

Registered Charity No. 1058319

KLINEFELTER'S SYNDROME ASSOCIATION (KSA)

TRUSTEES ANNUAL REPORT & ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2024

KLINEFELTER'S SYNDROME ASSOCIATION

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 18th June 2023)
 Mrs Alison Bridges (Vice Chair & Activity Weekend Organiser)
 Mr Michael Green (Treasurer until 20th October 2023)
 Mrs Sarah Gordon (Treasurer from 21st 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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 PO Box 250
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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.

KLINEFELTER'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

KLINEFELTER'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.

KLINEFELTER'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 18th 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 31st 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 31st 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 'S Gordon', with a stylized flourish underneath.

Mrs Sarah Gordon December 2024

KLINEFELTER'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 31st 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**

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

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

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

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 31st 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 31st March 2024 and 31st March 2023.

KLINEFELTER'S SYNDROME

3.

Detailed Statement of Financial Activities

Year Ended	31/03/24	31/03/23
<u>INCOME</u>		
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
	<hr/>	<hr/>
	35,911	24,534
	<hr/>	<hr/>
<u>EXPENDITURE</u>		
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
	<hr/>	<hr/>
	20,965	23,168
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Net Surplus/(Deficit) for the Year	14,946	1,366
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