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AspecTS

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International Growth Awareness Day

20th September annually

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TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

TURNER SYNDROME SUPPORT SOCIETY NEWSLETTER

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Please remember to renew your membership – see page 11

Editor's Message

Hi everyone and welcome to the latest edition of Aspects.

It was great to meet so many members who joined us on Saturday 10th October for the virtual 21st celebrations on zoom. It was lovely to see all the old faces and some new ones. We particularly enjoyed the dancers, well done Peter! Many thanks to Arlene for organising and leading the celebrations. Let's hope that we can all meet up next year and do justice to the anniversary of a truly wonderful society started by Arlene and others all those years ago.

Our best wishes to all the members who have been ill or/and had operations over these past months, we are thinking of you all and hope that you are recovering well.

Please ensure that you update your details (https://www.surveymonkey.co.uk/r/TSSS2018) and pay your fees as soon as possible, not doing so causes Arlene and Carlene so much extra work that they don't need at this very difficult time.

A big thank you to all the fundraisers out there as the society relies on these funds to keep the excellent work it does going. Keep up the good work.

And lastly a big thank you to all who keep the society running and offer their support through these difficult times, you know who you are, and to those that support them to do it.

Take care and stay safe.

Phil, Mag and Ellie

p.s. We have just added another bundle of joy to our family, Ellie has become an Auntie again to Elsie Grace born on 27/10/20 to our son Tom and daughter-in-law Katie.



Chair's Report



Hello everyone,

I hope that everyone is doing ok as it has been tough for lots of our Members over the past six months. I have certainly found it very hard. I was shielding from March to 31 July (I wasn't counting down the days!!!!)

The only excitement that I had was walking the dog most days so at least I was getting some fresh air. I did feel really down several times, but Steve tried his best to keep me "sane". I decided that I wanted a jigsaw, so Steve ordered one for me. I asked him for a Christmas scene (bad idea), so the jigsaw arrived (1000 pieces) and yes it was a Christmas scene with about 10 Christmas trees, lots of snow so it looks all the same to me. Needless to say, I have only managed to do the frame of the jigsaw since May. Hopefully I will get it done for Christmas as its sitting on my dining room table at the moment. I have been knitting a lot too which keeps me distracted and I don't talk too much (so Steve says).

We managed to get a wee holiday in August and we went to the Isle of Wight which was lovely. We had fantastic weather and the entertainment was fantastic too. We did a lot of sightseeing while there.

Steve is still working from home and I just don't know how we have managed this being together 24/7, we must be doing something right. I spend a lot of time baking and gardening too which is good for me. It looks like Steve will be working from home for the next few months and will continue until next year... dearie me !!!!!, I'd best get a job, eh!

Good news... Geoff proposed to Jazmine and of course she accepted. He proposed on the same weekend as they got the keys to their first house together. They are only about 10 minutes away, so I see them most weeks especially if I am cooking Sunday roast... Their house is lovely and they spent at least a month cleaning and decorating it and they have done a very good job.

As everyone is aware our International Conference in Stirling was cancelled which was a pity considering the amount of work that went into organising it so thank you to Arlene and Carlene for all their hard work and also to our wonderful Committee too for their commitment to the charity and all that they do to make sure that everything runs as best as it can. Hopefully next year things will get back to normal and that our friendship groups can start again.

I got a new partial knee replacement on 10th September. In Oxford they tend to have you in as a day patient, but of course nothing runs smoothly with me does it? I ended up in for 3 days as I couldn't put any weight down on my leg. The first two weeks were not very pleasant (it was hell), but after that I turned a corner. By the end of the 3 weeks I was walking without any crutches or my zimmer (yes, I had an old ladies zimmer). I must admit the zimmer was far easier to use than the crutches. It has been 7 weeks since my operation and I can't believe that I have no pain whatsoever which is brilliant. This time my recovery is far quicker that it was getting my left knee done a few years ago. I will be fit and well to do the Christmas shopping this year so Steve will be very happy. Then again with another blooming lock down which starts on November 5th, I just don't know whether the lockdown will actually finish 2nd December, we will all just have to wait and see what happens, won't we? We will all just have to use easyfundraising and raise monies when we all do online shopping so there is always a bonus in the shops being closed!!!

I hope that everyone is looking after one another and taking care of each other at these uncertain times.

Lots of Love

Susie (Mrs TSSS)

Arlene's Report



I hope this newsletter finds you all safe and well in these difficult and unprecedented times. We have worked hard on providing you with Covid 19 information. The workload has been a challenge but, one I hope we have met for you the members.

As you all know this has been a very difficult year for everyone. We had to make many difficult decisions and after a risk assessment regrettably, cancel all face to face events until at least the spring of 2021. We will keep this decision under constant review. I miss you all so much and cannot wait until we can all meet again in person. Hopefully sooner rather than later but only when it is safe for everyone to do so.

As I am sure you can appreciate it is a difficult time for all charities. We have been working hard to gather any information we have been able to get on Covid - 19 and share it with you. This has been a steep learning curve for us all. It is always worth checking the website for any updates. We do continue to be in contact with the TSSS Clinical Advisory Board and TS specialist across the UK, Europe and the World. We have an extensive list of useful websites for your information.

Please complete the survey if you have Turner Syndrome and have had Covid. It will help us understand the impact better. We will share it with our Clinical Advisory Board, https://www.surveymonkey.co.uk/r/WV3LQVC.

We are all well, although we have just been locked down again and can't have any one in our homes again. My gall bladder surgery, like many others, has been cancelled and so it is just a case of wait and see. I appreciate that many of you are yourselves shielding or stringently self-isolating. This is a really difficult time for all of you. We are here for you and doing our best to support you through this difficult time.

Please do take some time to read through the newsletter, even repeated articles have been updated with additional information. Don't forget to check out the website and Facebook to keep up to date with all the news and events. I am working between the house and the office at the moment, so please bear with us if you are waiting on an order. Please contact us if you were waiting on something and it has not arrived. We have had some post go missing recently. Don't forget we have a wonderful team of trustees and committee members that are there to help too.

We continue to do the normal day to day duties that are required, such as speaking to those who have had a new diagnosis, we have had a lot of understandable anxiety about Covid etc. I always try and give families the time that they need. I support members by phone, e-mail, Facebook, messenger, twitter etc. I complete all the paperwork that is involved and, believe me, there is a lot of it. That is why your support in giving us plenty of notice to send things out to you and to answer queries is appreciated. We have great support from the committee in lots of ways but, it is worth remembering that on a day to day basis it is just Carlene and I running the office.

The TSSS trustees and committee members continued support is very much appreciated. It takes a lot of hard work and dedication to keep the society running. Please be sure to read through the newsletter and keep checking our website for all the details. If you are interested in volunteering your services to the TSSS please contact the TSSS office and we can take you through what is involved.

Our thanks to our benefactor companies Ferring, Novo Nordisk and Pfizer who help us to deliver services to our members, their help ensures we continue to offer support and information to members throughout the country. We very much appreciate their support through unrestricted educational grants and projects. We have been lucky enough to get a £6000 grant from Pfizer Ltd towards providing online events. We are researching what members want, you will be getting a survey shortly. Novo Nordisk very kindly increased their regular support by £3500 to help us provide online services for our friendship groups.

All Members

Don't forget to renew your membership on the **1st of June** this year. Your support is invaluable to us. If you have not paid yet please do so ASAP, if you are struggling now do let us know. We will do our best to support you, we won't delete your record if you contact us. Especially now with the new GDPR rules you have to consent to staying on our database. If we do not have your consent, we will have no choice but to remove you from our database and we don't want to lose you. You, the members, are the most important part of the society and we are nothing without you.

Please consider setting up a standing order, it really does help us from an administration point of view. Chasing you for membership fees is time consuming and costly. Those of you who have been members for many years, can you please check that, if you are paying by standing order, it is for the correct amount? It should be a minimum of £30 per year or £2.50 per month. If you are paying via the online shop or by cheque or postal order the cost is £35 per year.

TSSS Stands at Conferences 2020: all events have been cancelled until Spring 2021.

GDPR

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. If you have not already completed the survey via the link, full details are on our website.

Thank you for your support with this exercise.

Please follow this link to complete the survey or opt out

https://www.surveymonkey.co.uk/r/TSSS2018

If you have any questions or need help completing the survey please do not hesitate to contact Carlene or Arlene at the office.

If you can afford an extra couple of pounds a month please join our **Give it up Give it in Appeal** it really does help us greatly and is very much appreciated.

Please note the TSSS office will close from 21st December 2020 to 5th of January 2021 for the Christmas and New Year Break. If you have an urgent need to contact me during this time, you can call my mobile 07947 554587.

Take care and stay safe

Best wishes

Lady Arlene x

TSSS Open - Seminar Days

TSSS Open - Seminar Days will resume as soon as it is safe to do so. Your health and well being is paramount.

TSSS Open Days are relaxed and informal events to bring local families together to share their experiences. Local doctors, nurses and TSSS committee members are available to offer help, support and information about Turner Syndrome and the TSSS. Children are welcome but there is no child care provision in place.

We charge £12 per adult and £6 per child, this is to cover the cost of refreshments and a light lunch. We do apply for grants to cover the costs of our Open Days. If we do get grants to cover the cost of the event, the charge will be refunded. If the cost is a barrier to you attending please contact Arlene, she will be happy to help. e-mail Arlene @ **turner.syndrome@tss.org.uk**.

Please note this year we are not hosting any Open Days due to Covid 19 unless the advice deems it safe to do so.

Following on from the success of the Oxford Seminar Days, Dr Helena Gleeson and her team have kindly offered to host a Seminar Day **(date TBC)** from 11am until 4pm at Queen Elizabeth Hospital, Birmingham. Theme of the day is sharing up-to-date medical information and services along with patient experiences, from the Birmingham TS Specialist Clinic Team. We are going to join together with families who are affected by Congenital Adrenal Hyperplasia [CAH] and Klienfelters Syndrome [KS], this is a rare opportunity to share experiences. There will be topics that affect all conditions with condition specific topics too. This event will mainly be covering adult services, although it will be of interest to girls who are nearing transition to adult services. The event is not suitable for children and we are unable to offer any childcare facilities, sorry.

