Helpline: 0300 111 4748
Website: www.ksa-uk.net

Klinefelter's Syndrome isn't rare……but it is rarely diagnosed

Annual Report by Trustees of the Klinefelter's Syndrome Association 2020 and 2021

In view of the difficulties of running an AGM in 2020 due to the pandemic, the Charities Commission permitted the trustees to postpone it. Therefore, the trustees are now presenting their report and financial statements of the charity for the years ended 31 March 2020 and 2021.

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

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 considerable efforts and 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 present a great opportunity 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.

Due to the pandemic, none of these events took place in the year 2020 to 21

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 has been postponed due to Covid.

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. Another meet has been agreed for September 2020. Grateful thanks to Professor Faisal Ahmed and his team and the Office of Rare Diseases who provided an excellent venue at The Queen Elizabeth Hospital in Glasgow, free of charge.

Due to the pandemic, none of these events took place in the year April 2020 to 21.

Social Meetings

Two social events were organised towards the end of 2019. However, due to lack of promotion and poor weather, they were poorly attended. We had planned further events in the spring of 2020 but with the uncertainty of Covid, these have been postponed.

Due to the pandemic, no events took place in the year April 2020 to 21

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.

This project is continuing. It will be finished later this year.

KSA AGM and Conference

The 2019 AGM and Annual Conference was held in Chiltern Hotel, Luton on 18th 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 to 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. Unfortunately, it seems unlikely that we will be able to hold our 2020 Conference in Derby as planned due to Covid.

Due to the pandemic, this event did not take place in the year 2020 to 21

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 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

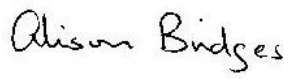
We started the year with only five trustees, the minimum permitted under the KSA constitution. We were delighted when, at the AGM Barry Duplock stood for election as Chair. Jane Lee and Jim Howard stood for election as trustees with the former taking on the role of Membership Secretary. Unfortunately, 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.

In July 2020 we thought we had found a membership secretary in July 2020 but, after being co-opted as a trustee, the member found that his circumstances had changed and he was unable to fulfil his duties and he stepped down in October without assuming the role. Unfortunately, Stephen Kemp, who was deeply involved in NHS contingency planning for Covid, resigned from his trustee role in March 2021 due to lack of time. However, we are delighted to welcome Jim Harkin who was co-opted as trustee and membership Secretary in January this year bringing our total to 8 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 donated, 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.



Alison Bridges

Vice chair of Trustees Klinefelter's Syndrome Association (KSA)