

Registered Charity No. 1058319

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

**TRUSTEES ANNUAL REPORT & ACCOUNTS**

**FOR THE YEAR ENDED 31 MARCH 2020**

**KLINEFELTER'S SYNDROME ASSOCIATION****Year Ended 31 March 2020****Contents**

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**KLINEFELTER'S SYNDROME ASSOCIATION****Reference and administrative information****Year Ended 31 March 2020**

Registered charity number: 1058319

**TRUSTEES:**

Mr Barry Duplock (Chair)  
Mrs Alison Bridges (Vice Chair, acting Membership Secretary  
& Activity Weekend Organiser)  
Mr Michael Green (Treasurer)  
Mrs. Claire Harkin (Honorary Secretary)  
Mrs. Roz Heinze  
Mr Kenneth Scott  
Mr Jim Howard  
Stephen Kemp

**ADDRESS:**

Engineers Cottage Homesford  
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DE4 5HJ

**BANKERS:**

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PO Box 1000 BX4 7SB

Co-operative Bank plc  
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 2020.

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 from 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**

#### **Awards & Charitable Grants**

Ferring Pharmaceutical awarded Klinefelter Syndrome Association a grant of £2,000 in April 2019. This was an unrestricted educational grant to support the Klinefelter's Syndrome Association, to raise awareness and provide support to patients and families.

Society for Endocrinology awarded the KSA £405 as reimbursement of costs associated with attending their exhibition.

## **KLINEFELTER'S SYNDROME ASSOCIATION**

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

#### **Update of membership Processes**

When we introduced KSA membership via the website in 2016, the process was very labour intensive. All information entered on the website had to be copied into the excel database which we then used to store all membership data. Some of the data then had to be copied into Mail Chimp which we use to send out information to our members. This made the Membership Secretary's job extremely onerous. One of our members, David Adams, offered to streamline the system. Thanks to his efforts and considerable work for some trustees, this was achieved in February 2020. There is still some manual input required but it is minimal.

#### **KSA Attendance at Medical Conferences and Shows**

The KSA believes that the most efficient way of increasing awareness of KS and the KSA amongst the medical professions, is by exhibiting at various medical conferences throughout the year.

- Clinical Update (CU) – endocrine - in Birmingham April 2019. Alison Bridges (AB)
- Primary Care and Public Health – medical professionals – at NEC May 2019. AB & KS
- Royal College of Nurses Congress – Liverpool. May 2019 Ken Scott (KS)
- RCGP conference in Liverpool in October 2019. AB & KS Many GPs seem genuinely interested in KS/XXY especially regarding fertility.
- BeS – endocrine - in Brighton in November 2019 (Endocrine). AB

The endocrine events are run by the British Endocrine Association and are a great for networking with interested endocrinologists and other Patient Support Groups (PSG). Because PSG representatives are allowed to attend most workshops and talks, it is interesting to hear what is new on the endocrine front and, importantly, what trainee endocrinologists are learning about KS/XXY. It is particularly useful to have a KS adult attend because the medical professionals can engage directly with them. It is heartening to see that more KSA members are willing to represent the KSA at these events.

#### **Activity Weekends**

The April 2019 event was a huge success with 32 residential members and 2 visitors. There was a good mix of adults and families. The 2020 event was fully booked but was postponed due to Covid. Activity Weekends recommenced in September 2021.

#### **Scottish Meeting in Glasgow September 2019**

This year 22 delegates attended this new event – double the take-up for last year! Feedback has again been excellent from both professionals and delegates. The September 2020 planned meeting was cancelled due to COVID 19. Grateful thanks to Professor Faisal Ahmed and his team and the Office of Rare Diseases who provided, free of charge, an excellent venue at The Queen Elizabeth Hospital in Glasgow.

#### **Social Meetings**

Two social events were organized towards the end of 2019. However, due to lack of promotion and poor weather, they were poorly attended. Planned social events in the spring of 2020 did not take place as COVID 19 restrictions made them against the regulations in force at the time.

#### **Website**

The KSA website is now functioning well but looks a little dated. Our IT support volunteer has agreed to help us update it in the coming year. We continue to be very grateful for his invaluable support. The website was redesigned and relaunched in 2022.

## **KLINEFELTER'S SYNDROME ASSOCIATION**

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

#### **KSA AGM and Conference**

The 2019 AGM and Annual Conference was held in Chiltern Hotel, Luton on 18<sup>th</sup> May 2019. In the morning we welcomed Dr. Tet Yap and his team from the KS Multi-disciplinary Clinic based at Guy's Hospital in London. Alexander Wilson also gave us some feedback on his research into language and XXY. In the afternoon Professor Gary Butler, paediatric endocrinologist, ran a workshop for parents. A variety of alternating workshops allowed parents, KS/XXY adults and partners to have their own sessions. The usual Friday Night Get-together gave those arriving on Friday the opportunity to make new friendships and renew old ones. There was further time to socialize at dinner on Saturday evening and many delegates stayed until Sunday to make the most of this opportunity to engage with others affected by KS/XXY. The 2020 Conference in Derby was cancelled due to Covid. However, as the KSA did not want to disappoint its members an online conference was held.

