Annual Report by Trustees of the Klinefelter's Syndrome Association 2021 to 2022

Objectives and activities of the KSA

The KSA exists to offer support and information about KS/XXY 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 KS/XXY particularly with the medical profession. Do tell your medical advisors that we offer free professional membership and suggest they visit our website.

The KSA works to promote and support research into the condition by promoting relevant research projects in newsletters, on our website etc.

Achievements and performance

Update of KSA website

This update which has been undertaken 'in-house' by a few volunteers has now been completed. I hope you have had a look at it. It is more interactive than previously and there is more content. Feedback so far has been good. The new format is easier to manage and we intend that the website will continue to evolve. We would love more content especially about diet, mental health, well-being etc. so please let us know if you have any suggestions.

KSA Attendance at Medical Conferences and Shows

To raise awareness amongst the medical profession, the KSA usually exhibits at various medical conferences throughout the year. Due to covid restrictions most were cancelled or were run as virtual events. Because we would not be able to use the personal approach, we decided that attendance at virtual events would not be worthwhile.

The first event we were able to attend was the October 2021 RCGP conference in Liverpool where Claire and Ken told as many GPs as they could about the importance of early diagnosis of KS/XXY.

Next was the British Endocrine Society (BeS) conference in Edinburgh in November 2021. Exhibitors are invited to attend talks making it a great opportunity to find out

about new research, treatments, initiatives and training.

It was especially useful to meet up with the other patient support groups (PSGs) and to attend the BeS meeting for PSGs. The BeS now links to the KSA website from their website.

Alison attended the BeS Clinical Update event in Birmingham in April.

Unfortunately, we had to cancel our booking for the Public Health and Primary Care event in Birmingham in May because Alison Bridges who was to attend, developed Covid at the last minute.

It is particularly useful to have a KS/XXY adult attend because the medical professionals can engage directly with them. Many thanks to Ken (Scott).

Activity Weekends

The September 2021 Activity Weekend, (the first since Covid appeared, was a huge success with thirty-six residential members and one visitor. There was a good mix of adults and families. This was a record number and we were delighted to see so many happy smiling faces. We ran an equally enjoyable one in April with thirty attendees. Both events were so joyful! Last one this year is in August – see the website – or Alison.

Social events

Because no 'in-person' meetings had been possible, trustee AJ Howard initiated some Zoom chats which many have enjoyed. They provide a great opportunity to chat, debate or just listen and feel less isolated. They run every other Monday so do drop in.

The first 'in-person' event was held in Cheshire on 21st May and was enjoyed by all who attended. Thank you to James who organized it.

Unfortunately, there will be no Glasgow meeting this year because the venue is not available.

KSA AGM and Conference

A joint 2020 and 2021 AGM and Annual Conference was held virtually in June 2021 due to pandemic restrictions. Over one hundred delegates registered and despite being virtual, there was considerable 'social chat.'

Improving the rights of people who have intersex conditions such as KS/XXY.

One of our volunteers, ex-chair of trustees, Paul Dutton, continues to work to with intersex organisations and in April 2021, after much hard work over the previous year, the Scottish Hate Crime Bill became Law in Scotland giving i/VSC people in their legislative protections.

Paul was also involved in the Reprofutures project with Exeter University which concluded in March. It produced reports and support materials for i/VSC people and those who seek to support them. There will be links to this on the website.

Research

Since September 2021 Claire Harkin, trustee and honorary secretary, has been conducting a qualitative research study for a Psychology MSc. The study is about gender identity among KS and XXY individuals. Claire is at the stage where she is now writing the research report, which is due to be submitted in August. Hopefully, it will be shared with the KS and XXY community from September.

Newborn screening

In June trustees Alison and AJ joined in three very interesting virtual workshops discussing possible parameters to identify conditions to be screened in a pilot involving up to 200,000 babies.

Membership of other organisations

The KSA continues to be a member of the Prescription Charges Coalition which is campaigning for the abolition of prescription charges for long-term conditions such as KS/XXY.

The KSA is also a member of National Council for Voluntary Organisations (NCVO) and the Specialised Healthcare Alliance (SHCA).

Claire represents the KSA in Eurogen, which is one arm of a European virtual network which works to improve diagnostics and treatment for patients for rare conditions such as KS/XXY which is considered rare only because it is underdiagnosed.

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.

Trustees

There has been no change in the trustees during this year but several people have expressed an interest in becoming trustees. We hope to work with them in the coming months to see how they can help the KSA with a view to them becoming trustees later.

All current trustees were re-elected last year therefore no elections are required this year.

Volunteers

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

Miscellaneous

Ken Scott organised large advertising hoardings at Newtonmore and Kingussie shinty clubs (in the Highlands) to raise awareness of KS/XXY. Ken generously sponsored the Kingussie board.

With the assistance of Mr. Tet Yap, Alison was put forward as a Platinum Volunteer and was lucky enough to be chosen. While very grateful for the honour, she feels

very strongly that the KSA is a joint effort.

Finally, I would like to thank everyone who donated, told someone else about the KSA (or KS/XXY), fund raised, organised a meeting, contributed to the Newsletter or helped the KSA community in any way. A little help from many people adds up to a great deal. You really make a difference.

Barry Duplock

Chair of Trustees Klinefelter's Syndrome Association (KSA)