To book your place, once the date is confirmed, please go to the website **www.tss.org.uk** or phone the TSSS office on **0141 952 8006** or email Arlene.

Covid 19 and how it affects the TSSS

I thought I would share with you how the TSSS has been affected by Covid 19 restrictions and lock downs. The impact has been considerable and we have done our very best to continue to offer you as much support as possible. You the members as always have been amazing with your support with various awareness campaigns, fundraising and supporting each other through social media. You are as always amazing I am so proud to be part of our TSSS family.

To begin with we had to make the very difficult decision to cancel the Turner Syndrome International Conference. Having worked for four years on planning the event it was soul destroying. And, to be honest it affected my normal optimism. We had many volunteers working incredibly hard to make it an excellent conference we were expecting about 500 people from 23 countries. I would like to take this opportunity to thank all of the TSI 2020 planning committee, Bobby one of our members and a dear friend came every week to the office and helped with planning and checking everything, Carlene who took on more tasks to allow me time to focus on TSI and Paula and the team at Stirling University for all their help.

Many people questioned why we cancelled and did not just postpone. We had a very diverse mix of delegates, travelling from 23 countries and the range of accommodation was considerable and varied greatly. We tried to secure alternative dates, but we would have to have hosted a very different event. With so much uncertainty regarding travel and lockdown the only way to secure full refunds was to cancel. Our objective was to ensure that no one was out of pocket as a result of the cancellation. It was not easy to achieve this and was indeed a very stressful time for myself, trustees and planning committee to make. We were also very aware of not having the TSSS UK incur any losses. I am pleased to say the only expense we had was logo design at £150 and pens which we hope to sell, which it will cover the out of pocket expenses. We are proud to say that although conditions of sponsorship were to return support if the event was cancelled, one of our funders, Novo Nordisk, have very kindly agreed that we can use the support to perhaps hold a physical or virtual event in the future. Many of you kindly donated to the TSI 2020 fundraising pages too. We will use the funds along with sponsorship for our future events, be they virtual or in person. We very much hope that we will be able to do something in 2021 or 2022.

We will just have to wait and see. There is a lot to consider, travel, funding, costs and much more. If it is possible, we will indeed do something as soon as we can.

Stephen, our co-chair and IT manager, had to very quickly upgrade all our software to ensure that working from home was more effective. This took a while, but we got there in the end and I am so grateful to Stephen for all his help and support. As you know IT is not my strength.

We had to very quickly gather up Covid 19 information and support for our members. At the time this was quite a challenge. Thankfully we work closely with the best specialists in the country who were all incredibly helpful, especially Dr Helen Turner who has been keeping in regular touch with us.

We then had to make the difficult decision to furlough Carlene. It is was our only option to hopefully protect her job in the future. Carlene understood completely and was supportive of the decision. That meant I had to cover all the work of the TSSS. She will return at the end of furlough scheme.

I have spent a lot of time looking for grant support. Sadly, we don't meet the criteria for many.

Arlene x



Children's story book released to help children and young people cope with COVID-19



A new story book that aims to help children understand and come to terms with COVID-19 has been produced by a collaboration of more than 50 organizations working in the humanitarian sector, including the World Health Organization, the United Nations Children's Fund, the United Nations High Commissioner for Refugees, the International Federation of Red Cross and Red Crescent Societies and Save the Children.

With the help of a fantasy creature, Ario, "My Hero is You, How kids can fight COVID-19!" explains how children can protect themselves, their families and friends from coronavirus and how to manage difficult emotions when confronted with a new and rapidly changing reality.

Download your free copy here: https://www.who.int/news/item/09-04-2020-children-s-story-book-released-to-help-children-and-young-people-cope-with-covid-19



Friendship Group Update

I hope you are all keeping well and safe under these strange and stressful times.

It has been such a shame that we have been unable to get together physically in recent months. The society has made the difficult but necessary decision to suspend all official get togethers until at least Spring 2021.

However, during the last few months a few of the friendship groups have got together, with a cuppa, over zoom for a catch up. This has been a really good way of keeping in touch with everyone and being a friendly face in these odd times! From a well-being point of view this has been beneficial and has proved to be very popular.

Some of the groups meet weekly, some fortnightly and some monthly.
Some meet in the evening during the week, some at weekends. It really does vary depending on what suits. You could even vary it so it suits most people. We have noticed that now people are getting back to some degree of "normality" that weekends are busy so weekday evenings are preferred. Especially now the nights are drawing in!

The basic zoom package, which is free of charge, limits the time to 40 minutes (although you can log back in again if you find that's not long enough!).

The host sets up a waiting room when organising the meeting so is then in control of who is admitted to the meeting. This means you do not get anyone gate-crashing! Zoom was initially thought to be not very good on the security side of things and many people were understandably nervous about using this platform but as time has gone on and more people are using zoom they have done a lot of work in a short space of time to rectify any issues they had. The society has put together a guide on hosting a zoom meeting for anyone who would like a copy.

From a personal point of view, I have very much enjoyed the zoom meet ups I've taken part in and have found them nothing but positive and a welcome ray of light in these difficult times.

Hayley x







Friendship Groups...



Please feel free to contact any of our friendship groups, please see details below. For more information on their events visit our website. www.tss.org.uk click on About Us and then Friendship Groups.

Friendship Group Co-ordinator Hayley Cleaver • 07763 606597

England

Central England Friendship Group
Jackie O'Keeffe • 07977 486898
shonaemily@aol.com
or Judy Burns • 07932 694131
judy5579@talktalk.net

Cumbria & Borders Friendship Group
Rachel Partington
07752 962250
rachelpb72@gmail.com or
Janet Williams • 07926 072418
janis2@btinternet.com

Devon Friendship Group
Louise Giles • 07763 212785
gileslou@hotmail.com or
Katherine Pearce • 07999 982051

Durham and Newcastle Friendship Group
Christine Morrison
07740 933475
cjmorrison58@gmail.com
or Julie Champion
07531 172860
jachampion@virginmedia.com

East Anglia Friendship Group
Joy Taylor • 07929 557726
joycataylor@hotmail.co.uk
or Sian Smith • 07725 885202
sian3x@yahoo.co.uk or
Claire Garrod • 07580 144585
claireprima79@outlook.com or
Victoria Flute • 07950 436584
vkhf1978@gmail.com

East Midlands Friendship Group
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tracyglasgow231@hotmail.com
or Tracey Payne • 07786 153598
traceypayne1974@btinternet.com or
Harvey Kent • 07971 575842
harvkent@btinternet.com or
Christine Farmer • 07501 223033
christine.farmer@carefabrics.com

Essex Friendship Group
Ella Phillips • 07815 562603
ella.phillips26@hotmail.co.uk or
Amanda McGowan • 07986 951085
mandy@mcgowanclan.co.uk

Greater Manchester & Merseyside Friendship Group
Ellie Hatcher • 078144 94698
elliehatcher@hotmail.com
or Emma Taylor • 07834 686691
ejbailey15@yahoo.co.uk

Home Counties West Friendship Group
Amanda Woodhall • 07527 751022
amandashort82@hotmail.com
or Caroline Cooper
07966 645255
cazhoward73@hotmail.com

Kent Friendship Group
Robyne Winstanley • 07979 410422
robynewinstanley@live.com or
Alison Dowle • 07980 545319
alisonleighriches@hotmail.com

Leeds & Yorkshire Friendship Group
Jane Raper • 07879 682125
jane@tsssuk.org.uk or
Charlotte Raper • 07468 494478
charlotte@tsssuk.org.uk

London & South East Friendship Group
Lisa Whiting • 07748 386580
lisa_w@talktalk.net

Mid Counties Friendship Group
Emma Dimbleby • 07773 622157
emma.dimbleby@gmail.com or
Katrina Squires • 07984 096762
keyneoncake@gmail.com

Rutland & Leicestershire Friendship Group
Tammy Ena Richards
07512 260559
tamerauk@yahoo.co.uk

South West Friendship Group
Danni Cook • 07992 468298
dmc250889@gmail.com

Swindon & Oxford Friendship Group
Emma Fitzpatrick • 07763 980579
emma.fitzpatrick1@ntlworld.com or
Mollie Dowler • 07930 301599
mollie.dowler@gmail.com or
Ali Andrews • 07912 983688
matt.sas@live.com

Sheffield and Yorkshire Friendship Group
Carly Lowe • 07545 225652
carly_lowe@hotmail.com or
Deborah Lowe • 07738 569833
deborah-lowe63@hotmail.co.uk

Isle of Man

Manx Friendship Group
Denyse Hill • 07624 201868
manxtsfriends@manx.net

Wales

Mid Wales Friendship Group / Ladies with TS Group
Hayley Cleaver • 07763 606597
hayleycleaver@hotmail.co.uk

North Wales Friendship Group
Gina Maddison • 07826 333592
gina_while@yahoo.co.uk
or Eleri Jones • 07769 153280
eleriajones@gmail.com

South Wales Friendship Group
Cathryn Jones • 07881 958854
Richard Jones • 07979 578893
richardallanjone@hotmail.co.uk

Ireland

Northern Ireland Friendship Group
Majella McParland • 07855 324776
majella.mcparland@ntlworld.com
or Naomi Campbell
07973 383761

Southern Ireland Friendship Group
Triona Keane • nursetmk@gmail.com

Scotland

North East Scotland Friendship Group
Judy McWilliam Robertson
07788 271855
j.robertson82@btinternet.com

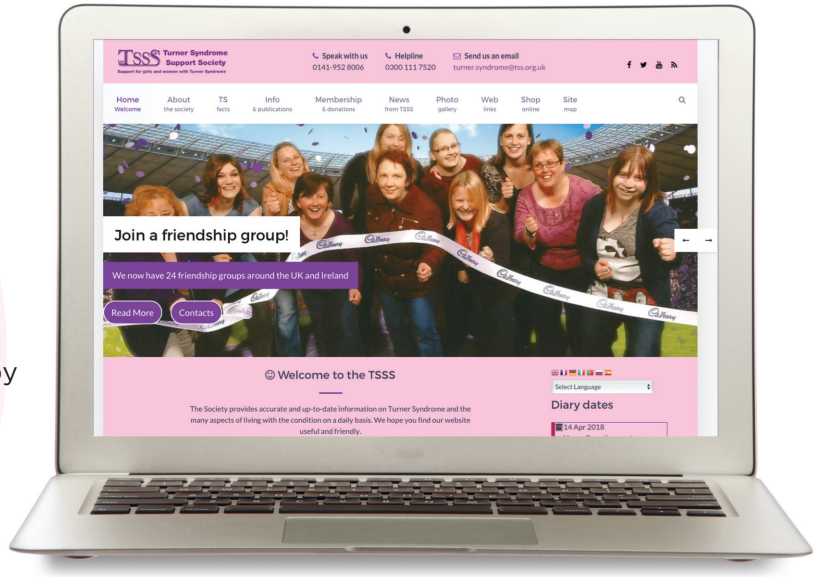
Scottish Friendship Group
Arlene Smyth • 07947 554587
turner.syndrome@tss.org.uk

TSSS Website

Please checkout our website, especially for up to date information on the TSSS UK Friendship Groups.

