contacts also often precipitate calls. A single contact can often result in multiple conversations. Alison Bridges and Ken Scott respond to the Helpline. Alison replies to website-initiated contacts but may involve other trustees as appropriate.

## **KLINFELTER'S SYNDROME ASSOCIATION** **Report of the Trustees Cont/d**

### **Activity Weekends**

KSA Activity Weekends were introduced in 2001 as a way of getting people who are affected by KS/XXY together in a relaxed environment. They provide a unique opportunity to meet others, of all ages, who are affected by KS/XXY. By the end of the weekend people seem to have grown in confidence and self-esteem and many say that they feel part of the wider KS/XXY community.

### **Social events**

Because our members are scattered across the country (and, indeed, the world) it is difficult to organise social events. To help plug this gap, two regular virtual chats have been arranged. The first, for all KSA members was initiated in January 2022 by trustee AJ Howard and in November 2023, Vicechair, Alison Bridges started one for parents and carers. Members who join in have said that they value the opportunity to 'meet' and chat with others who understand their experiences.

There was one In-person social meeting in Derbyshire in August 2023. It was attended by 3 dogs and 8 members who enjoyed a chat, a walk and some sustenance in the sunshine.

### **KSA AGM and Conference**

This was again a hybrid 'in-person'/virtual event. It was held in May 2023 at the Stuart Hotel in Derby. Amongst the speakers were representatives from both London KS/XXY clinics who ran 3 workshops for our delegates. Another very useful workshop on Advocacy was run by two of our members. The Conference helps to educate our members while developing peer support. Much of the content is available to members on the website.

### **Virtual and in-person support at Guy's and St. Thomas' KS Clinic**

KSA trustees have joined the team at Guy's and St Thomas' to virtually (and, when possible, in-person) to support patients and families at the Adults and Young Person's KS Clinics. They talk to patients and signpost them to support available outside of the clinics.

### **KS/XXY as an intersex condition**

People who have KS/XXY have atypical chromosomal pattern or karyotype. Because the chromosomes are neither XX- typical female or XY – typical male, KS/XXY is classed as an intersex condition. This can have serious ramifications when it comes to healthcare but that is often not understood by those affected by the condition or their medical professionals.

Intersex people often suffer from discrimination because their bodies may differ from the norm. Prospective KSA Chairman, Paul Dutton, continues to work with intersex organisations to raise the profile and support the rights of all people affected by intersex conditions such as KS/XXY. Chris Breen and Paul Dutton attended the Interconnected UK conference in March where Paul ran a workshop on how to navigate everyday life when you don't quite look the same as everyone else.

In October 23 Chris joined the working group for the development of a KS module (I-KS) in sdmregistries (I-DSD). In November they took part in a webinar - Creating welcoming and inclusive spaces for intersex and transgender people in Higher Education

<https://podcasts.apple.com/gb/podcast/creating-welcoming-and-inclusive-spaces-for-intersex/id1694281354?i=1000636661831>.

In February 24 they took part in a seminar by the Healthy Aging Research Group - Intersex: Inclusion within LBGTQI+

<https://harg.blogs.lincoln.ac.uk/2024/01/29/healthy-ageing-research-group-harg-lgbtqi-seminar-series/>.

## **KLINFELTER'S SYNDROME ASSOCIATION** **Report of the Trustees Cont/d**

### **Membership of other organisations**

The KSA is a member of, or works with, several useful organisations as detailed below:

- Ken Scott is a patient representative on the I-DSD steering committee and on the Rare Conditions' Patient Advisory Group
- Chris Breen is a member of Mental Health Partnership Network for Rare Diseases
- AJ Howard and Claire Harkin are patient representatives on the National Institute of Health and Care Excellence (NICE) forum, discussing the proportionate approach to technology appraisals and improvements to the NICE guidance concepts
- the National Council for Voluntary Organisations (NCVO)
- the Prescription Charges Coalition
- EURORDIS-Rare Diseases Europe
- ENDO European Reference Network
- UROGEN European Reference Network
- Genetic Alliance and Rare Disease
- Rare Conditions Network
- the KSA is affiliated to the British Endocrine Association which gives it some authority when corresponding with medical professionals
- the KSA has representation on the planning board for the new KS Paediatric Clinic at Guy's and St Thomas'

### **Structure, Governance and Management**

The KSA has been a charity since 1996 and is run by trustees who form the National Executive Committee (NEC). They are elected at the AGM or can be co-opted at any time. The KSA generally recruits from its membership but would be happy to recruit from outside if the opportunity presented itself.

