Dear Members

The TSSS offers support and information to girls and women who have Turner Syndrome (TS), their families and friends.  We take our responsibilities to our members very seriously and as part of the forthcoming General Data Protection Regulations (GDPR) we need each of our members to give their clear positive consent for us to hold and process your personal data. This includes any personal information about any of our members.

**Under GDPR you have a right to withdraw consent at any time.**

We will also have to ask you to reconfirm your consent from time to time to ensure that we are compliant with the legislation.  We plan to hold your data for 5 years before seeking your reconfirmation.

We will use your data to benefit others with TS in relation to treatment, education and attitudes towards those with TS.

The TSSS treats your data in the strictest confidence we never have and never would allow any third parties access to your data. The TSSS office holds your name and contact details on our secure database. This enables us to send you communications such as Aspects our newsletter, open day, seminar day and conference booking forms, fundraising opportunities etc.

If we have obtained your express consent to be listed on our contact list, your details will be circulated to new members of the TSSS.  All research is advertised to all members via our website, social media and Aspects newsletter. Should you wish to become involved you then opt in and contact the researcher directly.

TSSS friendship group coordinators give permission to circulate their contact details, so that if a members wants to join the group it is your decision to share your details with the Friendship group Co-coordinator directly, who will hold it in the strictest confidence too.

The data we hold allows us to know how many members we have at different ages, in different areas of the country, on different treatments etc. if we use this information it would be anonymised.

**We are taking this opportunity to not only obtain your consent but also to update our information to ensure that you are not only aware of the data we hold, but also to ensure that this is up to date.

Thank you for your support with this exercise.**

**Please click on this link to complete the survey or opt out** <https://www.surveymonkey.co.uk/r/TSSS2018>

If you have any questions please do not hesitate to contact me.

Yours sincerely



Arlene Smyth

Executive Officer /Data Controller