We have added some of the lovely photos taken by Thomas at conference. Don't forget our on-line shop.
You can renew your membership in the shop and please complete the GDPR survey too.

Please keep checking to see what's new on **www.tss.org.uk** please let us known what you think.



Facebook, Twitter & You Tube

Facebook

Please visit our public page, Turner Syndrome Support Society UK, Facebook page & like us www.facebook.com/TSSSUK this is our official public page.

There are numerous face book groups on my page, **Arlene Smyth**, some are open to non- members and some are open to TSSS [UK] members only, all are closed groups. To avoid confusion, I have added "OFFICIAL" to all TSSS [UK] groups. If it does not have the word official in the title it is not one of our groups. There are hundreds of TS groups, it is important that just because I may be a member of a group does not make it part of the TSSS. The Turner Syndrome Support Society Member-only group is given priority, if you have paid your membership and are not yet on the group, send me a request to join and I can add you to the group. Please note you must answer the questions asked (if you do not answer the questions, you will not be added on).

We also have '**Ask Arlene'** and '**Fabulous Faces of Turner Syndrome'** to name just a few. There are a number of trustees/committee members who are regular users who help us monitor the groups, **please remember the TSSS can accept no responsibility for other Facebook user's comments**. If you are concerned about a posting please let Arlene or any of the Trustees know and we will do our best to help. It is regrettable that because of the actions of a few we have had to reduce our groups and add pre-post approval. Please look at, and observe, the rules for the groups. Please think about who you are messaging to and only ever between 9am and 9pm if people don't reply, it is because they are busy, be patient and courteous at all times or you will be removed from the groups.

If you want to ask me a question and get a prompt reply please e-mail me directly - 'Arlene' at Turner.Syndrome@tss.org.uk.

Facebook messages are not given priority and answered only when I have time. I do my best to keep up but, sometimes it is not easy. Our Social Media Sub-committee are currently reviewing and updating our policy.

Twitter

We are on Twitter the TSSS official address is **https://twitter.com/TurnerSyndSoc** my own one is **https://twitter.com/TSSSARLENE**
We are hoping to use both Twitter and Facebook to help us raise awareness of Turner Syndrome & the TSSS. Any tips or suggestions are welcome. Ella has been working very hard on raising our profile. We now have a few celebrity followers. If any of you have or know any celebrity followers please help us raise awareness. A massive thank you to Ella, Charlotte & Ellie for all their help in raising our profile.

You Tube

We now have a You Tube Channel, please visit: **www.youtube.com/TurnerSyndromeSupportUK**

https://www.youtube.com/channel/UCXfR05RKs-RXfRRmMAhM4Mw

And check out our Animated Health Sketches: ***"Growth Hormone for Turner Syndrome"*** **https://youtu.be/4qieQT3UrBw** and ***"What is Turner Syndrome"*** **https://youtu.be/fA4jmD4OR-g**

Both sketches are sponsored by Pfizer Ltd. We are very grateful for their support.

And ***"The Importance of Growth Awareness"*** **https://youtu.be/iPD1jHQYonY**

Recently added - ***"Helpful Tips on TS nails - A guide on how to cut toe nails in girls and women with TS"*** by Mr Gordon Watt our podiatrist.

A guide to cutting patches for Pubertal Induction.
https://www.youtube.com/watch?v=9mvOYqYueUc&t=52s
Please share all of these as widely as you can.

Children's healthcare professionals launch new international online image bank to increase skin tone diversity of paediatric images used in medical education.

A new paediatric global collaborative project called Skin Deep has been launched today to address the lack of skin tone diversity of paediatric medical education images.

The project is led by the international medical education team, Don't Forget the Bubbles (DFTB) and the Royal London Hospital (RLH). The aim is to develop a free, open-access bank of high quality photographs of medical conditions in a range of skin tones for use by both healthcare professionals and the public. The team behind Skin Deep hopes that with time, this will improve education and recognition of conditions in all skin tones, reducing inequalities and improving patient care by ensuring that all children receive a timely diagnosis regardless of their skin colour.

Within paediatrics, the diagnosis of skin conditions and genetic syndromes relies on the recognition of characteristic features which can differ depending on skin tones. Despite this, the vast majority of medical textbooks and online resources only contain pictures of children or young people with light skin tones. Moreover, descriptions of rashes focus on redness or pallor, both of which are more difficult to recognise in darker skin tones or may not be present at all. This means that children with darker skin tones are often not diagnosed correctly or as quickly as those with lighter skin tones.

Some high profile work is already taking place to address this issue, particularly "Brown Skin Matters" set up by Ellen Margolis and "Mind the Gap" from UK medical student Malone Mukwende, which have successfully brought this issue into the spotlight.

DFTB is one of the largest free open access medical education resources available online and the team have strong international collaborative networks. The Skin Deep project started as part of DFTB in June 2020, but the overwhelming response has led to the launch of its very own website and social media channels today.

Skin Deep will complement and support the existing projects by using a double–pronged approach to increase the quality and quantity of images for medical education.

The team are calling on healthcare professionals and hospitals across the UK and the world to collaborate and be part of the project. They have developed a stream lined process to set up the project at individual hospital sites, including the appropriate governance and consent processes to ensure patient confidentiality and secure transfer of photographs. This is already successfully in place at the Royal London Hospital paediatric emergency department and many other hospitals across the UK, Australia and South Africa.

The team are also calling upon parents and guardians to submit their photographs through the website. All the submitted photographs will be reviewed by a team of dermatologists to provide the correct diagnosis and clinical terms. The images are only used with consent from parents, and pictures of children and case details will be anonymised on the website.

Dr Tessa Davis, Consultant in Paediatric Emergency Medicine at the RLH and co-founder of Skin Deep, has been impressed with the overwhelming response to the project. ***"We are delighted at the number of collaboration requests and images we have received from all over the world so far, and we are working hard to continue building up our bank of images. We would be grateful for any contributions from hospitals, organisations or individuals."***

Nensi Parekh, a nurse and lead for Skin Deep at RLH feels this project is incredibly important. ***"It highlights the need and importance of having a range of images of what skin conditions look like on darker skin tones so we can improve patient care"***.

If you would like to take part in this project, please contact the team via email at: **hello@dftbskindeep.com**

For further information about Skin Deep, please visit: Skin deep website: www.DFTBSkinDeep.com



Membership & GDPR Reminder

Membership 2020 was due on the **1st of June 2020** and costs £30 for annual standing order payments or £2.50 per month by standing order. Overseas membership is £35 a year. As the administration costs of processing cheques is now higher, if you wish to continue to pay by cheque or postal order the cost will be £35 a year. Remember you have control of a standing order not us. All members must complete the GDPR survey, one per family, please do it ASAP. If you have any queries please do not hesitate to contact the TSSS office. We are happy to help.

Fundraising News...

We very much appreciate that during these unprecedented times you may not be able to support us the way you would like to. We do understand, however there are things that you can do to support us without spending a penny.

Thanks to our amazing supporters shopping online with Easy Fundraising, on average, we receive £30 plus per month. Don't forget to use it to for all your online shopping, we now have 300 supporters which is an increase of 16, just wonderful, thank you to each and every one of you. With your help and by asking friends and families to support the TSSS without spending a penny we could easily get that number increased.

Your support really does make a difference please register and support us **https://www.easyfundraising.org.uk/causes/tsss**

We are also signed up to Amazon Smile, choose us when shopping and we get donations without any cost to you. **https://smile.amazon.co.uk/ch/1080507-0**

Thank you in advance for your support

Give it up, Give it in Appeal

A way of supporting the TSSS is to donate a regular amount each month. The commitment strengthens the society, ensuring that the support we give is protected for the future. You can choose the amount you wish to give per month, if you think of it as...

£3 as giving up a takeaway coffee a month

£5 as giving up a meal deal a month

£10 as giving up a takeaway a month

Some choose not to give up anything but set up the gift anyway.

Whatever you can do, we thank you from the bottom of hearts.



Fundraising will happen again when possible, we are a small charity, a great charity, and our support is vital to enrich the lives of those associated with Turner Syndrome. Thank you.

Easy to do:
www.justgiving.com/Turnersyndrome, top right, click **make a monthly donation**.

Smarteen Challenge

Teen Challenge and anyone else who wants to join in!

How many can you fill? Do you know you can collect over £10 of 20p's in a Smartie tube? Your mission please is to see if you can raise £10 by conference and pay it on the Smarteen just giving page

How you raise those 20p's is up to you. I wonder who fills the most? I will leave the teens reps and Ella and Meg to keep you posted how you lovely girls are doing. You can also watch the total rise on the Just giving page.

Have fun and thank you for your support

www.justgiving.com – please search Ella Phillips to find the page.



Merchandise & Publications

Please take a look at the online shop on the website **www.tss.org.uk**

We have recently updated the merchandise on our online shop, please do have a look. You could do some xmas shopping and help us at the same time. Last date for ordering is the 1st December 2020 for Christmas Delivery.

We are also in the process of looking at some packs, so that you can ask for a merchandise pack which will also contain some literature.



We have fantastic publications including:

"Lifelong Guidance and Support" Book

"Helping your Child Thrive and Succeed at School" booklet

"Employment booklet", "Partner's booklet"

"Who is the Woman I am Less than Anyway" Self Esteem booklet

Fact Sheets Series on numerous subjects – do take a look they all contain great information and tips.