#### **Trustees**

We started the year with eight trustees. Sylvia James-Yates was co-opted as trustee and Honorary Secretary in June 23. Sarah Gordon joined as Treasurer in October. The outgoing Treasurer, Mike Green, remains in a Trustee role. Sadly, our Chairman Barry Duplock passed away suddenly on 18<sup>th</sup> June 2023. When it came to giving friendship and support, he shone. Barry loved people and made everyone he knew feel special. He is sorely missed. Alison Bridges took over as acting Chair from June 2023. A new Chair will be elected at the AGM in May 2024.

After 4 years as Membership Secretary, Jim Harkin is stepping down due to pressure of work and trustee David Adams resigned in February 24. Alison Bridges is standing down as Vicechair after 5 years in the role. As at 31<sup>st</sup> March 2024 there were nine trustees.

#### **Volunteers**

We now have a small group of volunteers who can't commit to being trustees but who help in the everyday running of the KSA. Their support really makes a difference.

I would like to thank everyone who made a donation, told someone else about the KSA (or KS), fund raised, organised a meeting, contributed to the Newsletter or helped the KSA community in any way. A little help from a lot of people adds up to a great deal.

**KLINEFELTER'S SYNDROME ASSOCIATION**  
**Report of the Trustees Cont/d**

**Financial Review**

For a review of the financial performance please refer to the Statement of Financial Activities and Balance Sheet for the year ended 31<sup>st</sup> March 2024.

The Charity holds sufficient reserves to fulfil its policy objectives. We aim to maintain a minimum of 4 months' worth of expenses in the charity's bank accounts. If reserves fall below 8 months' worth of expenses an agenda item must be included at the next National Executive Committee meeting to discuss ways of increasing Charitable income in order to prevent cash reserves getting close to the 4 month minimum.

The KSA Trustees believe that the charity is a going concern as bank balances of £92,765 (£30,000 of which was paid to the KSA as a bequest but intended for Tet Yap's research team. The KSA is currently hold these funds on his behalf), are well in excess of annual expenditure of £21,063. There are no post balance sheet events to the date of this report to change the assessment that the KSA is a going concern.

Approved by the trustees and signed on their behalf by:

A handwritten signature in black ink, appearing to read 'Sarah Gordon', with a horizontal line drawn underneath it.

**Mrs Sarah Gordon      December 2024**

**KLINFELTER'S SYNDROME ASSOCIATION****Independent Examiner's Report to the Trustees  
of Klinefelter's Syndrome Association ("KSA")**

I report to the charity trustees on my examination of the accounts of the KSA for the year ended  
31<sup>st</sup> March 2024.

**Responsibilities and basis of report**

As the charity trustees of the KSA, 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 KSA's accounts carried out under section 145 of the Act. In carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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:

accounting records were not kept as required by section 130 of the Act; or  
the accounts do not accord with those records; or  
the accounts do not comply with the applicable requirements concerning the format 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 confirm that there are no other matters to which your attention should be drawn to enable a proper understanding of the accounts to be reached.

Signed: 

Date: 20/01/2025

Name: Lindsay Brett

Address: 6 St Andrews Close, Fearnhead, Warrington WA2 0EJ

Relevant professional qualification(s) or membership of professional bodies: FCA

**KLINEFELTER'S SYNDROME ASSOCIATION****Statement of Financial Activities****For the Year Ended 31 March 2024**

	<b><u>y/e 31/03/24</u></b>	<b><u>y/e 31/03/23</u></b>
<b><u>Incoming Resources</u></b>	<b>£35,911</b>	<b>£24,534</b>
Donations & Legacies	£22,342	£17,939
Charitable Activities	£10,626	£6,455
Investment Income	£0	£0
Other	£2,943	£141
<b><u>Resources Expended</u></b>	<b>£20,965</b>	<b>£23,168</b>
Charitable Activities	£13,465	£19,306
Other	£7,502	£ 3,862
<b>Net Income / (Expenditure)</b>	<b>£14,946</b>	<b>£ 1,366</b>
Total Fund Balances Brought Forward	£47,815	£46,449
Total Fund Balances Carried Forward	<u>£62,761</u>	<u>£47,815</u>