#### **Membership of other organisations**

The KSA is a member of the Prescription Promise Campaign – now known as the Prescription Charges Coalition - in association with another 18 major UK Charities. This is campaigning for prescription charges to be abolished for people with long-term conditions such as KS/XXY.

The KSA is also a member of National Council for Voluntary Organisations (NCVO) and Disability Rights.

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

The Klinefelter's Syndrome Association (KSA) was founded in 1990 and achieved Registered Charity status in 1996. It is an unincorporated association which has a written constitution. It is run by trustees who form the National Executive Committee (NEC) who are elected at the AGM. The NEC may in addition appoint not more than FIVE co-opted members but so that no-one may be appointed as a co-opted member if, as a result, more than one third of the members of the NEC would be co-opted members. Each appointment as a co-opted member shall be made at a meeting of the NEC called under clause K1 and shall take effect from the end of that meeting unless the appointment is to fill a place which has not then been vacated in which case the appointment shall run from the date when the post becomes vacant.

#### **Trustees**

We started the year with only five trustees the minimum permitted under the KSA constitution. We were delighted when, at the AGM Barry Duplock stood for election as Chair. Jane Lee and Jim Howard stood for election as trustees with the former taking on the role of Membership Secretary. Unfortunately, Jane had to stand down in November due to ill-health. Alison Bridges agreed to take on the role of acting Membership Secretary until a replacement could be found. We are very grateful to Jane for the work she put into the revision of the membership processes. In September Stephen Kemp was co-opted as a trustee and in March 2020 Claire Harkin was co-opted on as trustee and Honorary Secretary bringing the trustee total to 8.

#### **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 2020.

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 £39,388 are nearly twice as much as annual expenditure £20,435. 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:



**Mr Michael Green**

**19th February 2023**

## **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 31<sup>st</sup> March 2020.

#### **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:

1. accounting records were not kept 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 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.

In carrying out my examination I noted a lapse in the keeping of accounting records in the recording of income and expenditure. I was able to agree recorded income and expenditure to the bank statements and I was also able to evidence the majority of the sources of income and expenses that I examined in detail. However, I was unable to evidence the sources of two items: the paying-in-slip could not be produced for £682 income deposited by a trustee; and the expense form for a trustee's expense claim of £1154 could not be produced. In response you, the trustees, pointed out that the relevant supporting vouchers were mislaid as a part of the same one-off lapse in following the established procedures for recording and verifying income and expenditure that also affected the 31 March 2019 accounts which were finalised in May 2021 when these matters were brought to your attention, which was after the date that the above-mentioned lapses occurred. You have also confirmed that future lapses will be prevented by the implementation of improved procedures for the recording of income and expenditure which have been proposed and circulated amongst all those involved in depositing receipts and claiming expenses and will be formally approved at the next KSA National Executive Committee meeting which is planned to take place before 28<sup>th</sup> February 2023.

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: 12/3/2023

Name: Yasmin Syeda

Address: 95 Woodcote Grove Road, Coulsdon, CR5 2AN

Relevant professional qualification(s) or membership of professional bodies: ACA, ICAEW

**KLINEFELTER'S SYNDROME ASSOCIATION****Statement of Financial Activities****For the Year Ended 31 March 2020**

|                                     | <b><u>y/e 31/03/20</u></b> | <b><u>y/e 31/03/19</u></b> |
|-------------------------------------|----------------------------|----------------------------|
| <b><u>Incoming Resources</u></b>    | <b>£25,126</b>             | <b>£20,558</b>             |
| Donations & Legacies                | £14,789                    | £10,930                    |
| Charitable Activities               | £7,558                     | £8,371                     |
| Investment Income                   | £1                         | £2                         |
| Other                               | £2,778                     | £1,255                     |
| <b><u>Resources Expended</u></b>    | <b>£20,435</b>             | <b>£20,636</b>             |
| Charitable Activities               | £19,316                    | £19,297                    |
| Other                               | £1,119                     | £1,339                     |
| <b>Net Income / (Expenditure)</b>   | <b>£4,691</b>              | <b>(£78)</b>               |
| Total Fund Balances Brought Forward | 32,207                     | 32,285                     |
| Total Fund Balances Carried Forward | £36,898                    | £32,207                    |