Give It Up, Give It in Appeal, Easyfundraising & Amazon Smile

Our ongoing appeal really does help the TSSS, thank you so much to everyone who has set up a regular payment. So far we have had a good response from our members. We have about 25 people have set up a monthly payment; the range of donations has been from £5 a month to £30 a month. We are so pleased with all the support we are getting. We would love to send out a thank you card to everyone that has set it up. If you could contact the TSSS Office when you set up a payment, then we will pop a thank you card in the post.

We appreciate times are hard especially just now and you may not be able to donate to the TSSS as you were able to in the past. A great way to still help us and not spend an extra penny yourself is to join Easy Fundraising. Thank you to all our Easy Fundraising donors – **£118.48** for the second quarter of 2020.

Amazon Smile has raised **£105.80** between April & June 2020, thank you all so much. Please support us when you shop on Amazon Smile at **https://smile.amazon.co.uk/ch/1080507-0**, and Amazon donates to Turner Syndrome Support Society, at no extra cost to you.

Every penny helps thank you all so much. Keep up the good work!

Thank you to everyone who took on a challenge, donated, supported, shared posts, our heartfelt thanks and appreciation.





Great Weather Lottery

Please have a look at our fundraising wheel on the TSSS website – https://tss.org.uk/about/fundraising. We have been set a challenge to get new people playing The Weather Lottery. They have set up a rewards system please help us if you can. We have had a few winners recently.

There is new information on the Great Weather Lottery – visit our page **http://www.theweatherlottery.com/charitiesHomepagePlay.php?client=TURNE**



FUNDRAISING REGULATOR

The Fundraising Standards Board has been changed to the Fundraising Regulator; we are registered.

We are updating our fundraising guidelines at the moment please look at the website for more information. We can assure you that your data has always been treated with the strictest confidence and we will continue to do so. We would never sell data or use the services of a company to do direct marketing to our members. Small charities have a much more personal relationship with our supporters. The TSSS could not help and support others without your kind and donations and fundraising, we are so grateful to each and every one of you. Thank you from the bottom of our hearts. You are all amazing!

If you are planning an event post Covid 2019 please look at the website to familiarise yourself with the rules we pride ourselves on.

Donations List
June to September 2020

June 2020

Rebecca Regan has kindly donated **£50** including Gift Aid to our society.

Callum Brock has kindly donated **£12.50** including Gift Aid to our society.

Judith Ames has kindly donated **£25** including Gift Aid to our society.

Anne Gerrish has kindly donated £62.50 including Gift Aid to our society.

The **Seymour family kindly made** donations to us in lieu for birthday presents for Christine; they donated **£350** including Gift Aid.

Cliona Robertson kindly donated **£100** to our society for our Awareness Day on 21st June 2020.

Hayley Cleaver set up a Just Giving page for our Awareness Day this year and has raised **£330** including Gift Aid for our society.

Tamzyn Barrett has kindly donated **£82.50** in memory of her daughter Tilly.

July 2020

Caroline Marquis has kindly donated **£100** including Gift Aid to our society.

August 2020

Tatum & Michael Reid very kindly donated **£900** in memory of their baby daughter Ava Elizabeth who was sadly lost at 19 weeks. Thank you for thinking of others at this difficult time.

One of younger members **Kacey Reid** decided to exercise with her dog Coco over the lockdown this year and raise money and awareness for our society. Kacey has raised **£936.25** including Gift Aid so far. Keep up the good work Kacey!

We are sorry that this donation was missed out in previous newsletter. The lovely **Ruth Burns** completed the Prudential Ride from London to Surrey last year to raise money and awareness for our society. She has raised **£1056.74** including Gift Aid. Well Done Ruth!

Sarah and **Pippa** have continued to collect 20p for our Smarteens challenge. They have donated **£20** to our society.

September 2020

Andrew Coveney has donated **£187.50** including Gift Aid to our society. Thank you for your continued support.

We have received a **£67.50** including Gift Aid donation from **Arlene and family** after clearing out our wardrobes.

Alex Farmer has donated **£10** to the society.

Linda Brown former Mayor of Pembroke held a dog show in her area this year to raise money and awareness for our society. They raised **£261.34** for our society. Thank you to everyone involved.

Facebook Donations

We are so pleased with the response we have received with your donations through our Facebook page. We are so grateful to everyone that decided to request donations for our society in lieu of birthday presents or sets up a fundraiser over the past few months.

So that we can thank you properly please send us an e-mail as



Facebook do not give us your names. We do not want to miss anyone out.

We are so pleased to say that **£1854.06** has been raised between June and August 2020

This is a list of those who kindly set up a birthday or general fundraisers on Facebook for the TSSS.

Susan Wall, Bethan Wyn Parry Jones, Rebecca Wildman, Monika Marshall, Jen Porter, Michelle Taylor, Jaynee Louise Hyde, Chlo Ronan, Jaime Keleghan, Anna Hardie, Izzy Andrews, Nicola McNeil, Jordan Carr, Jaynee Lou Lou Hyde, Tracy Glasgow, John Downes, Clare Clements, Alix Douglas, Samantha Cubitt, Arlene Smyth & Emily Connor.

Thank you all so much for your continued support.

Please forgive us for anybody that we have inadvertently missed from these lists.

Just Giving

We have a lot of people taking part in different fundraising events over the next few months and that have Just Giving pages set up. Feel free to have a look and see if you can support the events in any way. Our thanks to everyone who takes on a challenge or host events to raise awareness and much needed funds for the TSSS.

Going through changes (but in our own time)

I'm a third-year student and I have a lifelong health condition. It's called Turner Syndrome (TS) and it affects approximately "1 in 2000 live female births" (figures from the UK Turner Syndrome Support Society website). This condition affects many aspects of life but for me right now it mainly means I am short and I find some things particularly hard (anything that requires good spatial awareness and also social things as I feel self-conscious, different and awkward). There are other factors of TS that will affect my life in the future but for now these are my main issues.



I'm twenty now but I was diagnosed in January 2015, when I was nearly fifteen (the time of diagnosis varies from person to person). Basically, I was growing and developing very slowly then, after diagnosis, I got the medication I needed to grow a few more inches and enter puberty.

For most people, the teen years are notoriously challenging and uncomfortable and getting this kind of news at 14 definitely changed more things than I could have anticipated. Despite this, however, some elements of the day of diagnosis were surprisingly ordinary. For instance, at the beginning of the day neither myself nor my family had ever heard of the condition (never mind knowing that I had it myself and always had done), and Mum and I just got the bus to my appointment, not knowing it would be a life-changing kind of a day. Then that evening, perhaps a little in shock, I went to my weekly local musical theatre group, just as I normally would (I'm still hopelessly devoted to musical theatre – never miss an Opsoc meeting or rehearsal if I can help it!). There's no good time or stage of life to hear news like this but it was certainly a huge change and a generally weird and uncomfortable day for us all.

For anyone else who's been in a position like this, you'll have your own experience and feelings about it and that's valid. I certainly have a tendency to always think that I'm wrong or an inconvenience (not sure if that's a Turner Syndrome thing or not, to be honest), but there isn't a right or wrong way to feel in this kind of situation.

Personally, on the day of the diagnosis and since, everything that I'd previously thought and felt about my past and present self, life in general and any kind of hypothetical future all changed and shifted and became even more uncertain. Not that I'd previously been someone who had the rest of their life planned out or anything, I never thought any future happiness was guaranteed, but since the diagnosis, even when it's not the main or only thing on my mind, I've still always felt different, conspicuous and extremely insecure. In all honesty, years before getting diagnosed, I did still have general feelings of inadequacy, but as a child, I was more carefree and distracted. School had its challenges but there was a lot that I enjoyed about it too. I had some brilliant teachers over the years and I always loved books, TV and films so it's no surprise I ended up studying English and Film. I am a geek (though really aren't we all about the things we love?) and I geek out about humour, romance, happiness and character arcs.

More than five years on, my feelings have changed quite significantly since the day of the diagnosis, as I'm more used to it and have met other lovely people with TS, but the feelings of insecurity, never measuring up and sensitivity are still around. I've always felt generally different from peers or other people in my life, but I sometimes even feel different to other girls and women with Turner Syndrome when I attend TSSS events (we are not all the same, after all).

Especially in times like this (with Covid-19, lockdowns etc.), when our face to face contact with others and groups is limited, I look more than ever to fictional characters to help me through and to find ways to think about personal growth and happiness, challenges, relationships and how people can change. After all, when you meet people in real life, you might know about some of their struggles, but it will take more time to feel you know everything about them or what makes them them, and the same happens in fiction. This piece is a little bit of my non-fictional story (not the beginning, not the end) and maybe it will help you in some way as you go about your life at uni this year. I hope so.

Heather

My story...



Hope you don't mind, I thought I'd share my personal Turners story.

Way back in 1986 I was married to M. Straight away we didn't use contraception as we wanted to start a family straight away. One year passed, no pregnancy. Three years passed, no pregnancy. It was starting to affect my mental health by now. I went to my GP and was referred to the hospital for tests. There followed all sorts of tests that took over most of 1990. By now friends and family were starting families and I sank deeper and deeper into dark depression. I had a breakdown, couldn't face going to work where there where pregnant colleagues and proud Nanas with photos. I sat at home with curtains drawn in case a pregnant lady or a new Mummy with a pram walked past. I wouldn't open the door to anyone or answer the phone. I couldn't face anyone; I couldn't face life.

As 1990 turned into 1991 all the tests came back to say nothing was wrong, it was unexplained infertility. 1991 was easily the worst year of my life. I had no life, no enthusiasm for life. I dragged myself through each day. I was so depressed and no one, it seemed could help me. I cried all day, every day. Why was life so cruel!

1992 started how 1991 ended. The only light in my dark life...I had finally been referred to the fertility clinic. I went for the initial appointments to go through what help was available. I had an appointment for 30th April to start our IVF journey. Was this really happening. I began to allow myself to be a little happier.

On 19th April I didn't get my period, I brushed it off...I'd been late before. The week went on, I tried not to think about it. After 6 years of trying I didn't dare let myself get excited. I told no one not even my husband. By Saturday 25th April 1992, hands trembling I did a pregnancy test every day thought it looked positive but it couldn't be could it? I took a sample to the local chemist. I went home, being told to ring in an hour. I rang, told the chemist why I was ringing and she said " congratulations, you are pregnant" the words I never thought I'd hear.