**KLINEFELTER'S SYNDROME ASSOCIATION****Statement of Assets and Liabilities****As at 31 March 2024**

	31/03/24		31/03/23	
<b>CURRENT ASSETS</b>		£		£
Prepayments and Accrued Income		0		0
TSB Bank		21,131		15,833
Co-Operative Bank		71,220		36,953
Paypal Account		410		4,464
		<u>92,761</u>		<u>57,250</u>
<b>CURRENT LIABILITIES</b>				
Creditors		0		0
Accruals and Deferred Income.		0		9,435
Research Liability		30,000		
		<u>30,000</u>		<u>9,435</u>
<b>NET ASSETS</b>		<u>£62,761</u>		<u>£47,815</u>
<b>RESERVES</b>				
<b>Unrestricted Funds</b>				
Reserves Brought Forward	41,556		37,259	
Surplus of income over expenditure for the Year	13,268	54,824	4,297	41,556
	<u>41,556</u>		<u>41,556</u>	
<b>Restricted funds</b>				
Reserve Brought Forward	6,259		9,190	
Surplus / (Deficit) for the Year	1,678	7,937	(2,931)	6,259
	<u>6,259</u>		<u>6,259</u>	
		<u>62,761</u>		<u>47,815</u>

**Notes to the accounts at 31 March 2024****1. Accounting policies****Basis of accounting**

The financial statements have been prepared on a cash accounting basis in accordance with the **Receipts and Payments** method, as permitted for small charities under **Section 133 of the Charities Act 2011** and the accompanying guidance issued by the Charity Commission for England and Wales.

Income is recognized when received, and expenditure is recorded when paid, rather than when incurred. As a result, the accounts do not reflect outstanding income or expenses at the balance sheet date. This basis of accounting is considered appropriate for the charity given its size and straightforward operations.

The accounts present a 'true and fair' view and the accounting policies adopted are those outlined in this note.

**Fund accounting**

Unrestricted funds are funds which are available for use at the discretion of the Committee in furtherance of the general objectives of the Charity and which have not been designated for other purposes. The restricted funds are to be used as per individual donors' wishes. These are usually to help fund shortfalls in activity weekends.

**Incoming resources**

Income is included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. Legacies are included in the Statement of Financial Activities when receipt is probable, that is, the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gift Aid is included in income when the claim has been received from HMRC.

Membership subscriptions are always treated as subscriptions. If a member adds an additional amount at the time of paying the subscription this is classified as a donation.

Grants and donations are only included in the SoFA when the general income recognition criteria are met. In the case of performance related grants, income is recognised to the extent that the charity has provided the specified goods or services as entitlement to the grant only occurs when the performance related conditions are met.

The restricted funds are used solely for the purposes of the Activity Weekend Subsidies given to members who attend this activity. Every year the excess of costs over Activity Weekend income reduces the amount of restricted funds.

**Resources expended**

All expenditure is accounted for on a cash basis and has been classified under headings that aggregate all costs related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with use of the resources.

The expenditure categorisations in the Statement of Financial Activities for the year ended 31<sup>st</sup> March 2024 are stated in line with SORP FRS102

**KLINEFELTER'S SYNDROME****2. Transactions with Trustees and Related Parties****Trustee Remuneration and Benefits**

For the years ended 31 March 2024 and 31 March 2023, none of the trustees have been paid any remuneration or received any other benefits from an employment with their charity or a related entity.

**Trustee Expenses**

Expenses were reimbursed to five trustees for the year ended 31 March 2023 amounting to £5,227.

The majority of these expenses related to trustees' attendance of exhibitions and external conferences as well as travel, food and accommodation for the Annual KSA conference. This was a modest increase compared to £4,536 in the year ended 31 March 2022.

**Transaction(s) with Related Parties**

There were no related party transactions for the years ended 31<sup>st</sup> March 2024 and 31<sup>st</sup> March 2023.

**KLINEFELTER'S SYNDROME**

3.

**Detailed Statement of Financial Activities**

<b>Year Ended</b>	<b>31/03/24</b>	<b>31/03/23</b>
<b><u>INCOME</u></b>		
Membership	1,818	2,031
Online Membership – Paypal	4,747	4,098
Donations and Sponsorships	15,277	4,684
Grants and Awards	500	7,000
AGM and Conference	3,146	855
Activity Weekend	7,480	5,600
Interest Received	0	0
Miscellaneous Income	65	141
Legacies and Bequests	1,264	125
Gift Aid	1,614	0
	35,911	24,534
<b><u>EXPENDITURE</u></b>		
AGM Conference	6,807	2,703
NEC Meetings	147	665
Newsletter	21	0
Exhibition and Related Travel Expenses	3,544	2,357
Postage and Stationery	468	56
Activity Weekend Costs	5,802	8,386
Helpline Phone	531	541
Website Costs - normal	1,295	775
- upgrade costs	0	0
Accountancy	131	0
Insurance Costs	96	157
PayPal Charges	116	191
Medical Costs	0	7,000
Miscellaneous Expenses	321	338
Advertising and Marketing	222	0
Database	1,417	0
Cost of raising funds	48	0
	20,965	23,168
<b>Net Surplus/(Deficit) for the Year</b>	<b>14,946</b>	<b>1,366</b>