**KLINEFELTER'S SYNDROME ASSOCIATION****Statement of Assets and Liabilities****As at 31 March 2020**

|                                                 | <b>31/03/20</b>   |                       | <b>31/03/19</b>   |                       |
|-------------------------------------------------|-------------------|-----------------------|-------------------|-----------------------|
| <b>CURRENT ASSETS</b>                           |                   | <b>£</b>              |                   | <b>£</b>              |
| Prepayments and Accrued Income                  |                   | 1,250                 |                   | 1,820                 |
| TSB Bank                                        |                   | 11,907                |                   | 7,870                 |
| Co-Operative Bank                               |                   | 23,965                |                   | 21,431                |
| CAF Bank                                        |                   | -                     |                   | 2,277                 |
| Paypal Account                                  |                   | 2,265                 |                   | 2,639                 |
|                                                 |                   | <u>39,388</u>         |                   | <u>36,037</u>         |
| <b>CURRENT LIABILITIES</b>                      |                   |                       |                   |                       |
| Creditors                                       |                   | 0                     |                   | 0                     |
| Accruals and Deferred Income.                   |                   | 2,490                 |                   | 3,829                 |
|                                                 |                   | <u>2,490</u>          |                   | <u>3,829</u>          |
| <b>NET ASSETS</b>                               |                   | <u><u>£36,898</u></u> |                   | <u><u>£32,207</u></u> |
| <b>RESERVES</b>                                 |                   |                       |                   |                       |
| <b>Unrestricted Funds</b>                       |                   |                       |                   |                       |
| Reserves Brought Forward                        | 21,944            |                       | 18,684            |                       |
| Surplus of income over expenditure for the Year | 4,545             | 26,489                | 3,260             | 21,944                |
|                                                 | <u>          </u> |                       | <u>          </u> |                       |
| <b>Restricted funds</b>                         |                   |                       |                   |                       |
| Reserve Brought Forward                         | 10,263            |                       | 13,601            |                       |
| Surplus / (Deficit) for the Year                | 146               | 10,409                | (3,338)           | 10,263                |
|                                                 | <u>          </u> |                       | <u>          </u> |                       |
|                                                 |                   | <u><u>36,898</u></u>  |                   | <u><u>32,207</u></u>  |

**Notes to the accounts at 31 March 2020****1. Accounting policies****Basis of accounting**

The accounts have been prepared on the accruals basis, in accordance with 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.

The accounts have been prepared under the historical cost convention with items recognized at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts.

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 an accruals 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 2020 have been updated in line with SORP FRS102 and the year ended 31<sup>st</sup> March 2019 comparatives have been restated accordingly.

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

For the years ended 31 March 2020 and 31 March 2019, 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 seven trustees for the year ended 31 March 2020 amounting to £8,964 (five trustees, £5,877 in 2019). These expenses were travel, accommodation, and subsistence to meetings in order to run the charity and organise its activities. The increase in the year ended 31 March 2020 compared to the previous year is driven primarily by the AGM being attended in person rather than being conducted online as was the case in the previous year.

**Transaction(s) with Related Parties**

There were no related party transactions for the years ended 31 March 2020 and 31 March 2019.

**KLINEFELTER'S SYNDROME**

3.

**Detailed Statement of Financial Activities**

| <b>Year Ended</b>                         | <b>31/03/20</b> | <b>31/03/19</b> |
|-------------------------------------------|-----------------|-----------------|
| <u><b>INCOME</b></u>                      |                 |                 |
| Membership                                | 2,182           | 2,699           |
| Online Membership – Paypal                | 4,133           | 3,141           |
| Donations and Sponsorships                | 6,070           | 3,786           |
| Grants and Awards                         | 2,405           | 1,304           |
| AGM and Conference                        | 2,691           | 4,406           |
| Activity Weekend                          | 4,867           | 3,965           |
| Interest Received                         | 1               | 2               |
| Miscellaneous Income                      | 213             | 415             |
| Legacies and Bequests                     | 2,564           | 0               |
| Gift Aid                                  | -               | 840             |
|                                           | <hr/>           | <hr/>           |
|                                           | 25,126          | 20,558          |
|                                           | <hr/>           | <hr/>           |
| <u><b>EXPENDITURE</b></u>                 |                 |                 |
| AGM Conference                            | 3,954           | 1,881           |
| NEC Meetings                              | 2,842           | 1,889           |
| Newsletter                                | 55              | 61              |
| Exhibition and Related Travel Expenses    | 4,644           | 5,392           |
| Postage and Stationery                    | 0               | 36              |
| Activity Weekend Costs                    | 4,720           | 7,303           |
| Helpline Phone                            | 721             | 795             |
| Website Costs - normal                    | 794             | 795             |
| - upgrade costs                           | -               | 0               |
| Accountancy                               | -               | 0               |
| Insurance Costs                           | 328             | 328             |
| Paypal Charges                            | 119             | 185             |
| My Donate Charges                         | -               | 0               |
| Miscellaneous Expenses                    | 672             | 825             |
| Booklets                                  | 1,586           | 1,146           |
|                                           | <hr/>           | <hr/>           |
|                                           | 20,435          | 20,636          |
|                                           | <hr/>           | <hr/>           |
| <b>Net Surplus/(Deficit) for the Year</b> | <b>4,691</b>    | <b>(78)</b>     |
|                                           | <hr/>           | <hr/>           |