I had no morning sickness; I was nailing this pregnancy thing (at last). I had the blood test for screening for Downs Syndrome. I was told that if I hadn't heard anything in 10 days the test was clear. I checked the post for a letter every day. Nothing arrived. On the morning of the 10th day there was a knock on the door... a midwife stood there. She explained that my blood test had come back to suggest the baby I was having had Downs Syndrome and I had an appointment with the genetics nurse the next day at 1pm. I had no sleep that night at all.

We went for the genetics appointment the next day. The nurse went through my test results. I was 26 but I had the same risk of a Downs pregnancy as a 42-year-old. I was offered an 'amnio' to find out. I needed to know, needed to prepare. I would have carried on with the pregnancy but I needed to know. They did the test that afternoon. I was sent home and told if I didn't hear anything within 3 weeks then everything was ok.

How I got through those weeks I have no idea. On the 20th day I was at home, on my own when a car pulled up outside. I recognised the driver; it was Kate, the genetics nurse. She came in and sat down. Told me that the baby I was carrying was a little girl and did not have Downs syndrome. She went on to say that she did, however, have Turners Syndrome. I had never heard of it. It only affects girls; it affects the sex chromosome. Girls with Turners Syndrome only have 1 X chromosome most girls have 2 X chromosomes. An X from their mum and a second X from their Dad. (An X from mum and a Y from Dad makes a male pregnancy). Girls with classic Turners only have 1 X with the 2nd totally missing. My baby had 1 X chromosome and part of the 2nd X chromosome, meaning that she had mosaic Turners Syndrome. She went on. Girls with any sort of Turners don't grow very tall. Only 2% of girls conceived with Turners make it to live

birth. Of those who make it 95% are born without ovaries. At this point I broke down. I knew what infertility was like to live with and I'd passed infertility issues on to my unborn baby girl. How could I live with that!

After birth Kate was under the children's clinic at the Hospital. She was scanned age 10 and I was told that she had ovaries but they couldn't tell me if they were functioning or not. At age 13 Kate had her first period spontaneously, as girls with Turners with no ovaries take hormone medication for general health and to make them bleed each month to keep the womb healthy in case a pregnancy by egg donation was possible. Kate had done it naturally with no hormone treatment. She only had 2 maybe 3 periods a year. At 17 she was scanned again. They were unable to say how long her ovaries would work for and she also had polycystic ovary syndrome. Pregnancy was unlikely.

I felt so guilty but it wasn't about me now it was about Kate. Unfortunately, it did affect me and quite badly in all honesty. If anyone I knew daughters got pregnant, I would literally hate them, cried for my baby girl who would probably never be able to get pregnant.

It was March 2015 and Kate had been unwell for a few weeks, picked a bug up from the nursery where she worked, I thought. She rang me one day to say she was constantly sick still after 3 weeks. Could she be pregnant? No, the Hospital had said that was very unlikely hadn't they! I picked up a test and said she needed to do it to rule it out before going to see her GP. I was with her when she did the test... it was positive! Shock, huge shock to both of us. In September 2015 she had Amelia. Kate was told to expect to go through early menopause at any time so following Amelia's birth, Kate and her partner chose not to use contraception and in October 2016 found out that she was pregnant again. June 2017 she had Callum. Kate and her partner decided they would like one more baby and April 2019 she fell pregnant but unfortunately miscarried at only 8 weeks. On boxing day 2019 she announced that she was pregnant again, unfortunately she lost it on New Year's Day. She fell pregnant again very quickly and baby Chloe is due in December.

I have no idea why my Kate is one of the lucky ladies with Turners, why my family have been blessed but I am grateful every day. I never expected to be a nana but I love every single second of it.

Karen x

Get Well Wishes

Susie Wall has been in hospital having a knee replaced and waiting to have surgery on her thumb too. We wish you a speedy recovery. Sending lots of love from all your friends at the TSSS.

Alice Burton has had a mild stroke as you can appreciate it was a bit of a shock. I am pleased to say she is doing well. We wish you a speedy recovery. Sending lots of love from all your friends at the TSSS.

Rachel Coysh has continued to improve and has come along way since last year following such a difficult time. We wish you a speedy recovery. Sending lots of love from all your friends at the TSSS.

A few members have had Covid, we wish you all a speedy and full recovery. Sending lots of love from all your friends at the TSSS.

Condolences

It is with great sadness that we learnt of the passing of a few of our members.



We learned that Barbara Drew, one of our Irish members passed away from Cancer. Many of you will remember Barbara from conference a few years ago, she helped us with our singing. We have such fond memories of the laughter at rehearsals. Barbara will be missed by all her friends at the TSSS. Our sincere condolences to her family and friends.



We were shocked to learn of the sudden passing of Caroline Atenstadt of a Heart Attack. Caroline had never missed a conference, she also enjoyed many of our friendship groups too. She will be missed by all her friends at the TSSS. Our sincere condolences to her family and friends. Our thanks to friends who have made a kind donation in Caroline's memory.

We have just learned of the passing of Janis Turner. She will be missed by all her friends at the TSSS. Our sincere condolences to her family and friends. Janis very kindly remembered the TSSS with a £1000 gift in her will. A very generous and thoughtful gesture that will make a difference to the TSSS.

Sadly, we have also lost a number of babies too. Our sincere condolences to all the families that have been affected.

Adventures in Romania...

The inspiring journey of Dinah Madge. While we all faced up to lockdown and all its challenges one of our members drove hundreds of miles to help others.

The adventure started when I was in Romania in March alongside Pete Malkin, who serves as a missionary in Romania, and a team from the UK. I really felt that I should go over for a longer period of time. As we returned from that trip the borders were closing behind us due to corona virus, and things became very uncertain.

Then two things happened, my friend Simona contacted me to say that she had found a flat for me, and my good friend Sue said she would come over with me to help with the driving. This was another confirmation. Sue's Vicar even said that Sue could work while in quarantine when she returned. The last confirmation was the borders. Pete, went ahead of us, with aid and resources in the van. If he got through the borders easily Sue and I would leave the UK.

Pete got to Romania and reported that there had been no guards at any border until he got to the Hungary/Romania one, amazing! So, on 20th July Sue and I set out in my small Polo. Sue helped me with the driving, and more importantly for me, the navigation. As you know finding our way is often challenging for those of us with Turner Syndrome. We arrived in Romania with a double rainbow in the sky and found my flat in Orastie, which Pete had got ready for me, so I immediately felt at home. Sue spent five days helping me get settled in and then returned to the UK to face two weeks of quarantine. What sacrifice! What good Christian friends I have.

Since being in Romania I have been working alongside Jessica and Tijs who work with the Roma gypsy community.



The van packed and ready to go



One of the newest members of the Roma community



Dinah's friends



Baby basket all ready

We have sorted clothes packages and filled beautiful baby baskets, which were given by Ann, the daughter of a lady at my Church. They are greatly needed as the Roma have very little and it is very hard bringing up a child in the village.

I have also helped at the homework club where some of the Roma children are learning to read and write. This will hopefully give them a better chance in life. I am trying to learn some Romanian. A big challenge!!

I am starting to meet with a group of people with special needs alongside Simona. Pete established the group and we want to continue with it and grow the work. We have had two meetings in the park and Simona and I have started to do some home visits and establish a team to help. Luckily the weather is hot, 25-28 degrees most days, so we can meet distanced and outside.

It is an exciting but challenging time, but we with Turners are used to challenges.

Dinah

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 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 days, seminar days 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.

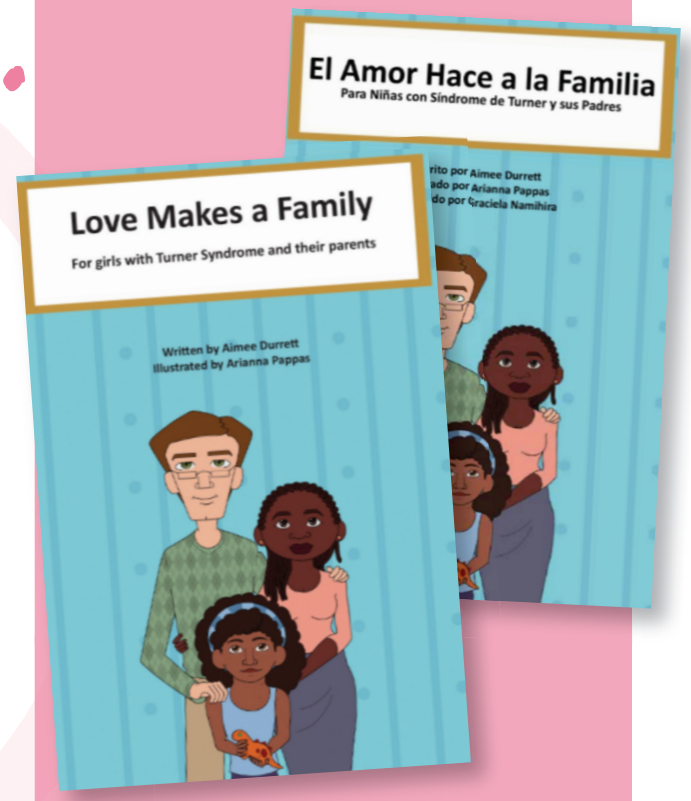
TSSS Friendship Group Coordinators give permission to circulate their contact details so that if members want to join the group, they can. It is your decision to share your details with the Friendship Group Coordinator directly, who will also hold it in the strictest confidence. The data we hold allows 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 anonymized.

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 data is up to date.

If you have not already completed the questionnaire please do so ASAP. To date only half of you have completed it. 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 or need help to complete, please do not hesitate to contact the TSSS office.



Love Makes a Family: for girls with Turner Syndrome and their parents

This is a children's book for girls with Turner Syndrome that focuses on infertility and family planning. The purpose of this book is to help parents and their daughters begin to have a positive, open, and continually evolving discussion about the many wonderful ways a family can be made. Digital versions of the book in English and Spanish can be accessed using the following link: https://gen.uncg.edu/lovemakesafamily/

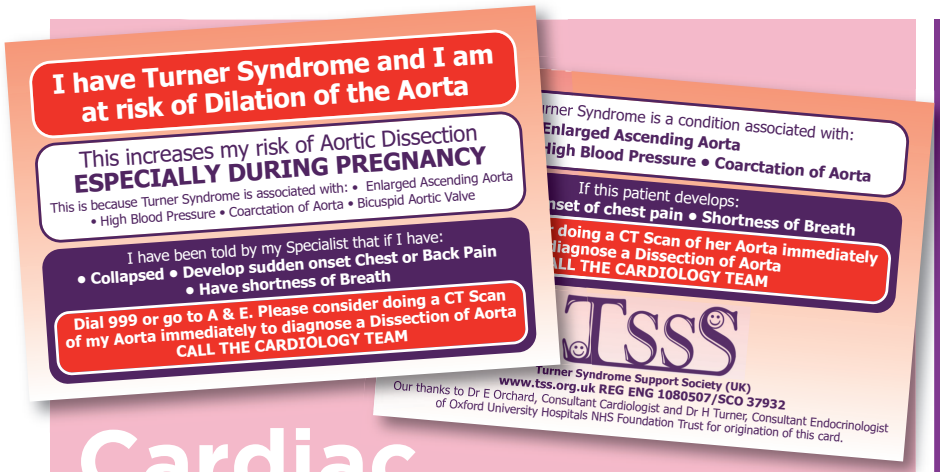
Thank you to Aimee Durrett for providing such a valuable resource to the Turner syndrome community. Thank you to all those who supported this project including UNC Greensboro, healthcare providers, TS Carolinas, and all the funders who made this possible. Our thanks to Denise Cullen from Turner Syndrome Global Alliance for allowing us to share with the TS community.

Thank You!

We are very grateful to Pfizer Ltd who have generously given us a grant of £6000 towards improving online services to our members. Thank you so much to those of you who completed the survey about online services.

We are working on a calendar of events over the winter months. Details will be on our website and social media. We will include topic led events such as Blood Pressure, Heart, Anxiety, Mindfulness, Cuppa and a chat Zooms, a virtual Kids Club with a Magic Show, there will be something for everyone. So, keep checking the website and our social media too.

We are very grateful to Novo Nordisk who generously added £3500 to their annual donation. We are going to use this grant towards helping and supporting our friendship groups. We are speaking to all the groups to establish what help they need to deliver online services. So, keep checking the website and our social media too.



Cardiac Alert Cards

Our Cardiac Alert Cards continue to be very popular, so much so that we have had to print more cards.

We are able to do this thanks to the families who raised money for Heart Awareness following the loss of their loved one. We are truly grateful to them. The Cardiac Alert Cards can be carried by any girl or woman with TS to alert paramedics, doctors, nurses or indeed any other health care professionals about the possible heart complications seen in TS. Our thanks to the team at Oxford University Hospital especially Dr Helen Turner. Dr Elizabeth Orchard and Emma Weingart for their dedication to their patients in designing this card. We will be circulating them as widely as possible at TSSS and HCP events throughout the country.

Should you wish a free cardiac alert card, please send a SAE to the TSSS office and we will post one out to you.

I am delighted to share with you that we already know that carrying this card has saved a life, please request one to carry with you.

Some useful websites you may be interested in:

http://www.boots-uk.com/our-stories/new-skin-scanning-service-launches-at-boots-uk/

https://issuu.com/neweconomics foundation/docs/five_ways_to_well-being? viewMode=presentation

Healthy sleep tips for children – NHS

https://www.nhs.uk/live-well/sleep-and-tiredness/healthy-sleep-tips-for-children/

https://www.thechildrenssleepcharity.org.uk/ professional.php

https://www.healthline.com/health/tips-get-your-kids-sleep

Anxiety & Stress websites:

We have identified some websites that you may find helpful if you are feeling stressed or anxious.

https://www.takeabreathhub.co.uk/

https://breathingspace.scot/

https://youngminds.org.uk/find-help/conditions/anxiety/

https://www.themix.org.uk/

https://www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/

30 Day Happiness Challenge

It's the little things in life that add up, in addition to the 30 things to try in the 30 day Happiness challenge, why not also write down 3 things you are thankful for each and every day. Take some time out each day for you, and say out loud positive statements about you. This could be anything but here are a few ideas: ***"I am strong"*** ***"I am good at..."*** ***"I am determined"*** ***"I am happy"*** ***"This is me".***







1. No social media day
2. Call a friend
3. Listen to favourite song
4. 15 mins of exercise
5. Fresh Flowers
6. Hug someone you love tight
7. Do one small act of kindness
8. Watch a funny movie
9. Dance to happy music
10. No complaining all day
11. Have your favourite treat
12. Colour a picture
13. Start a new book
14. Glam yourself up
15. Take a walk
16. Get a pedicure or your nails done
17. Get your hair done
18. Visit a lake or the coast
19. Spend one on one time with your favourite person
20. Go for a drive with no destination in mind
21. Write down what you're good at
22. Declutter a room
23. Buy something you really want
24. Plan a future dream holiday
25. Take a day off work
26. Bake a cake
27. Take a nap
28. Buy a gift for someone you love
29. Read the *Smiling is infectious* poem out loud
30. Draw the TSSS smile logo and colour it in, in purple ☺

Smiling is infectious

by Denis Kilcommons

Smiling is infectious, you catch it like the flu
When someone smiled at me today, I started smiling too
A single smile, just like mine, could travel round the earth
So, if you feel a smile begin, don't leave it undetected
Let's start an epidemic quick, and get the world infected.

The health benefits of... ...singing and dancing

The feel-good effects of singing are well known, but there is actual evidence that singing in groups can have a positive impact upon mental health. The act of singing releases endorphins, a hormone associated with feelings of pleasure. Oxytocin, another hormone released during singing, has also been found to alleviate anxiety and stress, while also boosting feelings of trust and bonding.

We are wired to feel pleasure when singing in groups instead of by ourselves, this is apparent when our Ladies and Teens sing together in the TS Choir, there is such a strong sense of belonging and something unique about the synchronicity of moving and breathing with other people.
A Swedish study carried out on a group of 18-year-old men and women suggested that the heart rates of those who sing in groups actually beat in sync with each other. Conference brings so many emotions, and Friday rehearsals and Saturday's performance have become much-needed therapy and should be considered as part of your healing and well-being plan.

Alongside the health benefits of singing, dancing is also proven to have physical and psychological positives, feeling positively transformed and experiencing a sense of bursting, or liberation — the release of built-up feelings and of relief.

It is such a privileged to be part of such a proven success at conference. We are looking at the possibility of an online choir so watch this space for more information.

Huge love and forever yours, Sam xx

TS International News

INTERNATIONAL COALITION OF ORGANIZATIONS SUPPORTING ENDOCRINE PATIENTS

ICOSEP

Children's Growth Awareness Worldwide Initiative

The International Coalition for Organizations Supporting Endocrine Patients (ICOSEP) is a revolution in support for endocrine patients, families, affected adults and the medical community.

It is a voluntary umbrella association representing individuals, organizations and groups who are impacted by a variety of medical conditions impacting children's growth. ICOSEP is directed by an independent board of global member organization leaders and hosted by the international division of The MAGIC Foundation, US.

Thank you to everyone for their support for International Growth Awareness Week this year. Again, we had a fantastic response mainly due to our superstars Charlotte & Freya who made a fantastic video for us. We had another great response; your support is much appreciated.

Every year the International Children's Growth Awareness Day will be on the 20th of September. We mainly drive everything through social media so if any of our young members would be interested in helping and supporting us please get in touch.







Please do have a look at the International Coalition of Organizations Supporting Endocrine Patients (ICOSEP) visit **www.icosep.org** for more information.

And the ***"Importance of Growth Awareness"*** **https://youtu.be/iPD1jHQYonY** please view and share to help raise awareness, thank you.

It is also well worth having a look at **https://morethanheight.com/**, it is a wonderful website and a great resource for anyone concerned about their child's height.

TS International Group Website

Following the cancellation of TSI 2020 we will continue to review the Covid situation and if at all possible, we will host an event as soon as we can. Details will be posted on the TS International Group Website TSI 2020.

Do take a look **www.tsint.org**, we have had a few new groups join. I will continue to put information on as and when I get it. Our thanks to Novo Nordisk for their support through an educational grant to establish the website. Keep checking for updates.

Endo-ERN

I am a proud member of **Endocrine European Reference Network** they have been working hard on gathering information on the effects of Covid 19 on endocrine patients. Do have a look at their website **https://endo-ern.eu/**

EuRReCa

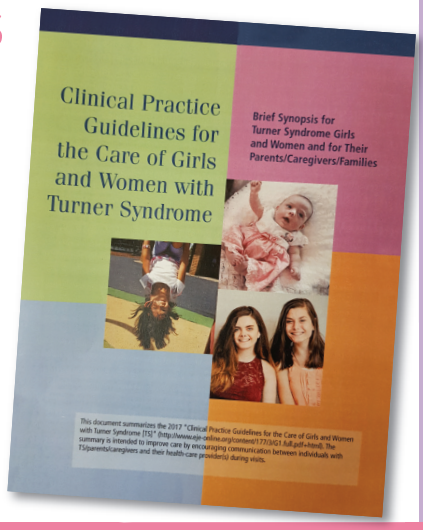
I am a proud member of the **EuRReCa** project, this is very exciting working to create registries on Rare Conditions across Europe. I do enjoy taking part and learning from the others involved in the project. Do have a look at their website **https://eurreca.net/**

I continue to work with the EuRRRCa project all virtual meeting now. They are working hard gathering data on Covid 19 and how it is affecting those who have rare endocrine conditions.

TS Clinical Practice Guidelines

The TS International Consensus Guidelines are still available and free to download from our website **www.tss.org.uk** free of charge. Share them as widely as possible.

There is both a **Patient Friendly Version** and a full Clinical version available.



UK News...

SPEG

I am the voluntary group member of the **SPEG/ Managed Clinical Network (MCN)** this is a network that strives to provide the best possible Endocrine care throughout Scotland. Their website is **www.speg.scot.nhs.uk** if you want to have a look.

The Office for Rare Conditions

I am proud to say that I am enjoying my voluntary role on the steering group for "The Office for Rare Conditions".

Based at the Royal Hospital for Children and the Queen Elizabeth University Hospital. It aims to improve the quality of life for children and adults living with a rare condition by raising awareness, working with health care professionals to improve care and increasing participation in multi-centre research. It is great to help and support my local hospital; it is a way of giving back after the excellent care Kylie received there. My role is to represent patients on the steering committee and to reflect patient experiences and views accurately. We have set up a Patient Advisory Group (PAG) for the Office for Rare Conditions and met some amazing families and started sharing their views and opinions with the steering group, ensuring families have a voice. It has been very exciting, and a lot has been achieved in a short time thanks to Prof Ahmed, Liz Dougan and Jillian Bryce. We have welcomed Shannon McMullen to the team, and she has very quickly fitted in to the team.

We are busy looking at apps to assist families and emergency care plans to assist families in an emergency. We have had a super week raising awareness in the atrium of the hospital. I was privileged to meet many wonderful families.

Have a look at the website:
www.officeforrareconditions.org

www.facebook.com/ORCGlasgow

https://twitter.com/ORCGlasgow

TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

Summary Annual Report 2019 - 2020 and Annual General Meeting Information

This summary has been created to give an overview of the Annual Report, whilst significantly reducing the cost of publication to the members. If you wish to read the Annual Report in its entirety, it is available on our website https://tss.org.uk and the TSSS Members Facebook Group or on request from the TSSS office e-mail turner.syndrome@tss.org.uk.

Trustee Statement

As Trustees we know that this will be a very difficult 12-18-month period. It will impact the Society in several ways, both functionally and financially. As a support society we have always prided ourselves on supporting and helping each other, whether on the end of a phone or in person. This will continue, possibly using different formats e.g. Zoom, email, webinars etc., but we will still be there as a Society. Our ethos will not change and whether laughing or crying, we will survive this together.

2020 Covid-19 Update

Whilst this Annual Report covers the period Apr 2019 to 31st Mar 2020, the effects that Covid-19 would have on the Society were beginning to be felt. With that in mind I thought we should explain a couple of the decisions that have been made post the official period of this report.

TSI 2020

Whilst we had to continue to work towards holding the International Conference, if there was any chance of it happening, the likelihood of cancellation became ever more certain. Whilst we wanted to do this as early as possible, we had to wait for the venue to cancel, as otherwise there was the potential of a cancellation fee, which the Society would have been liable for of over £50k+, as well as no refunds. As the venue cancelled, we were able to get all accommodation fees refunded to delegates which would not have happened if we had cancelled. This has massively skewed the accounts, as since the enclosed accounts were finalised, over £21,000 has been returned to delegates. Additionally, there is £10,000 in the accounts which was a grant towards the conference, so this needs to be held in Restricted Funds, until a decision is made on the way ahead in conjunction with the company who gave us the grant.

Furloughing Carlene

With the expected significant decrease in income, we made the difficult decision to furlough Carlene in April. This left Arlene having to run the office on her own during this difficult time, which included handling the cancellation of the International Conference and the refund of the delegate fees. With the introduction of flexible furlough, Carlene is working 1 day a week to help lighten the load. This is until the end of October when Carlene will return to her normal hours, but as I am sure you can appreciate, this has put a greater burden on Arlene during this time. Carlene, thank you for being so understanding of the decision and a massive thank you to Arlene for shouldering the burden during this difficult time.

TURNER SYNDROME SUPPORT SOCIETY [UK]

2019-20 Annual Report

All activities and accounts cover the period 1st April 2019 to 31st March 2020.

Publications & Literature

New Turner Syndrome Guidelines were launched as well as health checklists.

Open Day and Seminar Day

We held an Open Day in Sheffield in June, which coincided with our awareness week and had our 2nd very successful, oversubscribed, Seminar Day in Oxford in November led by Arlene and Dr. Helen Turner and her team.



Annual Conference

Another emotionally filled Annual Conference was held in Chorley in October where the Masters Award was given to Rachel Coysh having shown, especially in the previous year, what amazing TS spirt she had. Ambassadors Awards were given to Miss Kacey Reid, Team Penny (Penny Jones-Parry, Mum Frances, brother Dominic and Friend Charlie) and to an organisation Best Childcare, which was accepted on their behalf by Emily Raper.

Thank you to all our winners for all their efforts in helping the Society and promotion of awareness of TS, you are all worthy winners.



TSI 2020 & Meet the Expert

During the period of this report, the planning and implementation of multiple aspects for the International Conference in Stirling were being carried out. Accommodation and delegate booking facilities were launched and needed management to ensure both aspects were controlled. This involved an immense amount of work for the Office, whilst still planning and organising the annual conference as normal. Additionally, the ***Meet the Experts Day*** was requiring a different kind of expertise to ensure that it would also be a success whilst naturally flowing into the International Conference.



Medical Conferences

The Society continues to develop and foster relations within the medical profession by attending conferences in the UK (BES, BSPED) and Europe (ESPE). We were invited to join the Turner Syndrome ESPE Working Group.

Friendship Groups

These groups are important local area resources and Ex-Chair Hayley Cleaver co-ordinates these groups and they have made great advances under her guidance. They now cover most of the country.

Treasurer's Report

The Charity Commission requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the situation of the Turner Syndrome Support Society for that period. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Make judgements and estimates that are reasonable and prudent.
- Prepare the financial statements on the going concern basis.

To simplify membership administration there is a single joining date of the 1st June used every year.

The figures in this year's accounts are for 12 months.

As at the 31st March 2020 the closing balance of **£159,038.35** was made up of **£51,495.10** in the Reserves Account, **£54,097.30** in the Restricted Grants Account, **£3,163.43** in the Debit Card Account, **£50,253.17** in the Current Account, and **£29.35** in the Cash Account.

During the accounting year the Society received **£17,744.00** from benefactors, Novo Nordisk, Pfizer, Ferring Pharmaceuticals Ltd and Ipsen.

At the year end, 31st March 2020, a stock take was completed, and the value of the stock was **£5,334.58**.

The bank charges of **£323.89** cover all the bank accounts the Society currently holds, Current Account, Restricted Funds Account, Reserves Account and Debit Card Account.

The Processing credit fees of **£3,346.00**, were made up of the charges incurred from Just Giving, Pay Pal, Charity Checkout and Virgin Money Giving and have been paid by the Society.

Conference and Open Days are self-funding, and no money is made on these events. If the cost for a delegate to attend Conference increases, it is only due to the increase of costs incurred to the Society.

This year the Society's income is showing a large increase. Firstly, there was a single anonymous donation of **£10,000.00** and then **£31,680.68** was income received from delegates to attend the International Conference and sponsorship money. However, due to COVID-19 and the sad and devastating decision to cancel the International Conference the sum of **£21,680.68** has had to be refunded to all individuals, but this did not happen until after the financial year end in April 2020. Therefore, the true surplus for the year ending March 2020 is **£19,099.78**.

There is no guarantee of future income and the effects of COVID-19 is going to be huge, therefore we need to be mindful of this when planning for the future of the Society. Additionally, whilst grants have never been a significant income stream for the Society, due to the heavy administrative burden in producing them, we realise that this is an income stream that we cannot ignore and will therefore being put more emphasis on in the future. The on-going aim is to continue to ensure that value for money is achieved within all areas of expenditure and that the Society continues to seek to attract additional corporate benefactors, as well as increased membership and fundraising income.

Mrs J O'Keeffe



Treasurer • 10th Oct 2020

Turner Syndrome Support Society (UK)

Receipts and Payments Accounts • 1st April 2019 - 31st March 2020

Receipts	2019/2020 01/04/19-31/03/20	2018/2019 01/04/18-31/03/19
Memberships	£14,435.00	£14,268.50
Donations & Fundraising	£78,602.17	£63,033.31
Conference & Open Days	£29,201.65	£29,273.53
Benefactors/Restricted Funds	£17,744.00	£9,500.00
TS International Conference	£31,680.68	£0.00
Shop	£2,405.79	£3,071.04
Consult Fee/Expenses Received	£628.22	£1,852.35
Miscellaneous	£1,500.00	£263.00
Bank Interest Received	£188.55	£123.94
Sub Total	**£176,386.06**	**£121,385.67**

Opening Bank Balance	At 1st April 2019	**£108,257.89**	At 1st April 2018	**£102,553.26**
Total		**£284,643.95**		**£223,938.93**

Payments	2019/2020 01/04/19-31/03/20	2018/2019 01/04/18-31/03/19
Rent & Rates	£13,873.96	£14,863.09
Heat, Light, Insurance	£3,934.94	£2,589.70
Printing, Stationery, Postage	£13,834.05	£8,596.85
Conference & Open Days	£29,482.48	£28,010.90
Wages, Salaries & Employers NIC	£41,424.06	£40,198.07
Telephone	£1,405.38	£1,318.40
Computer	£4,298.46	£4,404.92
Professional Fees	£1,170.00	£1,689.36
Processing Credit Fees	£3,346.00	£2,122.89
Bank Charges	£323.89	£282.98
Equipment Hire & Maintenance	£2,479.71	£1,784.70
Literature & Brochures	£324.00	£91.97
TSSS Merchandise	£2,299.61	£3,436.15
General Expenses	£1,542.49	£1,189.93
Travel & Governance Expenses	£4,166.57	£5,101.93
Training Courses	£0.00	£0.00
Projects	£1.700.00	£0.00
Bad Debts	£0.00	-£0.70
Sub Total	**£125,605.60**	**£115,681.04**

Closing Bank Balance	At 31st March 2020	**£159,038.35**	At 31st March 2019	**£108,257.89**
Total		**£284,643.95**		**£223,938.93**

Surplus/Deficit for the year	**£50,780.46**
NOTES: Eventbrite refunded May 2020 Adler invoice for pens in May	 £21,680.68 £1,929.59

TURNER SYNDROME SUPPORT SOCIETY

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF TURNER SYNDROME SUPPORT SOCIETY

PERIOD FROM 1 APRIL 2019 TO 31 MARCH 2020

I report on the accounts of the charity for the period from 1 April 2019 to 31 March 2020 which is set out on the accompanying pages.

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND EXAMINER

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this period under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 (the 2006 Regulations) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

BASIS OF INDEPENDENT EXAMINER'S REPORT

My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

INDEPENDENT EXAMINER'S STATEMENT

In the course of my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act and section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act and section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations.

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Nicola Jane Cadwallader FCCA



For and on Behalf of
David Cadwallader & Co Limited • Independent Examiner • Chartered Certified Accountants
Suite 3 Bignell Park Barns • Chesterton • Bicester • Oxon OX26 1TD

21 September 2020

Annual General Meeting

This year we are unable to host our AGM in person as we would do normally, having had to cancel all face to face events until Spring 2021 at the earliest.

The Trustees and Committee members discussed how we could host our AGM and ensure you were updated and informed in as much detail as you would have been in person. We are offering a wide range of options for our members and to meet our legal requirements.

Therefore, we are going to publish our Full Annual Report and Trustees standing for election on the members Facebook page and on the TSSS website.

We will also publish a Summary of the Annual Report in the newsletter. Please follow this link to cast your vote, **https://www.surveymonkey.co.uk/r/WQKJN7Y** it will take 1 minute to complete.

Any questions can be e-mailed to the TSSS office in advance of the 30th November 2020.

Minutes of AGM 2019

TSSS Annual General Meeting • Saturday 12th October 2019
Park Hall Hotel, Chorley, Nr Preston, Lancashire PR7 5LP

Present:

Stephen Wall	*Chairperson/Trustee*
Susie Wall	*Chairperson/Trustee*
Arlene Smyth	*Executive Officer*
Jackie O'Keeffe	*Treasurer/Trustee*
Sam Cubitt	*Secretary*
Kerry Bruerton	*Trustee*
Jane Raper	*Fundraising Officer/Committee Member*
Kylie Smyth	*Committee Member*
Ali Andrews	*Committee Member*
Matt Andrews	*Committee Member*
Charlotte Raper	*Committee Member/Young Adult Representative*
Meg Cubitt	*Committee Member/Young Adult Representative*
Ella Phillips-Ansell	*Committee Member/Young Adult Representative*

Apologies: Simon Holden, *Vice Chairperson*

(continued on page 30)



Minutes of AGM 2019 (continued)

Welcome:

Stephen Wall welcomed everyone to the AGM and thanked everyone for attending the Society's 20th Annual Conference.

The minutes from 2018 AGM were proposed by Les Walker and seconded by Hayley Cleaver and additional copies of the AGM could be printed if requested. There were no trustees or committee members up for re-election this year.

A copy of the Annual report was given out which has also been put onto the Society's website for anyone to read. Again, if anyone wanted extras copies it was available to be printed. The report talks about the Open Days and other events/activities the Society has been doing during the last financial year. Arlene has attended a few other conferences during the year and has been very busy travelling from one end of the country to the other and also travelling overseas to Europe.

A tremendous amount of work happens behind the scenes with lots of miles covered and continuous work at the office including preparation for the International Conference in 2020. The register of interest and accommodation details went out for the International and the Society is beginning to get feedback.

Every year Jackie spends hours putting numbers into the computer and balances the accounts. The profit has gone down slightly due to a slight increase in the expenses. It was explained that all the money seen in the bank accounts was not just available for use of the Society's running costs but some is reserved and some restricted. The Society receives money from benefactors who restrict the money when donating and sometimes specify what the money is to be spent on, for example, producing fact sheets, open days, International conference, our annual Conference, heart cards, Aspects etc. Money which is kept in the current account is for the day to day running of the Society, wages, stationery, light and heat, telephone, repairs to the office, etc.

Stephen again would like to thank all the volunteers, trustees and committee for all their continued help, without them the Society would not happen and also thanked the members for continually fundraising and donating and they should be applauded.

There will not be the normal Conference next year at Park Hall due to the International taking place but there are ideas of having a party to celebrate the Society's 21st birthday.

Stephen asked if anyone had any questions, but there were none. He also said if anyone would like more information on how the Society is run or would like to volunteer then to approach any of the trustees or committee. There are 6 trustees who have the main responsibility for running the Society and are Stephen Wall, Susie Wall, Jackie O'Keeffe, Sam Cubitt, Kerry Bruerton and Simon Holden. To become a trustee you have to have been a committee member for a period of time first.

Finally, the confirmed date for the International in Stirling is 16th – 20th July 2020 and a draft programme has already been put together.

Stephen officially closed the AGM and wished everyone a great weekend.

Arlene thanked the trustees and committee for all their continued support.

TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

Agenda

Apologies

Minutes of 2019 AGM

Annual Report

Trustee Elections 2020

Any Other Business?

Trustee Elections 2020

Trustees standing for re-election are: Kerry Bruerton, Simon Holden and Jackie O'Keeffe

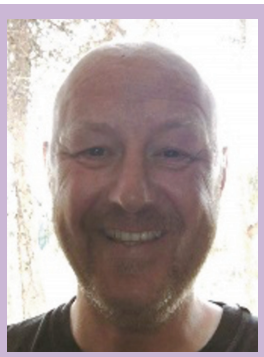


Hi, I am **Kerry Bruerton**, I am a woman with Turner Syndrome, I was diagnosed at about the age of 8 and in the late seventies early eighties there was little or no information available for my parents or myself. I am a Business Support Administrator with the local authority. I am proud of what the society and members have achieved over the last 21 years. Supporting anyone with a connection to Turners, whether it is a diagnosis, a parent, grandparent, carer to teachers and employers.



Hi, my full name is **Jacqueline O'Keeffe**, but everyone calls me Jackie and have been with my husband, Shaun, for 30 years. We became members of the Society back in 2000 when our daughter, Shona, was diagnosed with Turner Syndrome at 3 months old. Straight away we received amazing support from Arlene and the Society who helped us through some very difficult times.

After a couple of years I wanted to give something back to the Society so decided to become a committee member. After time I got more heavily involved and later became a Trustee followed by taking the position of Secretary. Our second daughter, Ciara, was born in 2005 and she immediately joined the TS Family. After another couple of years the Society's lovely Co-Chair, Susie Wall, due to health reasons took the difficult decision to resign as Treasurer and I was asked if I would take over the position. I had a very hard act to follow but said 'yes'. My family continue to get help and support and we have made many life long friends through the Society. 20 years later I continue to juggle my home, family and work life with that of the being Trustee and Treasurer of the Turner Syndrome Support Society but wouldn't want it to be any other way.



Hi, I am **Simon Holden**, I have been honoured to have been a trustee of TSSS UK over the last several years and to have witnessed the incredible growth of the Society and to see the amazing levels of support it offers to its members. The TSSS family and team is a fantastic one & I am proud to have contributed, in however small a way, to it over the years.

I am married, have three children and am a chartered surveyor working in the construction industry. We live in Nottinghamshire. I am a southerner living up north. My eldest daughter, Amy, was diagnosed with TS in 2001 and since then my wife & I, together with our family, have been involved with the Society in several ways and have benefitted from the support and guidance offered by every one of its members and friends. I have been a committee member, I stepped in to edit the ASPECTS newsletter for a while and was then invited to be a trustee – a position which I was delighted to accept. I am currently Vice Chair of the Society.

Please take one minute to complete the survey and cast your vote. Your continued support is very much appreciated **https://www.surveymonkey.co.uk/r/WQKJN7Y**

If you have any questions or would like a copy of the annual report please e-mail Arlene @ **turner.syndrome@tss.org.uk** or post to the TSSS office.

If you require this newsletter in different formats please contact the TSSS office.

TURNER SYNDROME SUPPORT SOCIETY TRUSTEES/COMMITTEE MEMBERS

Please contact any of them if you have any queries or points you would like to raise on TS or TSSS issues.

TRUSTEES

Chairs: **Susan/Stephen Wall** • Tel **07791 545747/ 07960 030162** • email **Susie@tsssuk.org.uk**

Vice Chair: **Simon Holden** • Tel **07810 794829** • email **Simon@tsssuk.org.uk**

Webmaster: **Stephen Wall** • Tel **07960 030162** • email **Stephen@tsssuk.org.uk**

Secretary: **Sam Cubitt** • Tel **07757 082945** • email **Sam@tsssuk.org.uk**

Treasurer: **Jackie O'Keeffe** • Tel **07977 486898** • email **Jackie@tsssuk.org.uk**
Kerry Bruerton • Tel **07513 113401** • email **Kerry@tsssuk.org.uk**

COMMITTEE MEMBERS

Jane Raper *(Fundraising Officer)* • Tel **07879 682125** • email **Jane@tsssuk.org.uk**

Charlotte Raper *(Adults & Social Media Representative)* • Tel **07792 839219** • email **Charlotte@tsssuk.org.uk**

Kylie Smyth *(Adult Representative)* • Tel **07825 091330** • email **Kylie@tsssuk.org.uk**

Meg Cubitt *(Conference Representative)* • Tel **07964 092672** • email **Meg@tsssuk.org.uk**

Ella Phillips *(Conference & Social Media Representative)* • Tel **07815 562603** • email **Ella@tsssuk.org.uk**

Dinah Madge *(Adult Representative)* • Tel **07765 097626** • email **Dinah@tsssuk.org.uk**

Phil Hatcher *(Dad & AspecTS Editor, Publications Representative)* • Tel **07522 356904** • email **Phil@tsssuk.org.uk**

Ellie Hatcher *(Adult & AspecTS Editor, Social Media Representative)* • Tel **07814 494698** • email **Ellie@tsssuk.org.uk**

Matt Andrews *(Dad & Fundraising Representative)* • Tel **07908 764224** • email **Matt@tsssuk.org.uk**

Ali Andrews *(Mum & Fundraising Representative)* • Tel **07912 983688** • email **Ali@tsssuk.org.uk**

Meg Andrews *(Adult Representative)* • email **MegA@tsssuk.org.uk**

Zoe *(Teens Representative)* • email **Turner.Syndrome@tsssuk.org.uk**

Grace *(Teens Representative)* • email **Turner.Syndrome@tsssuk.org.uk**

Hayley Cleaver *(Friendship Group Co-ordinator)* • Tel **07763 606597** • **Hayley@tsssuk.org.uk**

Thank you to all contributors to the Autumn 2020 issue of ASPECTS, the Newsletter of the Turner Syndrome Support Society (UK).
Contributions can be emailed to the TSSS office for the attention of the ASPECTS Editor.

Should you wish to share your story with the TSSS members, the deadline for next issue is 14th January 2021.

TSSS Office:
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Executive Officer
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Clydebank Business Park, Clydebank G81 2NR
Tel **0141 952 8006**
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